DEVELOPMENT OF AN ASSESSEMENT TOOL THAT MEASURES CHANGE OF KNOWLEDGE, ATTITUDE AND PRACTICE OF MOTHERS TOWARDS UNIVERSAL NEWBORN HEARING SCREENING PROGRAMME

By

Christine Graham

A thesis submitted in fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Medicine, University of KwaZulu-Natal.

2020

Preface

The basis for this research emanated from the Amajuba Universal New-born Hearing Screening Research Programme (UNHSP). Nevertheless, my passion for strengthening and enabling community health motivated me in this project and allowed me to develop a tool that affords community engagement. As the world of UNHSP emphasises family participation in a rural community, an awareness of the issue is crucial to overcome barriers of acceptability for current and future generations. With this in mind, the study was carried out with the support from the Department of Otorhinolaryngology in the School of Medicine, College of Health Sciences of KwaZulu-Natal, Durban in South Africa between October 2016 and January 2019 under the supervision of Dr. Y. Saman and Professor J. Seeley.

Declaration

I **Christine Graham** declare that:

(i) The research reported in this dissertation, except where otherwise indicated, is my original work.

(ii) This dissertation has not been submitted for any degree or examination at any other university.

(iii) This dissertation does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.

(iv) This dissertation does not contain other persons' writing, unless specifically acknowledged as being sourced from other researchers. Where other written sources have been quoted, then:

a) their words have been re-written but the general information attributed to them has been referenced;

b) where their exact words have been used, their writing has been placed inside quotation marks, and referenced.

(v) Where I have reproduced a publication of which I am an author, co-author or editor, I have indicated in detail which part of the publication was actually written by myself alone and have fully referenced such publications.

(vi) This dissertation does not contain text, graphics or tables copied and pasted from the Internet, unless specifically acknowledged, and the source being detailed in the dissertation and in the References sections.

Signed:  Date: 28th August, 2020

Christine Graham

Signed:  Date: 28th August, 2020

Dr. Yougan Saman - Supervisor

Dedication

To my dearest Ronnie and our daughters Lilian and Jordan

… with All Is Well mantra…

Acknowledgements

Immense gratitude to my creator and the Mahanta for giving me the opportunity and strength to do this research.

I earnestly thank the University of KwaZulu-Natal, College of Health Sciences for the scholarship which allowed me to conduct this study in the Department of Otorhinolaryngology, School of Medicine. I also cannot express enough thanks to my supervisors, Dr.Yougan Saman and Professor Janet Seeley, for their continued support and encouragement. I offer my sincere appreciation for the learning opportunities provided by moulding my thinking to go beyond my general understanding and to look at the bigger picture.

The completion of this project could not have been accomplished without the support of the Amajuba District Health Management as well as staff and nurses of Newcastle Provincial Hospital. Although I sometimes inconvenienced their daily routine their countless support assisted me throughout my research. Special thanks to all mothers who participated in the study from the beginning to the end: your contribution may gain something great in the future. Thanks also to the facilitators and research nurses for their assistance in the research. My gratitude is also due to the South African Red Cross and Air Mercy Services staff who were very helpful with travel arrangements.

My heartfelt thanks to all individuals who were involved in one way or another to the project: To Salome Pillay of the Department of Otorhinolaryngology, you are noteworthy and a trusted individual who gave me sincere and selfless support from the department and the university but didn't ask for anything in exchange; to Ayanda Gina for her invaluable support and assistance, especially the driving from dawn till dusk. Though sometimes we encountered rough times your perseverance in moving forward is much appreciated and duly noted.

I would also like to thank all my friends for their support: in finding balance - the Mango Tree Lunch Club – Pirindha, Ving and Sebastian. It was great knowing that you were always there. And for settling in the new environment and knowing there is assistance – Margaret and Martin Anderson, Debi and Robin Miller and Patsy and Stephen Wood.

To the Gallaba family, I cannot thank you enough for all the encouragement. Lastly my beloved Ronnie, Lilian and Jordan, your unconditional love kept me pushing even when I was at my lowest. Thank you.

Table of Contents

List of Acronyms

CHL – Childhood Hearing Loss

DHL – Disabling Hearing Loss

GI – Group Interviews

GIs – Group Interviews

HL – Hearing loss

HPCSA – Health Professions Council of South Africa

JCIH – Joint Committee on Infant Hearing

KAP – Knowledge, Attitude and Practice

LMIC's – Low-middle income countries

NHS – Newborn Hearing Screening

PCHI – Permanent Childhood Hearing Impairment

PHC – Primary Health Care

TNHS – Targeted Newborn Hearing Screening

UNHS – Universal Newborn Hearing Screening

UNHSP – Universal New-born Hearing Screening Programme

Abstract

Hearing loss is a common cause of disability and has increasingly become a global burden. Although Universal Newborn Hearing Screening Programme (UNHSP), as a public health initiative, provides detection and management services for childhood hearing loss, the loss to follow-up remains a challenge. For the optimal prevention of long-term speech-language, cognitive and social disability working with the communities concerned is important. Accordingly, this thesis reports on the process of developing a knowledge, attitude and practice (KAP) tool that captures mothers' understanding of childhood hearing loss and newborn hearing screening in Amajuba District, KwaZulu-Natal, South Africa. This research pursued an exploratory sequential, mixed method design which combines both qualitative and quantitative methodological approaches. For the qualitative approach, focus group interviews, using an interview guide, were conducted with the aim of identifying content area for the development of the tool. Inductive thematic analysis was used to analyse data. The themes identified were used to develop a tool which was then validated by face and content validity and which was analysed using descriptive statistics and content validity index respectively. A test-retest repeatability study was undertaken to assess stability then analysed with Cohen's kappa coefficient. Thereafter, a KAP survey was conducted to obtain a baseline.

Nine themes were obtained for the qualitative study: Perception of deafness; causes of deafness; identification of deafness; detection and treatment; beliefs; feelings; health seeking behaviours; further examination and support. A validated KAP tool was developed with twenty-nine items: 6 – demography; 6 – knowledge; 6 – attitude; 6 – practice and 5 – awareness. Both scale content validity index and item content validity index scored 1 for comprehensiveness and relevancy and 97% of participants stated that the tool was appropriate for face validity. Test-retest repeatability study results showed a Cohen's Kappa Coefficient of 0.87 (95% CI: 0.87, 0.87) for stability. The baseline KAP showed limited knowledge regarding childhood hearing loss amongst mothers in terms of a newborn hearing loss, causes, detection and treatment. Cultural factors such as birth and ancestral rituals were identified amongst the causes of hearing loss. However, the attitude towards early detection of hearing loss was positive and most mothers would accept screening if offered, although acceptance could be impeded by lack of finance, fear of equipment and the time required. Nonetheless, a health facility was mentioned as the first point of consultation and treatment. These research outcomes have demonstrated the feasibility of developing a validated KAP tool regarding childhood hearing loss and newborn hearing screening. The reported inadequate knowledge of mothers' KAP has informed practitioners and policy makers of the existing needs of this community. The outcomes will also allow for tailor-made awareness strategies comprised of health education and promotion of newborn and childhood hearing.

CHAPTER 1

Introduction

1.1 Background

The World Health Organisation defines hearing loss as a person's inability 'to hear as well as someone with normal hearing', which is 25 dB or less in the better ear or both ears (WHO, 2020). The degree of hearing loss (HL) can be described as **mild,** which is HL between 26 dB – 40 dB in the better hearing ear; **moderate,** referring to HL between 41dB – 60 dB in the better hearing ear; **severe,** referring to HL between 61dB – 80 dB in the better hearing ear and **profound,** referring to HL greater than 81dB in the better hearing ear (WHO, 2016). Moderate to profound hearing loss signifies disabling hearing loss in adults. However, with children, it is a hearing loss greater than 30 dB in the better hearing ear (WHO, 2020). Disabling hearing loss (DHL) is a common cause of disability that if left undetected or no action is taken leads to an increase in morbidity (WHO, 2004, 2020). Future projections of DHL show a soaring global burden, with an estimate of 933 million by 2050 (WHO, 2018b), due to a growing and an ageing population, leading to an increase of years lived with disability (United Nations Population Division, 2019; Vos *et al.*, 2017).

Approximately 466 million people, or 6.1% of the world's population, are affected by disabling hearing loss (WHO, 2018b). Of these, 34 million (7%) are children under the age of 15 years. The prevalence of DHL in children globally is 1.7% (WHO, 2018b). South Asia and the Asia Pacific regions have the highest prevalence of 2.4% and 2.0% respectively (WHO, 2018b). Sub-Saharan African estimates are not far behind with 8.9 million children affected and a prevalence of 1.9% of disabling hearing loss (WHO, 2018b). Furthermore, 'neonates and infants (with) … congenital or early childhood sensorineural deafness or severe to profound hearing loss' are estimated to be between 0.5/1000 and 5.0/1000 (WHO, 2009).

1.2 Literature Review

1.2.1 Permanent Childhood Hearing Impairment (PCHI)

PCHI is a health condition of the ear that is characterised by traits that may derive from either environmental or hereditary factors (Hazell, 2006; Lebeko *et al.*, 2015; WHO, 2009; Korver *et al.*, 2011). Environmental risk factors associated with childhood hearing loss include prenatal factors, where, *in-utero,* infections occur. Cytomegalovirus (CMV), rubella, Human Immunodeficiency Virus (HIV), syphilis and toxoplasmosis amongst others pose a threat to hearing (Olusanya, 2010; Korver *et al.*, 2011). The possible transference of these infections from the mother to her unborn child can result in congenital neurological

dysfunctions (Pugel & Cekinovic, 2011). During the peri-natal period, risks of asphyxia, hyperbilirubinemia, ototoxic medication and others may also predispose children to hearing loss (Olusanya, 2010; Karaca *et al.*, 2014). A good example of exposure to toxins can be tuberculosis (TB) treatment or loop diuretics. Additionally, complications during delivery, such as hypoxia and head injury, can also have an adverse effect on the child's development, including auditory dysfunction. During the postnatal period, encounters with chemotherapy or meningitis may increase the risk of hearing loss (Korver *et al.*, 2011). Hereditary factors, on the other hand, are determined by positive family history patterns or various genetic aspects. Generally, health threats during these periods can have a permanent damaging impact on the development of a child (Muse *et al.*, 2013).

1.2.2 The importance of early detection

Hearing loss has been considered a public health issue due to its serious lifelong impact on human function (WHO, 2018a). The first 36 months of human life are viewed as critical as it is the period when hearing loss can be identified and managed to prevent long-term effects. PCHI that is unidentified at birth adversely impacts on a child's speech-language and literacy as well as social-emotional development (Muse *et al.*, 2013). It is claimed that childhood developmental outcomes are influenced by early experiences which occur during the period when the brain is most receptive to change in response to the environment (Fox, Levitt & Nelson, 2010).

The detection of hearing loss in newborn babies and infants has become a reasonable expectation in many parts of the world (Padilla, 2008). Accordingly, Universal Newborn Hearing Screening Programmes (UNHSP) have been undertaken as a public health strategy to prevent the serious repercussions of childhood hearing loss and allow for early detection and amelioration of the condition (Patel & Feldman, 2011).

1.2.3 Universal Newborn Hearing Screening Programmes

1.2.3.1 Global context

UNHSP has been implemented under the umbrella programme of Early Hearing Detection and Intervention (EHDI). In 2007 the Joint Committee on Infant Hearing (JCIH) launched an early hearing detection and intervention (EHDI) programme, which was updated in 2013, to guide detection, diagnosis of, and intervention in childhood hearing loss (Muse *et al.*, 2013). The success of EHDI requires a systematic approach whereby screening is undertaken in the first month followed by a diagnostic assessment within 3 months and an intervention within 6 months (Muse *et al.*, 2013). Systematic and timely follow-ups have

demonstrated considerable benefits in terms of greater opportunities for referral, diagnosis and treatment and improved language skills during school age for the affected children (Hyde, 2005; Huang *et al.*, 2013; Nelson, Bougatsos & Nygren, 2008). This process can only be successfully achieved through partnership and collaboration between a variety of public and private agencies as well as between health professionals and parents/families (Neille, George & Khoza-Shangase, 2014; Gaffney *et al.*, 2014).

The introduction of EHDI has significantly increased global awareness of the importance of early detection of hearing loss. Accordingly, various countries in the world have shifted their priorities towards national promotion and compulsory implementation of UNHSPs as a strategy to prevent hearing loss. However, there is a great contrast between countries in the actual implementation of programmes due to the affordability and the availability of health care services. In high income countries in North America and Europe, UNHSPs are publicly funded and integrated within the health system whereby newborn hearing screening is compulsory before hospital discharge and about 95% of newborn babies are screened (WHO, 2014). In low-and-middle-income the initiative is poorly implemented and in some settings it is non-existent (WHO, 2013) given that they are not publicly funded. In Nigeria, for example, many births occur in clinics or at home, requiring an alternative strategy for hearing screening which are undertaken in immunisation clinics at the 6 week BCG vaccination stage (Olusanya, Wirz & Luxon, 2008). This calls into question UNHS services with respect to achieving the goal of universal health coverage whereby countries have committed to establish health financing systems that can provide accessible services to all people without suffering financial hardship (World Health Organization, 2005, 2010). However, the JCIH have recommended an alternative strategy for settings that lack UNHS services by considering the implementation of targeted newborn hearing screening (TNHS) which involves the continued surveillance of all infants with risk factors of PCHI (Muse *et al.*, 2013).

1.2.3.2 South African context

Although South Africa is categorised as a middle income country with a reasonably good health service, there are far-reaching inequities and inequalities observed across urban/rural as well as race and gender categories. (Coovadia *et al.*, 2009; Swanepoel, Störbeck & Friedland, 2009). The country has an extensive rural population which has limited access to skilled medical services. In 1994, the nation inherited a health service that favoured urban populations and specific race groups. The impact of apartheid on the black community is still evident in health care delivery in most of the impoverished communities (Levin, 2006). Whilst the development of health care services is ongoing, it is currently overstretched in terms of service

delivery and shortages of human resources for health. The large rural population and poor communities living in urban settings are most affected by all these factors (Mayosi *et al.*, 2009; Coovadia *et al.*, 2009).

It is estimated that over 6000 babies are born in South Africa every year with hearing loss, translating into 17 babies a day (Swanepoel, 2009). EHDI programmes have been proposed by the Professional Board for Speech, Language and Hearing Professions of the Health Professions Council of South Africa (HPCSA) acknowledging the JCIH 2007 position statement and its 2013 supplement (The Health Professions Council of South Africa, 2018). The HPCSA recommended that EHDI be implemented in the South African context with the first hearing screening to be done before 1 month and not later than 6 weeks and be linked to immunization; diagnostics to be done before 3 months and not later than 4 months and intervention before 6 months and not later than 8 months plus ongoing monitoring for infants with known risk factors (The Health Professions Council of South Africa, 2018). Nevertheless, at national level, newborn hearing screening (NHS) has not been conducted systematically with standardised systems yet to be established in public hospitals (Meyer & Swanepoel, 2011; Bezuidenhout *et al.*, 2018). Pockets of NHS services have been reported by several studies including a national review of NHS in the private health care sector (Meyer & Swanepoel, 2011); NHS conducted in a public hospital (Bezuidenhout *et al.*, 2018), in a community-based obstetric unit (De Kock, Swanepoel & Hall, 2016) and in primary health care (PHC) clinics (Khoza-shangase & Harbinson, 2015). Another study reported TNHS focussing on high risk hearing screening within an academic hospital complex (Kanji, 2016). Speech therapy and audiology departments of public hospitals in South Africa have reported the current status of newborn/infant hearing screening programmes as being fairly visible in one form or another (Theunissen & Swanepoel, 2008). Recently, the Netcare Group, a health care provider in South Africa, launched a NHS programme but with the provision of services largely based in private hospitals (Netcare, 2019) and in seven provinces (Eastern Cape, Free state, Gauteng, KZN, Limpopo, North West and Western Cape). Three provinces (Eastern Cape, Free state and Gauteng) have developed public-private partnerships in some hospitals (Netcare, 2011). Accordingly, the larger rural population may not have access to these services as they use public hospitals. Therefore, it could be argued that there is a limited number of NHS services available, leaving children at risk of PCHI (Swanepoel, Johl & Pienaar, 2013).

1.2.3.3 UNHSP challenges

Although UNHSP offers detection of hearing loss, the expected outcomes are often not certain (Muse *et al.*, 2013). Challenges encountered by UNHS in LMICs include a lack of prioritisation of NHS in national health programmes, inadequate human and financial resources as well as a lack of equipment (Olusanya,

2015; Bezuidenhout *et al.*, 2018). Where screening is available, other challenges may include the number of false positives (Olusanya *et al.*, 2007), poor follow-up of babies who do not pass their screening assessment and timely access to treatment due to poor access to quality interventions and rehabilitation services (WHO, 2009), which increases the risk of hearing loss (Swanepoel, Hugo & Louw, 2006; Tanon-Anoh, Sanogo-Gone & Kouassi, 2010). In another study in South Africa additional challenges to follow-up have been reported as a lack of parental time due to employment, appointment times being inconvenient, living far from the hospital, having other children to look after, a lack of funds for transport and the unavailability of transport (Kanji & Krabbenhoft, 2018). Additionally, a lack of support from health care professionals and meeting the associated costs of screening makes it challenging for parents/community to participate fully in NHS programmes (Swanepoel, Scheepers & le Roux, 2014). Finally, these challenges are aggravated particularly in LMICs, by 'poor infrastructure development and inefficient patient data management systems' (Olusanya, 2015). It is therefore important to consider carefully the challenges associated with screening as it cannot offer a guarantee of protection against adverse consequences (Olusanya, 2008).

The implementation of screening programmes, in the absence of intervention, may be considered unethical in some regions, but this can also be viewed as a starting point in resource deprived settings (Olusanya, Neumann & Saunders, 2014). In South Africa, for example, in addition to the challenges noted above, other issues include the NHS not being included in maternity birthing packages, inadequate human resources, a lack of equipment as well as the influence of ambient noise, which can distort the screening results (Theunissen & Swanepoel, 2008; Khoza-shangase & Harbinson, 2015; Bezuidenhout *et al.*, 2018). Overall, UNHS is a practicable public health initiative that can address hearing loss but for optimal 'language, social, and literacy development for children who are affected' it requires working in partnership and collaboration with a range of stakeholders (Muse *et al.*, 2013; Frieden, 2014).

1.2.3.4 The Role of Community Knowledge, Attitude and Practice (KAP) in enhancing UNHSP

The JCIH stated that the provision of quality, accessible NHS services offering families unbiased information on all options and in a culturally sensitive manner, is a requisite for effective early hearing detection (Muse *et al.*, 2013). Accordingly, a KAP survey can play a role in generating information that will be used to enhance public information strategies and communication messaging (WHO, 2008). By working in collaboration and partnership with families, (Muse *et al.*, 2013), a KAP survey will highlight issues and barriers that may facilitate effective planning and programme delivery (WHO, 2008) in line with a UNHSP 'family-centred approach' known as family-centred early interventions (FCEI) (Moeller *et al.*,

2013). A KAP survey will also offer solutions to improve the quality of FCEI practice guidelines that work with families across overlapping and holistic service delivery to achieve optimal outcomes in the hearing of the child (Moeller *et al.*, 2013).

An evaluation of UNHSP, reporting the challenges of loss to follow-up in NHS, raised questions of acceptability and accessibility, whereby families' knowledge of, and attitude towards the UNHSP process and hearing loss was assessed (Shulman *et al.*, 2010). The literature review (see Appendix 8) presents studies which have assessed parental knowledge in terms of the causes of hearing loss and UNHSP and with respect to attitude, measured families' and mothers' experiences, satisfaction, opinions and anxieties (Park *et al.*, 2006; Olusanya, Luxon & Wirz, 2006; Swanepoel & Almec, 2008; Fitzpatrick *et al.*, 2007; Mohd Khairi *et al.*, 2011; Rajagopalan *et al.*, 2014; Scheepers, Swanepoel & Roux, 2014; Young & Tattersall, 2007, 2005; Crockett *et al.*, 2005; MacNeil & Stone, 2007; Akilan, Vidya & Roopa, 2014; Mazlan *et al.*, 2014). A review conducted by Ravi and colleagues confirmed that ear discharge was a well-known risk factor but also revealed that the lack of parents' knowledge in relation to other risk factors may be due to unfamiliarity with the medical terms used in the measurements (Ravi *et al.*, 2016b). The review presented the strength of parental knowledge regarding certain risk factors but also explained the reasons for a lack of knowledge of other risk factors. This sheds light on the role of knowledge and attitude towards UNHSP as it provides a picture of the community perspective regarding the UNHSP process and hearing loss. KAP also plays a role in identifying gaps, needs and strengths of the community of study. The sharing of information between communities and researchers allows for the identification of challenges that may hinder the voluntary uptake of NHS services. The recognition of these challenges could enrich FCEI by integrating the insight and knowledge generated by the KAP into UNHSP. The consideration and integration of families' knowledge into UNHSP can be viewed as a strategy to ensure that UNHSPs are both accessible and acceptable (WHO, 2009). Overall, the role of a KAP tool in UNHSP is to provide implementors with important information that can be used to make strategic decisions about ear and hearing care (WHO, 2018a).

1.3 Problem Statement

The challenges of the UNHS programmes, such as the inconclusive results of screening, affects mothers emotionally and the loss to follow-up increases the risk of hearing loss (Kennedy *et al.*, 2000; Swanepoel, Hugo & Louw, 2006; Moeller, White & Shisler, 2006). Studies assessing the reasons underlying the loss to follow-up are not uncommon in many UNHSPs. The main focus of these assessments is on the knowledge and experiences of families in terms of perceptions, views, beliefs and feelings (Fitzpatrick *et al.*, 2007; Olusanya, Luxon & Wirz, 2006; Fox & Minchom, 2008; Swanepoel & Almec, 2008). These assessments identified a knowledge gap in families regarding UNHSP processes and in some instances

family attitudes influenced the loss to follow-up (Ravi *et al.*, 2016b). In LMIC's, knowledge and attitudes regarding hearing loss are entrenched in socio-cultural factors within the community and can create challenges to the voluntary uptake of NHS services and further interventions (Olusanya, 2015).

There are also issues that need to be addressed regarding the measurement tools used in these studies (see Appendix 8). The methods used for gathering data in research must be precise, accurate and consistent. In quantitative studies this can be achieved through an assessment of the reliability and validity of the measurement tool. Reliability refers to the stability and accuracy of the measurement tool and validity is whether the tool measures what it claims to measure (Coughlan, Cronin & Ryan, 2007; Jack *et al.*, 2010). For example, some studies have introduced a new measurement tool assessing knowledge and/or attitude but without reporting on its reliability or validity, which in some studies has been acknowledged as a limitation (Park *et al.*, 2006; MacNeil & Stone, 2007; Scheepers, Swanepoel & Roux, 2014). Other studies used an adapted tool where they claimed reliability, as previously reported, was sufficient (Swanepoel & Almec, 2008; Suppiej *et al.*, 2013; Rajagopalan *et al.*, 2014; Mazlan *et al.*, 2014; Fox & Minchom, 2008). However, it is essential that if a researcher has used an adapted tool and applied it to a new population then it is necessary to indicate how the reliability and validity were established (Polit & Beck, 2010; Coughlan, Cronin & Ryan, 2007). Overall, there is a lack of reported validity of the measurement tools in the literature. The absence of these qualities in the measurement tools demonstrates a weakness in the quality of methods and findings (Polit & Beck, 2010).

In qualitative studies, reliability and validity are still contentious concepts (Polit & Beck, 2010), whereby a researcher is required to report on the process of data collection rather than the measurement tools . This process consists of prolonged engagement, persistent observation, comprehensive field notes, audio-taping and verbatim transcription, triangulation (data or methods); saturation of data and member checking (Polit & Beck, 2010). The assessment of the process is more concerned with the various methods of data collection and whether the techniques used provide sufficient data to support a holistic understanding of UNHSP processes and childhood hearing loss.

Therefore, from the perspective of understanding the socio-cultural factors that can influence loss to follow-up and the lack of voluntary uptake with regard to NHS services, there is a need to develop a KAP measurement tool that can be tailored to the local context. This will enable a more efficient process of awareness creation regarding childhood hearing loss and NHS.

1.4 Significance of the Study

As a component of a larger UNHS research programme undertaken in South Africa this study can be viewed as part of a broader campaign to highlight the plight of children with hearing loss. The JCIH encourages families to participate as they play a major role in effective UNHS service delivery (Muse *et al.*, 2013). Parental uptake of NHS services can be influenced by health promotion and health education during the antenatal period and beyond to enable parents to make informed choices (Olusanya, 2015). However, to develop health promotion and health education material, there is a need to understand the socio-cultural factors which influence parent's understanding of childhood hearing loss and UNHS. I developed a KAP measurement tool that was designed in line with the socio-cultural context of the Amajuba district community. The tool was then used to establish a baseline of mother's knowledge, attitude and practice which determined their behaviour towards compliance with the programme. Although I was unable to assess any change of behaviour after the health education intervention, as the UNHS research programme was completed during my first year of research, the baseline will still inform us about the existing KAP in this community. The findings of the baseline KAP will however, be integrated into the final model of a national UNHSP, with significant implications for policy in relation to health education and promotion materials. This will ensure that the socio-cultural inhibitors that influence parental uptake of services can be addressed in a sensitive manner.

1.5 Theoretical/Conceptual Framework

The study will be guided by the KAP theory, which measures Knowledge, Attitude and Practices of the relevant community. KAP theory operates at an analytic level with respect to the community in relation to the topic of study, with an assumed linear narrative between the three components (Warwick, 1983; Launiala, 2009). The narrative starts with knowledge, defined as the capacity to use information that has been acquired and retained from various means such as basic education or public/community information sharing (Badran, 1995; Chien-Yun *et al.*, 2012). The reasoning through which knowledge is acquired is usually a process of comprehension and being cognisant. From this perspective, the knowledge possessed by mothers about childhood hearing loss (CHL) and UNHS helps us to establish how much and what they know.

Acquiring certain knowledge or beliefs in relation to an object orients an individual to a particular point of view or attitude (Holdershaw & Gendall, 2008). Attitude is a speculative construct that cannot be observed but can be understood as having positive or negative leanings towards a certain situation (Azjen, 2005). To a certain extent attitude is viewed as an attribute which guides, influences, directs and shapes actual

behaviour (Fishbein & Ajzen, 1975). Thus, mothers may have positive or negative attitudes towards UNHSP and CHL based on preconceived ideas, values, beliefs and feelings that are entrenched in the everyday life of a community.

Practice, or behaviour, denotes the action taken as being influenced by the acquired knowledge and understanding as well as attitude (Chien-Yun *et al.*, 2012). With the influence of knowledge and attitude, practice measures the action taken to address issues of CHL and UNHS. In the absence of a UNHSP in the district of study, the behaviour/practice could only be assessed hypothetically (Launiala, 2009). Therefore, a UNHSP informed by KAP data will target knowledge through health education and health promotion strategies with the belief that this would inspire positive attitudes and eventually a change of practice/behaviour (WHO, 2008). The KAP data will thus be expected to inform UNHSP providers about action they can take to sensitize communities about hearing loss.

1.6 Research Questions, Aim and Objectives

1.6.1 Research Questions

The research sought to develop a context-specific tool to assess the knowledge, attitude and practice of mothers towards UNHSP processes and childhood hearing loss by exploring the following questions.

1) What is the feasibility of developing the KAP survey tool?
2) What is the baseline of Knowledge, Attitude and Practice of mothers towards UNHSP process and hearing loss?

1.6.2 Aim

To develop a validated KAP survey tool that can measure the knowledge, attitude, practice and behaviour of mothers towards UNHSP processes and childhood hearing loss.

1.6.3 Specific Objectives

1) To determine emerging themes of mothers' knowledge, attitude and practices towards UNHS programmes processes and childhood hearing loss
2) To develop a KAP survey tool using the themes which emerged from focus group interviews (FGIs) with respect to the knowledge, attitude and practice of mothers
3) To evaluate the validity of the KAP survey tool

4) To evaluate the repeatability of the KAP survey tool
5) To obtain a baseline of knowledge, attitude and practice of mothers regarding UNHSP processes and hearing loss
6) To determine the compliance or non-compliance with UNHSP processes as influenced by mother's knowledge and attitude

1.7 General Methodology

1.7.1 Study Design

The research used a mixed method, which refers to a combination of qualitative and quantitative research approaches, to achieve a real sense of the breadth and depth of the study (Johnson, Onwuegbuzie & Turner, 2007). An exploratory sequential mixed methods design was pursued which involved exploring the qualitative data, analysing it and then using the findings at the quantitative stage of the study (Creswell, 2013). The design was appropriate as the purpose of the research was to develop a KAP tool from the qualitative data generated and subsequently generalised to a larger sample. The research followed defined guidelines on how to combine these approaches starting with qualitative data collection and analysis, building to quantitative data collection and analysis and finally interpretation (Creswell, 2013). These defined guidelines have been seen as problematic as they can constrict researchers with a standardised methodology which can deny the opportunity to assess their position, which has been shaped by the ideas and content of the research (Timans, Wouters & Heilbron, 2019). This is known as 'reflexivity'. However, the mixed method provides a 'better understanding of the multifaceted and complex character of social phenomena' such as this research into the KAP of mothers towards UNHS and childhood hearing loss (Greene, 2008).

1.7.2 Sampling procedure

The study used homogenous sampling of pregnant women attending clinics. To give an equal opportunity for all women to be part of the study, simple random sampling was applied (Thompson, 2012; Bornstein, Jager & Putnick, 2013). A sample was selected during the ante-natal clinics by getting a list of the number of mothers attending the clinic on the day.

1) For qualitative data, a simple random sampling was conducted from a list of mothers, due to attend ante-natal clinics on the day of the study, as obtained from the nurse on duty

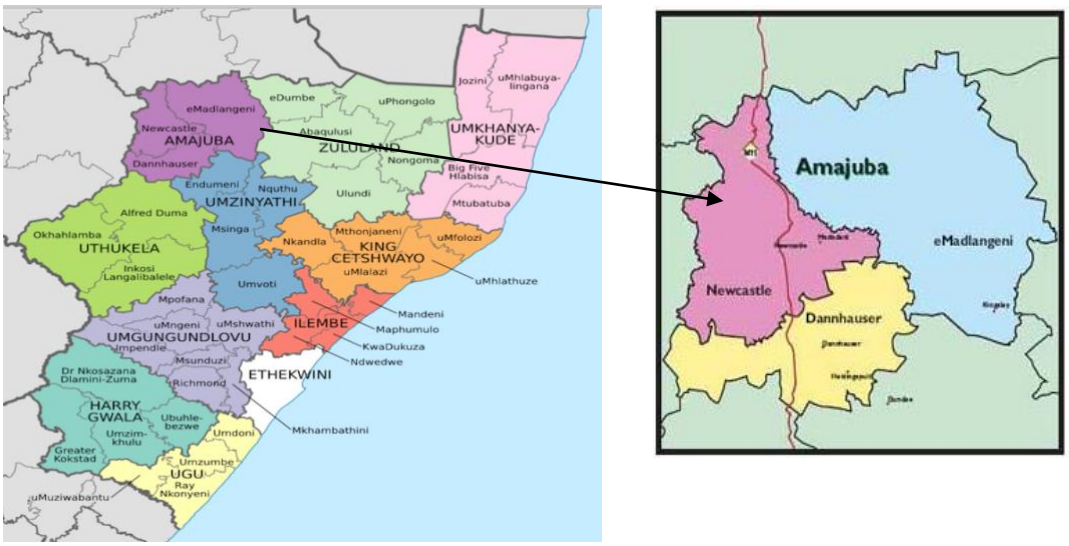
2) For quantitative data, a simple random sampling was used for repeatability, face validity and a KAP survey following the process outlined above. With respect to content validity, experts were recruited from various disciplines, including audiology, otorhinolaryngology and public health.

1.7.3 Data collection and data analysis

The data from the qualitative and quantitative approaches was collected and analysed separately. The data collection process first comprised an exploratory phase pursuing a phenomenological approach using focus group interviews to obtain a broad understanding of the knowledge, attitudes and practices of mothers towards UNHSP process and hearing loss (Creswell, 2013). The data was then analysed by an inductive thematic analysis which involved identifying and coding emergent themes within data (Kalra, Pathak & Jena, 2013). During the design and validation phase, data was collected through an evaluation of the draft questionnaire by a panel of experts to obtain content validity. It was then administered to a small sample of the study population for face validity. Thereafter, it was administered to another sample for a repeatability test. The data was then analysed by frequencies and percentages for content and face validity using Cohen's kappa coefficient for the repeatability test (Polit & Beck, 2010; McHugh, 2012). The assessment of the validity of the tool showed the strength of evidence regarding the generalisability in terms of people and time (Polit & Beck, 2010). Finally, the tool was administered to a larger sample through a survey. It could be argued that the integration of these methodological approaches has strengthened the research, as both methods have their strengths and limitations which complement each other (Creswell, 2013; Morgan, 2018).

1.7.4 Study Area

The study was conducted in Amajuba District, located in the North-Western part of KwaZulu-Natal (KZN). Amajuba District is situated on the border of KZN, Mpumalanga and The Free State province. It is roughly half way between the two major cities of Durban and Johannesburg. Three municipal areas fall under the District, namely, Newcastle, eMadlangeni and Danhauser. The District consists of an urban community and a rural community. The health needs of the community are catered for by 3 provincial hospitals (Madadeni, Newcastle and Niemeyer), 1 private hospital (Medi-clinic Newcastle) and approximately 40 clinics. Access to specialist health care in this region is limited.



According to the census of 2011 the demographics of Amajuba, in comparison to KZN and the whole of South Africa, (Statistics South Africa, 2014, 2012) were as follows:

	Amajuba District	KwaZulu Natal Province	South Africa
Population in millions	499,839	10, 267,300	51,770,560
Gender (% of total Pop.)			
Female	52.2	52.5	51.3
Male	47.7	47.5	48.7
Age Groups (% of total Pop.)			
0-14	33	32	29.2
15-64	61.7	63.1	65.5
65+	4.7	4.9	5.3
Population Group (% of total Pop.)			
Black	93.1	86.8	79.2
Coloured	0.7	1.4	8.9
Indian/Asian	2.6	7.4	2.5
White	3.4	4.2	8.9
Education attained ≥20 years (%)			
No School	8.0	10.8	8.6
Matric	31.4	31.2	28.9
Higher education	9.0	9.1	11.8
Unemployment Rate (%)	39.1	33	29.8

The province of KwaZulu-Natal has the second largest population in South Africa with 19.8% of the total population following Gauteng which has 23.7% (Statistics South Africa, 2012, 2014). In terms of race, the black African group is the largest in Amajuba, KZN and South Africa. As shown in the demographic table

above the study population in Amajuba reflects both the provincial and the larger South Africa population profile.

1.8 Thesis Overview

The background of this thesis is covered in Chapter 1. Chapters 2–4 have been presented as manuscripts and chapter 5 consists of the synthesis of the manuscripts, conclusion and recommendations.

Chapter 2: Mapping the content of mothers' knowledge, attitude and practice towards universal newborn hearing screening for development of a KAP survey tool

Most of the measurement tools of previous KAP studies have been developed using mainstream public health knowledge and have been applied in urban areas where UNHSP programmes are implemented. The existing structure of knowledge of UNHSP can be difficult to understand by a lay person, resulting in issues of acceptability during implementation. These tools would be difficult to use in rural areas where any health condition is deeply intertwined in everyday socio-economic and socio-cultural practices and meanings. In this qualitative study, I explored the Knowledge, Attitude and Practice of expectant mothers towards UNHSP processes and hearing loss in the Amajuba district. The study aims were to obtain and establish the content area from the mothers' perspective, as part of the process of developing a tool.

Chapter 3: Development, repeatability and validity of mothers' knowledge, attitude and practice of universal newborn hearing screening measurement tool

Most studies have not reported or only partly reported on the accuracy and consistency of the measurement tools used. In this chapter, I explained the process of the development of the KAP tool. I then analysed and stated the face and content validity. Thereafter, I analysed and reported the repeatability of the study and presented the validated tool. I also explained the feasibility of developing the KAP tool.

Chapter 4: Mothers' knowledge, attitude and practice towards universal newborn hearing loss and childhood hearing loss

In this chapter I provided the baseline of knowledge, attitude and practice. The chapter also demonstrated how knowledge and attitude influenced the practice of compliance or non-compliance with UNHSP processes.

Chapter 5: Synthesis, conclusion and recommendation of the thesis

In the final chapter, I synthesised all previous chapters to summarise all findings with respect to achieving a validated measurement tool for UNHSP and childhood hearing loss. I also presented the conclusion of the thesis and provided recommendations for future research.

The literature review in Chapter 1 highlighted the need to consider the community understanding of childhood hearing loss and newborn hearing screening to increase parental uptake of the services provided. It was this recognition which inspired this research into the development of a KAP tool that could address issues of compliance or non-compliance with early detection services. Chapter 2 therefore provides a study to define the content area for developing a KAP tool from a mother's perspective. The focus is on Objective 1 of the research project which is to determine emerging themes of mothers' knowledge, attitude and practices towards UNHS programmes processes and childhood hearing loss.

CHAPTER 2

Mapping the content of mothers' knowledge, attitude and practice towards universal newborn hearing screening for development of a KAP survey tool

PLOS ONE

RESEARCH ARTICLE

Mapping the content of mothers' knowledge, attitude and practice towards universal newborn hearing screening for development of a KAP survey tool

Christine Graham[1]*, **Janet Seeley**[2], **Ayanda Gina**[3], **Yougan Saman**[1,4]

1 Nelson Mandela School of Clinical Medicine, University of KwaZulu Natal, Durban, South Africa, **2** Department of Global Health and Development, London School of Hygiene and Tropical Medicine, London, United Kingdom, **3** Department of Audiology, University of KwaZulu Natal, Durban, South Africa, **4** Ear Nose and Throat Department, University Hospitals of Leicester, Leicester, United Kingdom

* cgtinagrm333@gmail.com

OPEN ACCESS

Citation: Graham C, Seeley J, Gina A, Saman Y (2019) Mapping the content of mothers' knowledge, attitude and practice towards universal newborn hearing screening for development of a KAP survey tool. PLoS ONE 14(2): e0210764. https://doi.org/10.1371/journal.pone.0210764

Editor: Matthew Lee Bush, University of Kentucky, UNITED STATES

Received: September 24, 2018

Accepted: January 1, 2019

Published: February 20, 2019

Data Availability Statement: All relevant data within the manuscript and its Supporting Information files.

Funding: The authors received no specific funding for this work.

Competing interests: The authors have declared that no competing interests exist.

Abstract

Understanding mother's knowledge, attitude and practice (KAP) of permanent childhood hearing impairment (PCHI) is essential for the success of universal newborn hearing screening (UNHS) as poor compliance and follow-up remains a global challenge. To determine content area for a questionnaire that measures PCHI-related KAP in rural mothers, we trained moderators who interviewed 145 pregnant women (17 groups) from 5 ante-natal clinics. Interviews were recorded, transcribed, summarised and analysed using thematic framework analysis. Four knowledge themes were identified: 1) PCHI was perceived as the malfunction of hearing leading to disability; 2) a poorly-responsive/communicative child may have PCHI; 3) lifestyle, hereditary and environmental factors are significant causes of PCHI; 4) medical management of PCHI was doubted, with some advocating birth and ancestral rituals. Two themes were identified for attitude: 1) beliefs that PCHI was emotionalised due to the negative lifelong impact on the child and family; 2) UNHS processes were favourable though some preferred other belief systems. Three themes were identified for practice: 1) doctors were the first choice followed by traditional healers; 2) willingness to continue follow-up although challenges exist; 3) minimal family support during consultation. The contextualised KAP of women regarding UNHS processes and PCHI provided content area for the design of a KAP tool.

Introduction

Permanent childhood hearing impairment (PCHI) is a significant cause of disability and can have an enduring impact on cognitive, emotional and social development particularly with regards to the functional limitations of speech and language acquisition [1]. Hearing loss may be present at birth and can result from environmental and prenatal factors, congenital infections and genetic causes [2]. Hypoxia, hyperbilirubinemia, meningitis, chronic otitis media,

mumps, measles, cytomegalovirus, trauma, ototoxic drugs and head injury are causes of neonatal and childhood hearing loss [3].

The reported prevalence of disabling hearing loss varies globally as it depends on context. In a well- resourced country such as the United States the estimates are 1.83/1000 newborns rising to 2.7/1000 before the age of five years and 3.5/1000 during adolescence [4]. In sub-Saharan Africa disabling hearing loss is estimated at 1.9% which translates to 19 children per 1000 [5].

Universal newborn hearing screening (UNHS) has become the standard of care in many countries. In the United States and the United Kingdom there are established programmes where almost all babies are screened shortly after birth. Early hearing detection and intervention (EHDI) attempts to lessens the impact on the family and the child as UNHS services aim to be accessible, coordinated and culturally sensitive to support the child, family and community [6]. However, diagnostic follow-up and effective compliance for intervention may be more difficult to achieve as it requires the pragmatic partnership between the health service and families and even in well-resourced settings this remains a challenge [7]. The cost-effectiveness of such programmes however is increasingly becoming evident as we mitigate against the effects of a lifetime of disability. However, in poorly resourced settings, with many competing health priorities, there must be good evidence that the programme can deliver good compliance before policy makers are willing to invest.

For a programme to be successful and cost-effective it is essential that the community, defined as users of early hearing detection services, participates at the level of screening, follow-up as well as for diagnostic procedures and interventions [8]. This will require multiple, time-consuming visits often at the patient's own expense and where access to healthcare may be challenging. Hence, there is a need to understand the effect of socio-cultural processes on hearing loss and disability in local communities, particularly mothers, so that we can tailor health promotion materials that target their needs [9]. The majority of the literature assesses knowledge and attitude in relation to the experience of NHS that are already in operation [10–15] with relatively few studies undertaken across the world to determine maternal views on HL and the attitudes towards the screening prior to the commencement of a programme.

Accordingly, in this study we determined content area regarding KAP towards UNHSP process and childhood hearing loss (CHL) of expectant women at Amajuba district as part of the process of developing a KAP survey tool. In this study, knowledge is understood as perspectives; attitude as positive and negative inclinations and practice as the action taken in encountering issues of HL or UNHSP process. Using group interviews we initiated a purposeful exchange with women, regarding UNHSP content, to provide the framework in which to understand KAP. The KAP constructed by women is a representation of concepts and meaning that is powerful and thorough about CHL and UNHS. This representation can underline themes for developing a KAP survey tool that will be connecting within participants cultural framework.

Methods

Study area

The study was conducted in ante-natal clinics in a rural community in KwaZulu-Natal, South Africa where there are no newborn hearing services.

Study design

The study undertook a qualitative phenomenological approach and used group interviews for data collection. Although the approach is susceptible to researcher and respondent bias, we minimised the potential impact of these biases from the questions, the participants and the facilitators [16]. Facilitators were trained prior to interviews and guided by the interview protocol. This allowed

them to present the questions considerately, enabling the participants to disclose their true beliefs, opinions and feelings without distortions [17]. We pursued this approach because of the focus on context and the quest to understand the phenomena studied in a naturalistic setting [17].

Participants

Being pregnant was a requirement for participation in the study. Although a qualitative approach rarely uses a systematic approach in sampling, this study conducted a simple random sampling so that all mothers could have an equal chance to participate in the study [17]. Recruitment was done through a meticulous process of first obtaining a number of pregnant women registered to attend the clinic on the day. Since the list was numbered, we wrote each number separately in a piece of paper and tossed in a box and picked ten numbers randomly. We then identified the names from the registered list to obtain participants for group interviews. After the selection, we approached the women and invited them to participate in the group interviews. Most of the selected participants in all sites agreed to participate, except for a few who were either not feeling well and others who failed to turn up to the agreed venue. A total of 145 pregnant mothers at 5 clinics (36 –Nellies Farm; 33 –Osizweni 2; 34 Rosary; 22 – Lulama and 20 –Madadeni 5) were recruited for the study.

The group interviews

Group interview (GI) was the research method for data collection. It is a method characterised by an amalgamation of group interaction and the researchers selected topic. To provide structure, the interviews were guided by semi-structured, open-ended questions that were developed by a thorough literature search conducted in English about CHL, UNHS and KAP studies. It can thus be viewed as group interaction guided by a researcher on a topic [18,19]. We chose GIs because they substantiate the ability to capture social significance of a phenomena in a more effective way than individual interviews. In this case GIs will shed light about women KAP of CHL and newborn hearing screening (NHS) to enable us identify themes for the development of a KAP tool.

GI's were conducted from April–June 2016, whereby each GI was comprised of five to ten participants and lasted between 45 minutes to 1 hour. A total of 17 GIs were conducted at the five sites: Nellies Farm clinic—4; Osizweni 2 clinic– 4; Rosary clinic– 4; Lulama clinic– 3; and Madadeni 5 clinic– 2. Since the Zulu language is the mother-tongue of the majority of the population, the interview questions guide was also translated in Zulu by a professional from linguistic department of a University. Thereafter, these Zulu questions were shared with health professionals at Newcastle hospital for clarification about the local dialect as this would provide ease and comfort. The GIs were conducted by 5 facilitators recruited locally whose criteria included interpersonal skills, computer literacy as well as fluency in English and Zulu. Local facilitators provided a space for a degree of similarity, based on living in the same locality and speaking the same language as the participants. A day's training was provided to the facilitators prior the GIs, then they were given an interview protocol for guidance throughout the interviews. The protocol allowed for a standard to be maintained from one group to another and from one site to another [17]. Since the study involved minimal risk due to its non-invasive nature, at the beginning of each interview, a prepared information sheet was read out to the participants and then verbal consent was requested. It was a process informed consent whereby participants were reminded throughout the interview that they had a right to withdraw if they felt uncomfortable [18]. Then personal introductions of the group and demography was collected.

The objective of the interviews was to explore several issues about HL and the UNHS process as identified from the literature comprising the following: maternal views, opinions,

perceptions in relation to causes, treatment, detection; their attitudes regarding these issues at personal, family and community level; and maternal routine practices in terms of seeking treatment and assistance networks in the health context. To strengthen the quality of the study we used Lincoln and Guba's (1985) 'trustworthiness' framework that encompasses the criteria of credibility which refers to the truth of the data; dependability referring to the stability of the data, and authenticity refers to the researcher demonstrating faithfully the realities of the study group [18]. Therefore, to establish credibility and authenticity all interviews were audio recorded, transcribed and translated verbatim. In addition, the researcher or the facilitator made observations of each GI and took notes on body language, moods and attitudes as well the overall environment. In terms of dependability, each response which was not clear was taken back to the participant to clarify what they meant. Then an independent reviewer was given the transcripts and the audio to verify the quality of the data. Hence, information about KAP of CHL and UNHS process was described in the words of the expectant mothers and according to the meanings given from their own community. Generally, GIs elicited a wide range of information about women's ideas and feelings regarding HL and UNHS process, whilst shedding light on the diverse perspective of mothers between and within groups [19].

Data analysis

Thematic analysis was used to analyse the data. The coding of the transcripts was done manually using a "Microsoft Excel 2016", a spreadsheet programme which enabled us to build a pattern of participant's descriptions of ideas and significant statements by focusing on their meanings towards CHL and the UNHS process. It should be noted that the coding was a combination of emerging and predetermined codes, as the questions came from the content of CHL and NHS. Further, the coding allowed us to generate categories that eventually informed us about the emerging themes. Then an inductive process (which is 'working back and forth between themes' and transcripts), was used to determine an inclusive set of themes [17]. Thereafter, a deductive process was employed by thoroughly examining the transcripts to verify that all evidence collected was included in the identified themes. To ensure rigor through credibility and dependability of 'trustworthiness', GI data within and between study sites was triangulated against the themes and the descriptions in which mothers shared their diverse expressions about CHL and the UNHS process were contrasted and reinforced with extracts from the transcripts. To acquire consistency in all processes from the transcripts, coding and thematic analysis was shared amongst all the authors for verification.

Each transcript was labelled by the first letter of the clinic followed by the group interview number (Nellies Farm–N1, N2, N3, N4; Osizweni 2 –O1, O2, O3, O4; Rosary–R1, R2, R3, R4; Lulama–L1, L2, L3; and Madadeni 5 clinic–M1, M2). The results are presented by "a few, some, several GIs, etc." to give a broader sense of the weight of the participant's reality and putting emphasis of the existence of the multiple realities about their understanding of CHL and NHS in their everyday lives. Participants were also identified by a number indicating the site, interview label and age in years. We used study site identification as we assumed that interactions of the diversity of socio-cultural life gives meaning and transmits knowledge of this phenomena within the wider community [20].

Ethical considerations

The study obtained ethical approval from the Biomedical Research Ethics Committee (BREC)–No. BFC261/16 (sub-study of BFC421/15) at the University of KwaZulu-Natal. Informed consent was obtained from the participants and they were guaranteed confidentiality within possible bounds. Participants had the right to refuse participation as the study was voluntary.

Findings

The study group comprised of women aged between eighteen and forty years as shown in Table 1 below. It is important to note that there was a large group of single women in the study sample which is representative of the general status in South Africa [21].

The descriptive accounts of women's knowledge, attitude and practice in the study identified nine themes. The broad phenomena of knowledge, attitude and practice are presented below in a more integrated assessment of the interviews, with the identified themes followed by contextual illustrations. These illustrations identified women aged 18–20 years as younger, those aged 21–30 years as middle-aged and age 31–40 years as older women. The use of age groups simply shows the age dynamics of the study group.

Knowledge

In exploring knowledge, four themes emerged from the group interviews comprising the perception of deafness, causes of deafness, indication of deafness and detection/treatment.

Perception of deafness. The perception of deafness echoed women's description of deafness or being deaf. Most women, in almost all the GIs (16/17), perceived deafness as the

Table 1. Characteristics of participants.

Clinics	Distribution in GI's—*N*(Age range)				Total *N*
	1	2	3	4	
Nellies Farm	8(18–36)	9(18–29)	9(18–36)	10(18–31)	36
Osizweni 2	8(18–36)	10(19–36)	8(22–40)	7(22–35)	33
Rosary	9(18–35)	7(21–31)	10(18–34)	8(18–34)	34
Lulama	5(22–28)	7(24–28)	10(23–31)	-	22
Madadeni 5	10(18–34)	10(18–34)	-	-	20

Clinics	Distribution in Age range–*N(%)*		
	18–20	**21–30**	**31–40**
Nellies Farm (*N* = 36)	16(44)	14(39)	6(17)
Osizweni 2 (*N* = 33)	7(21)	18(55)	8(24)
Rosary (*N* = 34)	11(32)	16(47)	7(21)
Lulama (*N* = 22)	0	21(95)	1(5)
Madadeni 5 (*N* = 20)	3(15)	12(60)	5(25)
Total (*N* = 145)	37(26)	81(56)	27(19)
Marital Status (*N* = 145)			
Married	3(2)	11(8)	5(3)
Single	32(22)	67(46)	20(14)
Living with a partner	2(1)	3(2)	2(1)
Education (*N* = 145)			
No school	0	1	2(1)
Primary	16(11)	25(7)	8(6)
High school	20(14)	49(34)	16(11)
Higher education	0	6(4)	2(1)
Employment (*N* = 145)			
Employed	2(1)	17(12)	8(6)
Unemployed	22(15)	55(12)	19(13)
Students	13(9)	9(6)	0

N = number of participants

https://doi.org/10.1371/journal.pone.0210764.t001

malfunction of the sense of hearing leading to a dysfunction in the child. Some middle-aged and younger women (9%) described deafness as the defects of the ear. They said:

"I think it is a nerve in the ear that is not right" (O1.3, 27 years)

"I think the problem is with the eardrums" (M1.7, 24 years)

"Sound waves do not enter in the ear and the vibrations are not good, it is a blockage in an ear" (O3.2, 20 years)

On the other hand, some participants (43%) across groups considered HL as simply a hearing problem whereby the following older women said:

"It is when you cannot hear the sounds around you" (N4.1, 31 years)

"It is the difficulty in hearing" (M1.3, 33 years)

Women in about half of the GIs (8/17) made suggestions for what should be done if a baby was born with HL. Several middle-aged women (15%) stated the need to get help urgently as the dysfunction of the child may provide an array of challenges in family, school and community settings, verbalised in the following manner:

"The child will have problems at home with other children and when s/he start schooling. The challenges will be hearing others" (M1.5, 25 years)

"Babies born with hearing loss needs to get special treatment before it gets worse. If delayed it can damage baby's eyes and the baby will be incapacitated." (N2.2, 29 years)

They suggested that the assistance required from the government or professional agencies as follows:

"The government need to do something like awareness about the problem of hearing loss . . .as it may save those children" (R3.7, 22 years)

"There is a need for some professional help so that they counsel us and tells us which steps to take so that the babies can get better" (O4.3, 23 years)

Nevertheless, in very few GIs (4/17), some middle-aged women (6%), declared knowing nothing more about deafness than seeing people that are deaf. Further, the perception of a baby being born with a HL was incomprehensible and this was supported by some older women (7%) as well. The articulated statements include:

"I have never heard of a baby being born deaf" (L1.3, 22 years)

"It cannot be, the baby is still young for hearing anything" (L2.5, 27 years)

"There is nothing to think about. It is God's will" (L3.3, 34 years)

Women's diverse perspectives of deafness were further described in terms of the causes of HL.

Causes of deafness. The descriptions given by participants about the causes of deafness led to the identification of this theme. In the context of newborn hearing loss (NHL), over half of the GIs (9/17) acknowledged that pregnant mothers' lifestyle behaviours and hereditary

factors were the main causes of hearing loss. Mostly, middle-aged women (19%) expressed that pregnant mothers that were exposed to smoking, alcohol and drug consumption as well as poor diet were more likely to have newborns with HL:

"When the pregnant mother uses drugs or consumes alcohol that will affect the baby and become deaf" (N1.2, 21 years)

"I think it may be caused by pregnant mother taking too much alcohol. I have a relative who was doing that when pregnant and her child was born with ears that were always discharging" (M1.5, 25 years)

"Those babies whom their mothers did not get healthy food while pregnant" (N4.2, 26 years)

Several women (10%) in just over half of the GIs (12/17) across all ages mentioned genetics as a probable cause of NHL. These women said:

"It is a hereditary disease, for example, when one member of the family has a hearing problem, then a child might be affected" (R1.7, 19 years)

"It can be hereditary, as there are some conditions which are passed on to children" (L3.7, 28 years)

"Maybe it is genetic, a condition that can be passed on from one generation to another" (M2.1, 33 years)

In over half of the GIs (9/17), women mentioned late attendance at the clinic, non-attendance and non-adherence to health professional advice can lead to NHL. These views were shared by young and middle-aged women (11%) in this way:

"Those babies whom their mother started the clinic late during their pregnancy" (N3.6, 28 years)

"When the mothers are used to not coming to the clinic for immunization of the child it also put the baby in the risk of hearing loss problem" (R4.7, 20 years)

The transmission of diseases from mother to child such as sexually transmitted infections (STI's) and HIV/Aids were articulated by participants in a few GIs (6/17). Women across all age groups expressed their opinions that pregnant mothers with these conditions are more likely to give birth to babies that have HL.

"It is by STI's, when having sex when pregnant while being infected, you will sometimes give birth to a child who have hearing problems" (O1.7, 18 years)

"It can be parents that are HIV positive have caused the child to be deaf" (L3.1, 25 years)

"When the mother comes to test her HIV status and found it negative, and never come back to repeat it in three months while her status changed to positive then the baby will be affected and have a problem of hearing loss." (R3.1, 32 years)

Additionally, middle-aged women (7%) in a few GIs (6/17) said that pregnancy complication may lead to NHL

"It is a baby who is born pre-maturely, like 7 months. The body is not developed properly in other things" (O2.3, 26 years).

Regarding infant hearing loss, participants conveyed the causes of deafness as being rooted in environmental factors. In over half of the GIs (10/17), several middle-aged women (23%) emphasised that babies being brought up in noisy, dusty and unhygienic areas are more likely to acquire hearing loss. Their responses included:

"Too much noise may lead to hearing loss problem" (M1.7, 24 years)

"Hygiene may cause the loss of hearing, when you don't clean the ear of a child s/he can get infection and put the child in the risk of hearing problem" (R2.2, 27 years)

In several GIs (9/17), views that ear infections developed by either dangerous objects being inserted in the ear or water entering the ear were expressed by some middle-aged women (14%) as follows:

"It can be an infection especially when the ears have a lot of discharge" (L3.4, 30 years)

"It is an infection which can block an eardrum" (O3.2, 24 years)

In a few GIs (5/17), various younger and older women (5%) viewed children that were subjected to physical and emotional abuse as more likely to have HL. This comprised of berating and hitting a child regularly.

"I think it is the baby that is always scorned and beaten by her/his parents" (M1.6, 18 years)

"When a child stays with non-biological parents who physically and emotionally abused her/him it will lead to deafness" (R1.2, 35 years)

Additionally, cultural factors were also acknowledged by several older and middle-aged women (8%) in a few GIs (5/17) as being the causes of hearing loss. The description was provided in the context of not adhering to traditional or ancestral rituals as well as spiritual, superstitions and bewitchment factors as expressed below:

"Sometimes a child will be affected if the family did not perform a new baby welcoming ritual. In our traditions, certain rituals need to be performed to welcome the child in the home" (L1.4, 28 years)

"Sometimes it can be a religious problem or sometimes the ancestors are punishing you or you maybe bewitched" (R4.3, 34 years)

"There are many causes that we all know, some are being told by our elders such as when an owl hoots on the roof of your house and baby is in the house, that baby will not hear again, unless the family perform specific rituals" (L1.5, 28 years)

Participants perspectives on causes of HL were expressed differently for newborns and older children, which led to the understanding of how women identify a child with HL.

Identification of deafness. We explored the possibility of participants ability to identify a child with HL in their own community. Participants said that a non-responsive and non-communicative child may be suspected of having a condition causing HL. In nearly all GI's (15/17), women (11%) said that poor communication and no response in daily interactions was the

highest indicator that a child is having a HL problem. These characteristics would be apparent in infants, toddlers and older children and was verbally stated by young and middle-aged women as follows:

"The child cannot play with others as s/he cannot recognise any sounds in their surroundings" (N4.3, 20 years)

"When you are giving instructions to your child, they might not respond unless you shout or get closer" (M1.2, 25 years)

In very few GIs (4/17), several middle-aged women (5%) said that a third-party member can inform the family of the likelihood of HL in a child. The third party may include teachers, children or a doctor. Such were their comments:

"The other children might pick it up when they are playing and report to parents" (L1.7, 28 years)

"Sometimes the teacher can tell you that a child has a problem and is not coping well at school. Then you can know that child had the hearing loss problem" (R4.1, 28 years)

Several middle-aged women (6%) in some GIs (4/17) said observable delays in child development can indicate a problem of HL:

"I think a parent can know because there will be difficulties and delay of talking." (L2.1, 28 years)

"The child will not grow up like other children, s/he will delay in body growth." (L3.4, 30 years)

The perspective that HL cannot be identified in a newborn was shared by younger and middle-aged women (2%) in very few GIs (3/17):

"It is not easy to identify a newborn baby that has a problem of hearing, maybe after two years" (R3.3, 20 years)

"If the child was born like that it will only be after three months you could notice as the sense of hearing is not developed yet" (L1.2, 26 years)

Some young women (8%), in very few GI's (3/17), related soreness of ears as an indication of a HL problem and some also said they did not know how to identify a child with HL. As verbally expressed:

"If you touch their ears they cry and become aggressive about simple things" (M1.6, 18 years)

Detection and treatment. Participants were asked the possibility of detection of HL by health professionals in hospitals and possible treatments for CHL. In the majority of GIs (16/17), particularly middle-aged women (42%) said that HL can be detected by health professionals in a newborn, as they usually conduct several procedures after delivery and prior to being discharged. Their statements included:

"I think doctors can detect because they have skills and equipment to identify hearing loss" (N2.1, 21 years)

"Yes the doctor can detect that because they examine the baby before going home" (R4.1, 30 years).

There were several women (1%) in very few GIs (2/17) that were not aware, that the detection service for newborns could be provided by health professionals.

"I don't think that doctors can diagnose if newborn baby has a problem of hearing loss, because at that stage the baby cannot hear anything" (R2.5, 21 years)

"It will be a little bit too soon for the doctors to see on a newborn, maybe when they are 6 weeks to 2 months" (O1.1, 24 years)

Nevertheless, in over half of GIs (13/17), some younger and middle-aged women (22%) responded that detection was impossible.

"No, I have three children and I have never heard any doctor saying that, so I do not believe it can be possible" (L3.3, 28 years)

"I don't think the doctors can identify that, because sometimes they ask you 'can the baby see, can the baby hear you' I don't think they can identify that problem" (R4.4, 19 years)

Furthermore, several younger and middle-aged women (12%) expressed their trust in the doctors and the health care facility as the only place where they can get treatment for a child with a HL condition.

"The doctors know what the treatments are. I will listen to what doctors says and I will do whatever they say" (O1.1, 24 years)

"The clinic and hospital is the only place that I can find the treatments of hearing loss" (R4.2, 18 years)

In very few GIs (4/17), some women mentioned that HL can be treated by traditional healers or with other remedies. Treatment done by traditional healers was described by a young woman as follows

"I will take to the *sangoma* (traditional doctor) because maybe the child has a problem of ancestors rather than wasting time to clinics" (R1.6, 19 years)

She further clarified about the treatment provided by traditional healers, as illustrated below:

"Using culture methods may be the best way to treat the hearing loss. There are some local herbs like (indlebelendlovu = ear of an elephant) from the traditional doctors they can cure the hearing loss problem" (R1.6, 19 years)

Other women explained that even natural home remedies are considered as treatment for HL:

"The breast milk of the mother can cure the hearing loss problem. . . . in my family my sister's child had that problem of hearing and we were told by elders to put breastmilk and the ears became well" (R1.4, 21 years)

Attitude

In exploring attitudes, two themes were identified comprised of beliefs and feelings.

Beliefs. Interactions of our everyday life shape what we think and believe. This theme was more about participants' beliefs, opinions and thoughts about CHL and NHS. The gravity of a HL condition was believed to be the most problematic throughout one's life. In the context of education and employment, in over half of the GIs (11/17), women believed that the child could experience challenges during his/her education that may result in difficulty in getting employment. Whereas, in a few GIs (6/17), younger and middle-aged women (5%) believed that due to lack of education the person will be dependent. As they commented:

> "A child with hearing loss cannot cope at school. . .when it comes to her studies she cannot do well" (R1.4, 21 years)
>
> "It will be hard for that person to get employed and will always be dependent on the family" (N1.1, 19 years)
>
> "The child would not do well at school or may not get education and this would affect the family" (L3.10, 21 years)

Additionally, a lack of communication was believed by several middle-aged women (17%) of over half of the GIs (13/17) that the child would be vulnerable to many threatening situations, such as fire, vehicles on the road and rape. This viewpoint was conveyed as follows:

> "The child would be in danger at all times–on the roads, near fires, so the family needs to look after all his life" (L2.7, 28 years)
>
> "The child can easily be raped by someone because she will just give respect to older male on whatever they say" (R4.5, 23 years)

The lack of interaction with family members and community was believed by some younger and middle-aged women (10%) of a minority of GIs (4/17) to affect the child at personal level, leading to a feeling of depression and isolation. Women articulated this view in the following manner:

> "When the child cannot hear, other children can tease him . . . which can drive the deaf child to psychological problem" (R2.3, 31 years)
>
> "It is very difficult for the child with lack of communication s/he might have a feeling of isolation. S/he can even end up hurting herself such as committing suicide" (L3.2, 28 years)
>
> "You become a joke in the community as people will just laugh at you" (N1.1, 19 years)

The feeling of isolation can also be due to the stigma and discrimination that can be experienced by the child within the community, as described by some women in a few GIs (3/17):

> "It is a stigma in the community and families would always be afraid as the child would not be able to play with other children" (O2.4, 23 years)
>
> "Some of families usually ignores the deaf child because s/he cannot communicate and discriminated against" (R3.3, 20 years)

Stereotypes, which can lead to discrimination, was also expressed by women as follows:

"Most of the deaf people are short tempered and it becomes difficult to communicate with them" (N2.5, 19 years)

Nonetheless, when participants were asked about their beliefs, in almost half of the GIs (7/17), women of all ages mentioned cultural factors to be associated with HL. These women felt that traditional healers were more capable of resolving hearing loss. They also believed HL to be a condition that can be solved spiritually.

"Those doctors at the clinic they do not help in those situations like that, I would rather go to find help in our cultural ways—traditional doctor (*sangoma*)" (R1.9, 18 years old)

"If there are no signs of improvement (at the clinic) I will go to church and pray to God" (L2.5, 29 years)

"As I am a Christian and I believe in prayers so I will think it's a spirit and ask a church member to pray for me" (O2.3, 26 years)

Feelings. The 'feeling' theme arose from a question that asked participants' how they would react, what they would do immediately and how would they feel if their child is identified with hearing loss. In all GIs, women expressed the feeling of being emotionally upset if informed that their child had a HL condition. These feelings of women varied between and within GIs. Participants in over two thirds of GIs (15/17), spoke about being emotionally upset in terms of crying, hurt, sad and unhappy. These following middle-aged women expressed the sense of helplessness, hopelessness and were inclined to self-pity as they see a bleak future for the child:

"I really don't know what I do, but I will feel at a loss" (M2.4, 25 years)

"I will feel bad, because my child will not have a good future" (R4.5, 23 years)

Nonetheless, in over half of GIs (9/17), several younger and middle-aged women (8%) said that they would accept the situation and get whatever help was provided to them. The anticipated assistance comprised of seeing special doctors, sign language teachers and social workers. Some statements from women were as follows:

"I will be hurt and feel sad but I will become calm and take further steps to help my baby" (N1.5, 28 years)

"We need to ask the Department of Health to counsel us and help us to learn sign language, so that we can communicate with our babies" (O1.5, 20 years)

Other women, in very few GIs (2/17), said that even though they would be emotionally upset, they would call upon their family and relatives to make decisions.

"It will be painful, I will cry and talk to my family. They must decide what to do" (L3.10, 21 years)

"There will be nothing I can do, I will just cry and tell my family" (L2.4, 21 years)

Practice

In terms of practice, three themes emerged: health seeking patterns, follow-up examinations and support systems.

Habitual health care practices/health seeking patterns. We all have certain habits that we follow when we are ill, which is determined by our circumstances and environment [22]. Women in this study explained their habits in seeking well-being during ill health. Most women, in all GIs, mentioned that their first choice of consultation was a professional health worker at the health facility. Most of the younger and middle-aged women (39%) visit a health facility whenever they are not feeling well:

"When I am not well, I normally seek medical help at the clinic" (N3.8, 18 years)

"I had always gone to the clinic, whenever I have a problem, as much as I can" (R4.5, 23 years)

The responses were similar even when they were asked where they would take a child if s/he is identified with HL. Some of the younger and middle-aged (23%) comments were:

"I will consult a doctor that can help with that problem rather than sit at home where I cannot find help" (R1.1, 18 years)

"I will take my child to the clinic for any treatment so that my child can be better" (M2.8, 24 years)

However, for a substantial number of women, in over half of the GIs (9/17), traditional healers were mentioned as the first point of consultation. This was expressed by younger and older women (7%) as follows:

"I normally go to the traditional healer, there are some local herbs that treat all everyday illnesses" (M1.1, 34 years)

"I usually go the traditional healer because most of the problems like hearing loss, eye problems and others are happening because of ancestors. So, traditional healers can tell me what I must do" (R1.9, 18 years)

In the context of their child being identified with HL, some of the middle-aged women (13%) stated:

"I will take the child to the traditional healer, maybe he will see the causes and find out what is wrong" (O2.10, 25 years)

"I will go to the traditional healer, maybe the child has been bewitched" (M1.4, 25 years)

The following middle-aged women, however, will visit traditional healers as a second option when they received unfavourable results from the clinic:

"I usually consult the doctor first, if I cannot get help, I consult the traditional healer" (R2.7, 27 years)

"I will go to the clinic first, then other means such as traditional healers or church" (O2.5, 25 years)

In a few GIs (5/17), some women reported their preferences to self-medication such as pharmacies and natural/local remedies rather than clinics. Some assertions from middle-aged and older women (6%) were as follows:

"Most of us do not go to the clinic because you stay long there due to long queues and not get much help. We prefer to go to pharmacy" (O3.5, 34 years)

"I go to clinic when it is necessary, I usually get medication from the chemist" (L1.4, 28 years)

"I usually pray and use natural remedies" (L3.3, 28 years)

Visiting the church when not feeling well was mentioned by some middle-aged women (7%) in a few GIs (4/17). Some of their comments include:

"I usually go to church and then at the clinic" (N2.4, 25 years)

"For me I usually get healed with prayers, I only come to the clinic for check-ups" (L2.5, 27 years)

"I normally go to church first and ask the pastor for a prayer after that I consult the doctor" (R3.4, 24 years)

Even when a child is identified with HL, their comments were similar such as:

"I will go to church and ask for a prayer because this will be a serious situation in my life" (R1.4, 21 years)

Follow-up examinations. This theme emerged after participants were asked about their willingness to comply with additional appointments arranged by the health professionals. In all GI's, the majority of women were prepared to attend the appointments given. However, in most GIs, the extent of willingness varied between these women as some were ready to attend all scheduled appointments while others would not. Some of the comments of willingness to attend by middle-aged and older women (29%) were as follows:

"Every appointment that is scheduled, because I want my child to get help and be able to communicate with others" (M2.1, 33 years)

"As many times. I will follow all the instructions given by the doctor or nurses at the clinic" (N2.1, 21 years)

"I will honour all appointments" (L3.9, 27 years)

A small number of women (3%), from very few GI's (3/17), mentioned attending limited appointments due to financial constraints, time and lack of trust of the devices used for check-up. These issues were expressed as follows:

"I will attend only two times in a year because I am not trusting those machines, maybe they can affect my baby ears" (R1.5, 29 years)

"Once a month, I have many other responsibilities and the day you come to the clinic it takes almost the whole day" (L1.2, 26 years)

"Quarterly when necessary, as transport cost money and there are many issues to resolve at home (L2.5, 27 years)

Support systems. As visitation to the clinic may be frequent when a child is identified with HL, having an understanding of support received from the family is important, as there

would be minimal likelihood of failing to attend appointments. In over two thirds of the GIs (15/17), the majority of women asserted that they were more likely to go alone to seek treatment for their children. Younger and middle-aged women (42%) verbalised as follows:

"I go alone because there is no one who can go with me" (R2.4, 24 years)

"Women usually go alone with their babies at the clinic" (O1.7, 18 years)

"We normally go alone, I think everyone here agrees with me (the group nodded)" (N2.5, 19 years)

In almost a half of the GIs (7/17), several women said they preferred and received support from other members of the family and some from friends. This was expressed by younger and older women (14%) as follows:

"I prefer to be with someone like my sister because at any situation I need support. It is very sensitive with my immune system to get support from my family" (R1.7, 19 years)

"It will depend how sick the baby is, if very sick I go with relative, but if it is not serious I will go alone" (O3.3, 40 years)

Overall, the understanding of childhood hearing loss expressed by these mothers has generated a great deal of information and suggestions, which were subsequently constructed into nine themes as demonstrated above.

Discussion

The overall purpose of this study was to explore maternal knowledge, attitude and practice towards CHL and NHS in a rural community to identify themes for the development of a KAP survey tool. The findings suggest various factors that need to be considered in designing such a tool as the understandings and meanings given to HL and NHS are complex, spreading across individual, family, community and cultural levels.

Contextually, gathering information of community KAP is essential to an ear health needs assessment to determine the potential acceptability of UNHS and to ensure effectiveness. Health needs assessments afford an understanding of the needs and integrates the results into service delivery [23]. The current study identified the diversity of knowledge associated with perception, causes and identification of deafness as well as detection and treatment. Although age related differences in overall perceptions were evident, they can be explained by a theoretical perspective of meaning, which refers "to the way self considers its past experiences" [20]. For example, the reported descriptions of CHL and its causes were greater with middle-aged women, followed by older women, with less from the younger women. This finding reveals that the middle-aged and older women responded according to their past experiences of either having a child or interactions with those with a child. The viewpoints of women reflected their personal experiences, everyday interactions and encounters with their world [20]. The younger women, on the other hand, lacked the experiences of being a mother and their interactions with others may have been limited. Additionally, despite the large percentage of single women, the above perspective of meaning, was unclear with regards to marital status as there was no difference of responses between married and single women.

These findings point towards constructing measures that can provide a description of women's understanding of the HL and its intricacies. This includes constructing measures of causes; whether families can identify a child with HL; whether HL can be detected in a

newborn and their comprehension of possible treatments. The potential construction of measures is similar in nature with the previous measurement tools that have primarily sought to understand families knowledge of infant HL and NHS [13,15,24–30]. These studies focussed on measuring participant's views about the risk factors of infant HL and perspectives on NHS.

Disparities between the two are that the potential measures to be constructed from the findings of this study will be strongly influenced by the concepts shared by women regarding CHL and NHS, whilst the previous measures were largely influenced by biomedical science. Biomedical science pursues concepts within its culture, for example postnatal infection, ototoxic medication, in-utero infections, measles, jaundice, etc, included into previous measurement tools as risk factors of CHL [31–34]. Although the biomedical approach provides families' needs in terms of knowledge or lack of it in relation to risk factors, it does not support the complex relationship between individuals and their settings, community and biology whereas this study set out to learn how mothers described their understanding of childhood ear health [35,36]. Accordingly, the apparent misconceptions about the causes of CHL from this study highlights the inadequate knowledge within the study group across all ages. This lack of knowledge will be factored in to the tool by constructing measures of all known and unknown causes of CHL. The developed tool could then capture the bigger picture of the community and eventually inform policy and practice and address the needs accordingly.

Other studies used tools that focused on measuring anxiety or satisfaction of families during or after the NHS processes by examining their emotions after the results of screening [14,26,27,37–39]. All these can be aggregated as attitude as the assessment involves a predisposition of participants to respond either positively or negatively towards NHS processes [40]. Generally, the descriptions of women's beliefs about CHS and NHS demonstrated their evaluations of the study phenomena which has been influenced by existing events and experiences of everyday life, eventually shaping their beliefs. Conversely, women in this study indicated a continuum of emotional feelings during NHS process even when one's child is identified with HL signposting to a potential construct measure. Although the emotional aspect of the findings sound like the measures of previous studies [12,14], the context is quite different particularly in relation to the timing of assessment. Previous studies' measurements tools were mostly used during or after the screening process [14,24,38]. This study findings will allow for the potential tool to be used from the planning to the implementation phases of UNHS programme.

Additionally, findings also demonstrated themes which can allow us to understand the typical routines of women in seeking health, whether they are easily persuaded to attend further visits to health facilities as well as the existing support networks during child ill-health which will inform the practice domain.

The perspectives of parents in previous studies, in well-established UNHS in developed countries[12,41], compared to these findings, vary slightly in terms of individual experiences and context. The experiences of parents, in these countries, reflect well-resourced NHS services where the expectation of good outcomes are expected. In this study, the experiences of women exist where services are poor or non-existent. However, there are similarities between these countries and the study population with regard to the expected benefits of screening and the emotional impact on the mothers when a child is identified with HL [12,41].

Understanding mothers KAP in its context not only allowed us to identify themes that will enable us to develop a KAP survey tool, but also highlights the chances of making an impact since we met women within their own social cultural framework [36]. The guiding principle for the development of the tool is to contextualise the data into the knowledge, attitude and practice domains. Since the effectiveness of UNHSP depends on community acceptance of the services, the themes obtained would guide the development of the questionnaire. The study has identified four themes (perception, causes, identification of HL, detection and treatment)

for the knowledge domain; three themes for the attitude domain and three themes for the practice domain. The themes identified indicated the strengths and limitations of the KAP which formed the basis for the development of questionnaire material.

Limitations and implication to research

The limitations of this study include women being studied in isolation, where there are strong social structures and systems, and thus data collected may not be representative of the whole community. The KAP concepts obtained are embedded within their social and cultural aspects (religion, set of beliefs, traditions etc.) of everyday life which is dynamic and cannot be uncritically assumed to be the only truth. Hence, we might have failed to gather sufficient information on significant socio-cultural factors that could present challenges in the implementation of UNHS programmes. In addition, group interviews have a tendency of social desirability bias, although we tried to minimise this by using local facilitators and dialect during interviews [16,42], there is still a chance of the study being affected.

However, based on the themes obtained from this study, it would be possible to develop questions to capture data for the constructs of knowledge, attitude and practice. We believe that there is a potential to develop a KAP tool that would be broad enough to measure in detail all aspects of the three constructs.

Conclusion

The study has established holistic data in terms of recognising the participants in the framework of the whole (where and how they expressed the phenomena meaningful) rather than assuming irrelevance (reduction or abstraction of data) to certain aspects of their explanations. Participants perspectives on CHL and NHS clearly demonstrates how identified themes were content sufficient in each KAP domain. The methodology in this study provides empirical information that directs us to the type of questions to be included in the survey tool. The questions will comprise of perception, causes, identification, treatment of CHL, as well as likelihood acceptance of NHS, their beliefs and feelings about early detection. It also clearly influences the responses to be incorporated in the tool and guides us to include the concepts of a community's everyday language in relation to CHL and UNHS. Accordingly, it ought to be easier in terms of developing questions that are understood by future study participants in this community.

Supporting information

S1 File. Interview guide questions–Zulu version.
(DOCX)

S2 File. Interview guide questions–English version.
(DOCX)

S3 File. Themes–GI minimised data.
(DOCX)

Acknowledgments

The authors wish to thank the women who participated in the study. We also thank the Department of Health and the Newcastle hospital staff for their support during the study.

Author Contributions

Conceptualization: Christine Graham, Ayanda Gina, Yougan Saman.

Data curation: Christine Graham.

Formal analysis: Christine Graham, Janet Seeley.

Investigation: Christine Graham, Ayanda Gina.

Methodology: Christine Graham, Janet Seeley.

Project administration: Christine Graham, Ayanda Gina, Yougan Saman.

Resources: Christine Graham, Yougan Saman.

Supervision: Christine Graham, Janet Seeley, Yougan Saman.

Validation: Christine Graham, Janet Seeley, Yougan Saman.

Visualization: Christine Graham.

Writing – original draft: Christine Graham.

Writing – review & editing: Christine Graham, Janet Seeley, Ayanda Gina, Yougan Saman.

References

1. Kral A, O'Donoghue GM. Profound Deafness in Childhood. N Engl J Med [Internet]. 2010; 363 (15):1438–50. Available from: http://www.nejm.org/doi/abs/10.1056/NEJMra0911225 PMID: 20925546
2. Korver AMH, Admiraal RJC, Kant SG, Dekker FW, Wever CC, Kunst HPM, et al. Causes of permanent childhood hearing impairment. Laryngoscope. 2011; 121(2):409–16. https://doi.org/10.1002/lary.21377 PMID: 21271598
3. Raine CH, Archibold S, Sirimanna T, Dasgupta S. Management of the Hearing Impaired Child. In: Watkinson JC, Clarke RW, editors. Scott-Brown's Otorhinolaryngology and Head and Neck Surgery Volume 2: Paediatrics, the Ear, and Skull Base Surgery. 8th editio. Boca Raton: CRC Press; 2018. p. 75–93.
4. Morton CC, Nance WE. Newborn hearing screening—a silent revolution. N Engl J Med. 2006; 354 (20):2151–64. https://doi.org/10.1056/NEJMra050700 PMID: 16707752
5. WHO. WHO global estimates on prevalence of hearing loss. 2012;1–15. Available from: http://www.who.int/pbd/deafness/WHO_GE_HL.pdf
6. Muse C, Harrison J, Yoshinaga-Itano C, Grimes A, Brookhouser PE, Epstein S, et al. Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing. Pediatrics [Internet]. 2013; 131(4):e1324–49. Available from: http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2013-0008 PMID: 23530178
7. Shulman S, Besculides M, Saltzman A, Ireys H, White KR, Forsman I. Evaluation of the universal newborn hearing screening and intervention programme. Pediatrics [Internet]. 2010; 126 Suppl(August): S19–27. Available from: http://www.ncbi.nlm.nih.gov/pubmed/20679316
8. Engle PL, Black MM, Behrman JR, Cabral de Mello M, Gertler PJ, Kapiriri L, et al. Strategies to avoid the loss of developmental potential in more than 200 million children in the developing world. Vol. 369, Lancet. 2007. p. 229–42. https://doi.org/10.1016/S0140-6736(07)60112-3 PMID: 17240290
9. Napier AD, Ancarno C, Butler B, Calabrese J, Chater A, Chatterjee H, et al. Culture and health. Lancet. 2014; 384(9954):1607–39. https://doi.org/10.1016/S0140-6736(14)61603-2 PMID: 25443490
10. Ravi R, Gunjawate DR, Yerraguntla K, Rajashekhar B, Lewis LE. Knowledge and attitude of parents/caregivers towards hearing loss and screening in newborns–a systematic review. Int J Audiol [Internet]. 2016; 2027(August):1–8. Available from: https://www.tandfonline.com/doi/full/10.1080/14992027.2016.1215560
11. Young & Tattersall H. Parents ' of Deaf Children Evaluative Accounts of the Process and Practice of Universal Newborn Hearing Screening. J Deaf Stud Deaf Educ. 2005; 10(2).
12. Fitzpatrick E, Graham ID, Durieux-Smith A, Angus D, Coyle D. Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. Int J Audiol. 2007; 46:97–106. https://doi.org/10.1080/14992020600977770 PMID: 17365061

13. Hardonk S, Desnerck G, Loots G, Van Hove G, Van Kerschaver E, Sigurjónsdóttir HB, et al. Congenitally deaf children's care trajectories in the context of universal neonatal hearing screening: A qualitative study of the parental experiences. J Deaf Stud Deaf Educ. 2011; 16(3):305–24. https://doi.org/10.1093/deafed/enq055 PMID: 21367846

14. Mazlan R, Lee T, Sarah SZ, Abdullah A. A questionnaire-based study on parental satisfaction with a universal newborn hearing screening programme in Kuala Lumpur, Malaysia. Int J Pediatr Otorhinolaryngol [Internet]. 2014; 78(2):348–53. Available from: http://dx.doi.org/10.1016/j.ijporl.2013.12.014 PMID: 24380662

15. Akilan R, Vidya R, Roopa N. Perception of ' mothers of beneficiaries ' regarding a rural community based hearing screening service. Int J Pediatr Otorhinolaryngol [Internet]. 2014; 78(12):2083–8. Available from: http://dx.doi.org/10.1016/j.ijporl.2014.09.009 PMID: 25288387

16. DeVon H a., Block ME, Moyle-Wright P, Ernst DM, Hayden SJ, Lazzara DJ, et al. A psychometric toolbox for testing validity and reliability [Electronic Version]. J Nurs Scholarsh. 2007; 39(2):155–64. https://doi.org/10.1111/j.1547-5069.2007.00161.x PMID: 17535316

17. Creswell JW. Research Design: Qualitative, Quantitative and Mixed Method Approaches 4th ed. Vol. 53. SAGE Publications Inc.; 2013. 273 p.

18. Polit DF, Beck CT. Essentials of Nursing Research: Appraising Evidence for Nursing Practice 7th Ed. [Internet]. Seventh Ed. Lippincott Williams & Wilkins; 2010. 626 p. Available from: https://web2.aabu.edu.jo/tool/course_file/lec_notes/1001391_Essentials of Nursing Research Appraising Evidence for Nursing Practice Essentials of Nursing Research Polit.pdf

19. Rabiee F. Focus-group interview and data analysis. Proc Nutr Soc. 2004;655–60. PMID: 15831139

20. Daher M, Carré PD, Jaramillo A, Olivares H, Tomicic A. Experience and meaning in qualitative research: A conceptual review and a methodological device proposal. Vol. 18, Forum Qualitative Sozialforschung. 2017.

21. Maluleke R. Early Childhood Development in South Africa [Internet]. Vol. IV, Education Series. Statistics South Africa, Private bag X44, Pretoria 001; 2016 [cited 2018 Dec 12]. Available from: www.statssa.gov.za

22. World Health Organization. WHO | The determinants of health [Internet]. WHO. World Health Organization; 2010 [cited 2018 Nov 7]. Available from: http://www.who.int/hia/evidence/doh/en/

23. World Health Organization. Community Health Needs Assessment [Internet]. WHO Library Cataloguing-in-Publication; 2001. Available from: http://www.euro.who.int/__data/assets/pdf_file/0018/102249/E73494.pdf

24. Olusanya BO, Luxon LM, Wirz SL. Maternal views on infant hearing loss in a developing country. Int J Pediatr Otorhinolaryngol. 2006; 70(4):619–23. https://doi.org/10.1016/j.ijporl.2005.08.004 PMID: 16154646

25. Park AH, Warner J, Sturgill N, Alder SC. A survey of parental views regarding their child's hearing loss: A pilot study. Otolaryngol—Head Neck Surg. 2006; 134(5).

26. MacNeil JR, Stone S. Evaluating Families' Satisfaction With Early Hearing Detection and Intervention Services in Massachusetts. Am J Audiol •. 2007; 16(June).

27. Fox R, Minchom S. Parental experiences of the newborn hearing screening programmeme in Wales: A postal questionnaire survey. Vol. 11, Health Expectations. 2008. p. 376–83. https://doi.org/10.1111/j.1369-7625.2008.00504.x PMID: 19076665

28. Swanepoel D, Almec N. Maternal views on infant hearing loss and early intervention in a South African community. Int J Audiol. 2008; 47 Suppl 1:S44–8.

29. Rajagopalan R, Selvarajan HG, Rajendran A, Ninan B. Grandmothers ' perspective on hearing loss in children and newborn hearing screening. Indian J Otol. 2014; 20(1):20–4.

30. Ravi R, Yerraguntla K, Gunjawate DR, Rajashekhar B, Lewis LE, Guddattu V. Knowledge and attitude (KA) survey regarding infant hearing loss in Karnataka, India. Int J Pediatr Otorhinolaryngol [Internet]. 2016; 85:1–4. Available from: http://dx.doi.org/10.1016/j.ijporl.2016.03.012 PMID: 27240486

31. Stich-Hennen J, Bargen GA. Risk Monitoring for Delayed-Onset Hearing Loss. In: A Resource Guide for Early Hearing Detection & Intervention [Internet]. National Center for Hearing Assessment and Management. Utah State University; 2008. p. 1–20. Available from: http://www.infanthearing.org/ehdi-ebook/2015_ebook/10-Chapter10RiskMonitoring2015.pdf

32. Olusanya BO, Renner JK. Predictors of growth velocity in early infancy in a resource-poor setting. Early Hum Dev [Internet]. 2011; 87(10):647–52. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21620593 https://doi.org/10.1016/j.earlhumdev.2011.05.002 PMID: 21620593

33. Karaca CT, Oysu C, Toros SZ, Naiboğlu B, Verim A. Is hearing loss in infants associated with risk factors? Evaluation of the frequency of risk factors. Clin Exp Otorhinolaryngol [Internet]. 2014; 7(4):260–3. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25436043%5Cnhttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC4240481 https://doi.org/10.3342/ceo.2014.7.4.260 PMID: 25436043

34. WHO. Childhood Hearing Strategies for prevention and care. WHO Libr Cat Dat [Internet]. 2016; Available from: apps.who.int/iris/bitstream/10665/204632/1/9789241510325_eng.pdf

35. Campbell NC, Murray E, Darbyshire J, Emery J, Farmer A, Griffiths F, et al. Designing and evaluating complex interventions to improve health care. Br Med J. 2007; 334(7591):455–9.

36. WHO. WHO | The Ottawa Charter for Health Promotion [Internet]. First International conference on health promotion, Ottawa, 21. November 1986. 2013. p. 3–5. Available from: http://www.who.int/healthpromotion/conferences/previous/ottawa/en/%5Cnfiles/162/en.html

37. Crockett R, Wright AJ, Uus K, Bamford J, Marteau TM. Maternal anxiety following newborn hearing screening: the moderating role of knowledge. J Med Screen [Internet]. 2006; 13(1):20–5. Available from: http://www.ncbi.nlm.nih.gov/pubmed/16569301 https://doi.org/10.1258/096914106776179854 PMID: 16569301

38. Suppiej A, Cainelli E, De Benedittis M, Rizzardi E, Bisiacchi PS, Ermani M, et al. Failure of hearing screening in high-risk neonates does not increase parental anxiety. J Matern neonatal Med [Internet]. 2013; 26(9):932–5. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23327442

39. Mohd Khairi MD, Noor Rafidah K, Affizal A, Normastura AR, Suzana M, Mohamad Normani Z. Anxiety of the mothers with referred baby during Universal Newborn Hearing Screening. Int J Pediatr Otorhinolaryngol. 2011; 75(4):513–7. https://doi.org/10.1016/j.ijporl.2011.01.009 PMID: 21292333

40. Azjen I. Attitudes, Personality And Behaviour 2nd Ed. [Internet]. Open University Press; 2005. Available from: https://psicoexperimental.files.wordpress.com/2011/03/ajzeni-2005-attitudes-personality-and-behaviour-2nd-ed-open-university-press.pdf

41. Young A, Tattersall H. Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. J Deaf Stud Deaf Educ. 2007; 12(2):209–20. https://doi.org/10.1093/deafed/enl033 PMID: 17277310

42. Nederhof AJ. Methods of coping with social desirability bias: A review. Eur J Soc Psychol. 1985; 15 (3):263–80.

Chapter 2 provided us with the themes of mothers' understanding of childhood hearing loss and newborn hearing screening. In Chapter 3 a detailed process of designing and validating the tool is presented. This chapter addresses the next three objectives which are to develop the KAP survey tool using the themes which emerged from focus group interviews with respect to the knowledge, attitude and practice of mothers (objective 2), to evaluate the validity (objective 3) and the repeatability (objective 4) of the KAP survey tool.

CHAPTER 3

Development, validity and repeatability of mothers' knowledge, attitude and practice (KAP) of Universal Newborn Hearing Screening measurement tool

Submitted to International Journal of Audiology

Development, validity and repeatability of mothers' knowledge, attitude and practice (KAP) of a Universal Newborn Hearing Screening measurement tool

Christine Graham[a]*; Janet Seeley[b] and Yougan Saman[c]

[a]Nelson Mandela School of Medicine, University of KwaZulu-Natal, Durban, South Africa; [b]Department of Global Development, London School of Hygiene and Tropical Medicine, London, UK; [c]Ear, Nose and Throat Department, University Hospitals of Leicester, Leicester, UK

*Corresponding author: cgtinagrm333@gmail.com

ABSTRACT

Background: The assessment of the validity and reliability of measurement tools in research provides quality data. However, evidence of the validity and reliability of parental knowledge and attitude regarding childhood hearing loss and newborn hearing screening is scarce.

Objective: To design a KAP survey tool regarding childhood hearing loss and a Universal Newborn Hearing Screening Programme of the rural Amajuba district and then test for validity and test-retest repeatability.

Methods: Face validity was conducted with 20 mothers and a content validity index was determined by two rounds of assessments, the first by 7 experts and the second by 3 experts. The kappa statistic was used to measure the stability of the tool using data from 160 mothers where repeated measurements were applied at two-week intervals. The feasibility of developing a tool was assessed by applying the criteria of science, population and resources.

Results: A KAP tool was developed with twenty-nine items. For face validity, 97% of the participants reported that the items were clear; wording was appropriate and easy to read and the language was natural. Content validity produced excellent results with a scale and content validity index of 1. Test-retest repeatability for the KAP tool was good with a Cohen's kappa coefficient of 0.87 (95% CI: 0.87, 0.87). Individually, the knowledge scale had a kappa of 0.86 (95% CI: 0.77, 0.95); the attitude scale had a kappa of 0.87 (95% CI: 0.76, 0.99): the practice scale had a kappa of 0.86 (95% CI: 0.75, 0.97) and the awareness scale had a kappa of 0.92 (0.83, 1.00). The development of a KAP tool was shown to be feasible, given sufficient time, funds, motivation and a study population.

Conclusion: The development of the tool was feasible and the study produced a valid and reliable tool that can be useful in generating quality evidence of a community's KAP with respect to childhood hearing loss and newborn hearing screening. Evidence gathered could also be used to tailor health education and health promotion material of for a Universal Newborn Hearing Screening (UNHS) programme in a culturally sensitive manner to promote service uptake.

Keywords: newborn hearing screening, reliability, validity, KAP

Introduction

A Universal Newborn Hearing Screening Programme (UNHSP) is a public health initiative established for the prevention of childhood hearing loss (CHL). Permanent childhood hearing impairment (PCHI) is a significant cause of disability (WHO, 2016). Endorsed by the World Health Organisation (WHO) for early hearing detection, UNHSP attempts to reduce the impact on the family and the child through accessibility of services and management of the condition (WHO, 2017). However, the foremost challenge in the delivery of UNHSP is the diagnostic follow-up and effective compliance with the intervention as it requires a pragmatic partnership between the health service and families (Shulman *et al.*, 2010). It is fair to say that the success of the programme depends on the full participation of UNHSP service users at the level of screening, follow-up, diagnostic procedures and further intervention (Engle *et al.*, 2007).

It is believed that more effective UNHSPs will result from a better understanding of the wider context of the community's knowledge and perspective about ear health. The existing literature however, refers to the maternal knowledge and attitude to UNHSPs which has been obtained from well-established programmes that are part of mainstream health care services (Young & Tattersall, 2007; Crockett *et al.*, 2006; Park *et al.*, 2006; Fox & Minchom, 2008; MacNeil & Stone, 2007; Fitzpatrick *et al.*, 2007; Suppiej *et al.*, 2013). In developing countries research comes predominantly from urban areas, either in immunisation clinics or community settings (Olusanya, Luxon & Wirz, 2006; Swanepoel & Almec, 2008; Mohd Khairi *et al.*, 2011; Ravi *et al.*, 2016b; Mazlan *et al.*, 2014). The recognition that the perspectives of families and/or communities regarding CHL and NHS is important as it can produce evidence that can improve a child's hearing health outcomes through health promotion strategies (Swanepoel & Almec, 2008; Ravi *et al.*, 2016a).

Nevertheless, in poorly resourced settings, with many competing health priorities, there must be good evidence that the program can deliver good compliance before policy makers will be prepared to invest (Olusanya & Newton, 2007). To obtain good quality evidence there is frequently a need to determine the reliability and validity of measurements tools. In a quantitative approach, meeting this requirement will demonstrate the tool's stability for reliability and its ability to measure what it is supposed to measure for validity (Coughlan, Cronin & Ryan, 2007; Jack *et al.*, 2010). Ideally, any new or adapted measurement tool if applied to a new population needs to indicate how the reliability and validity were established (Polit & Beck, 2010; Coughlan, Cronin & Ryan, 2007).

It was therefore necessary to develop a tool that will be acceptable to a rural community. As a component of Amajuba UNHSP research programme, the main goal of the current study was to assess whether the newly developed knowledge, attitude and practice (KAP) survey tool, regarding childhood hearing loss and UNHSP, is valid and reliable. The first objective of the current study was to design an appropriate KAP tool, followed by the second objective of validating the content as reviewed by a panel of experts from several disciplines and face validity as evaluated by participants from the community of the study. The third objective measured the test-retest repeatability designed to assess the reliability of the KAP tool. We then demonstrated the achieved validity and repeatability of the KAP measurement tool.

Methods

KAP survey tool construct development

The questionnaire was developed in English using significant findings from our previous qualitative study (Graham *et al.*, 2019) and also incorporated key theoretical aspects from the KAP literature (Kumar, 2015). The questions were designed to identify the key concepts with respect

to CHL and UNHSP, as commonly shared by the community, to deepen our understanding of the issues (WHO, 2008; Launiala, 2009). It was thus constructed according to the broader concepts of KAP which are based on the premise that we can measure the existing knowledge, perspectives and actions taken with respect to CHL and UNHS. This can then offer space to increase the provision of information that can change their current KAP and ultimately, their behaviour (WHO, 2012). Hence, the questionnaire also included the concept of behaviour.

The initial draft tool was developed with twenty-five items. However, after content validation it was revised to twenty-nine items including two contingency items (filter questions), which reduced the numbered items to twenty-seven. These were then divided into four scale constructs and one demographic section as described below:

(1) Demographic: 6 items

(2) Knowledge scale: 6 items in total; 3 items have three response options (Yes/No/I don't know) and the other 3 have multiple response options.

(3) Attitudes and Behaviour scale: 6 items in total: 1 item with yes/no response; 3 items have multiple responses and 1 has a rating scale (very seriously to not seriously) and 1 has one choice response from different statements.

(4) Health care seeking (Practice) and Behaviour scale: 6 items in total: 3 items have multiple responses; 2 items have one choice from several statements and 1 item has a dichotomous response option.

(5) Awareness scale: 5 items in total; 3 items have multiple response options; 1 item has a choice from several statements and 1 item has a dichotomous option.

Participants and procedures

In assessing validity and reliability the sampling was approached differently. The data was

collected between November 2016 and March 2017.

Content validity

For content validity, the tool was evaluated by a team of seven experts from the disciplines of audiology, otorhinolaryngology and public health. The experts were first asked if they would like to participate in the study. After acceptance, a formal letter of invitation with the evaluation form was sent to the expert. These experts reviewed the questionnaire for comprehensiveness as well as relevancy of the scale's content and content domain (Waltz, Strickland & Lenz, 2010; Polit & Beck, 2010). They came back with comments in relation to the wording and added two questions. However, after the content validity index (CVI) analysis was done it was found that the practice scale construct did not achieve the required CVI. Therefore, the questions were revised, with the input from the experts. Then a second team of three experts was invited to evaluate the relevancy of the questionnaire with regard to the scale's content and content domain.

Translation of the tool

Thereafter, we engaged a professional from the linguistic department at University of Kwa-Zulu Natal to translate the questionnaire into the Zulu language as this was the medium of communication used by most participants. The translated questionnaire was then taken back to the community where another expert translated it back into English. The principal investigator, working with two research assistants (recruited nurses for the larger study who are Zulu speakers from the same community), then reviewed each item for the appropriateness of spoken language in everyday settings as well as the structure of questionnaire.

Face validity

A face validity exercise was conducted by recruiting twenty participants from three ante-natal

clinics (Madadeni 1, Stafford, Osizweni 3) at the study site. Convenience sampling was applied to identify seven, seven and six participants from each clinic respectively, chosen from those waiting for consultation. We asked the pregnant women selected if they would like to review the questionnaire and participate in the study. Those who accepted were first given a consent form, then a review sheet and a questionnaire.

Repeatability

Repeatability is a test-retest reliability exercise which demonstrates the consistency of the measurement tool that has been administered at two or more points with short intervals between tests (Kumar, 2015). The questionnaire was thus used to conduct a test-retest repeatability study with a sample of 160 participants, recruited randomly from the Newcastle hospital ante-natal clinic. We first established the total number of pregnant mothers attending the clinic that day, enumerated them separately on pieces of paper before shuffling them in a box. We then picked twenty numbers at random and correlated these numbers with the names on the registered list of the day. Participants were first briefed about the purpose of the study and were then notified that they would be required to repeat the same exercise after two weeks. Thereafter, they were asked for written consent and to self-administer the questionnaire independently without discussing with anybody. However, some participants were accompanied by their mother, sister etc. and we felt it acceptable to allow them to complete the questionnaire together. Normally, repeatability requires participants to repeat the same exercise at a later date. Data collection took 6 weeks, with the first test data collected over a two week period in early-mid February 2017. Refreshments and snacks were given to the participants as a token of appreciation. Thereafter, we had an interval of two weeks before the re-test data was collected in early-mid March 2017. During the second phase of data collection we devised a mechanism to encourage participants to come to the hospital for

the study arranging four time slots every day, over a two week period. Since we had participants' contact details, we called each participant and asked them to choose a day and a time slot when they would be available for the study. This was an arduous task that required persistent phone calls and follow-ups for those who did not turn up on the first call. We used transport subsidies, refreshments and snacks to encourage them to come.

Data analysis

Content validity and face validity

Content Validity addresses issues of the comprehensiveness and representativeness of the content domain. Experts rated the items as follows: 1- not relevant; 2 – somewhat relevant; 3 – relevant and 4 – very relevant. To analyse the data, we used the Content Validity Index (CVI) measurement. CVI refers to the extent to which an instrument covers the content it is supposed to measure (Polit & Beck, 2006). This measurement provides two results: Item Content Validity Index (I-CVI) which measures the efficacy of the item and Scale Content Validity Index average (S-CVI/Ave) which measures the efficacy of the scale. The criteria used for analysis is that of I-CVI of .78 and S-CVI/Ave of .90 or higher for 6 to 10 experts and I-CVI of 1 for 3 to 5 experts (Polit & Beck, 2010). By using Excel, the I-CVI was calculated as the number of experts who rated relevant or very relevant divided by the total number of experts. Whereas, the S-CVI was calculated by averaging the proportion of items 3 and 4 amongst experts.

For face validity, we used descriptive analysis, where participants evaluated (1-strongly disagree; 2 – disagree; 3 – agree and 4 – disagree) the tool with respect to clarity, wording, readability, layout and language (DeVon *et al.*, 2007).

Repeatability

To analyse the data for test-retest repeatability, SPSS version 24 was used. Repeatability is a measure of reliability and since the measurement scales were nominal, Cohen's Kappa was considered as an appropriate statistic (Watson & Petrie, 2010; McHugh, 2012). Kappa is a measure which determines the amount of agreement between measurements that is greater than the amount expected by chance alone. Kappa allowed us to calculate observed agreement between the two measurements and adjust for agreement expected by chance then normalise the values to create a coefficient from -1 to 1. The negative value demonstrates that the observed agreement is less than that expected by chance and when the value is 0 the observed agreement can be justified by chance and when it is 1 there is a perfect agreement. As suggested by Landis and Koch, Cohen's Kappa strength of agreement will be interpreted as follows ≤ 0 as poor; 0.00 – 020 as slight; 0.21 – 0.40 - as fair; 0.41- 0.60 – as moderate; 0.61 – 0.80 as substantial and 0.81 – 1.00 as almost perfect agreement (Landis & Koch, 1977). Any kappa that is below 0.60 implies insufficient agreement, suggesting slight confidence in the study results. For all items that had multiple responses we used dichotomous options by scoring 'yes' for one and 'no' for zero and calculated the Cohen's kappa. We analysed each variable separately and then a pooled kappa for the item. For the rest of the items we calculated kappa to the item directly. A pooled kappa was also used for knowledge, attitude and practice as they are individual constructs and were later used for the full instrument. A pooled kappa is the averaging of all observed agreements and of all the expected agreements which were then set into the kappa formula (DeVries *et al.*, 2008). A standard error was also computed for each item, scale construct and the total instrument which allowed us to understand the degree of uncertainty in the kappa estimate results. This gave meaning to the kappa by providing 95% confidence intervals.

The feasibility of developing a KAP survey tool

To assess the feasibility of developing the KAP survey tool we followed the guidelines of the 'research study feasibility tool' which focusses on three assessment criteria, science, population and resources (Institute of Translation Health Sciences, 2017). We then selected components that were applicable to the assessment of the tool, as follows:

Science: Whether 1) the tool will make a contribution to the existing body of knowledge, 2) the research team was motivated during the process of developing the tool and 3) the procedures of developing the tool were realistic

Population: Whether 4) it was easy to access the study population during the process and 5) the incentives for participants were sufficient

Resources: Whether 6) time was sufficient for the whole process of developing the tool – designing, data collection, capturing and analysing and 7) funds were sufficient and did not delay the study.

Ethics

Ethical approval was obtained from the Biomedical Research Ethical Committee (BREC) University of KwaZulu-Natal - No. BFC261/16 (sub-study of BFC421/15). Voluntary informed written consent was obtained for participation which included maintaining confidentiality and anonymity within possible bounds.

Results

Content validity

The results of the second stage of rating all items were rated very relevant by the experts with a total agreement on all 23 items, resulting in an I-CVI of 1. All scale constructs had a S-CVI/Ave

of 1, demonstrating that the measurement tool was valid in content.

Face Validity

The rating for the assessment of face validity was established at one to four and all participants rated the questionnaire three or four. Ninety percent indicated that the instructions were clear and understandable. Ninety five percent indicated that the wording was appropriate and that the readability was suitable. All of them indicated that the questions were easy to answer, the language natural and the layout was good.

Test-retest Repeatability

The repeatability study consisted of 160 participants, all of whom were expectant mothers from the ante-natal clinic. The demographic characteristics of the participants are shown in Table 1.

Table 1: Characteristics of participants and descriptive analysis (N=160)

Characteristics		**Frequency**	**Percentage**
Age	18 – 20	27	17
	21 – 30	80	50
	31 – 40	44	27
	Over 40 years	9	6
Marital Status	Married	22	14
	Single	135	84
	Living with a partner	3	2
Religious Belief	Muslim	1	1
	Christian	103	64
	Hindu	2	1
	African Ancestral	54	34
Level of Completed education	No school	4	2
	Primary	31	19
	High school	81	51
	College	36	23
	Higher Education (University)	8	5
Current employment status	Employed	27	17
	Unemployed	108	67
	Student	25	16

The reliability of the questionnaire was determined by test-retest repeatability. Item-specific results are shown in each scale construct, with item numbering according to the numbering in the questionnaire as follows:

Knowledge

The kappa values for 5 items show almost perfect agreement, which indicates the clear structure of the items. One item, however, indicated only a substantial level of agreement, demonstrating an inconsistency by the participants in the two point assessment when compared to other items of knowledge.

Table 2: Cohen's Kappa Coefficient of the Knowledge scale construct (N=160)

Item	Assessment Criterion	Test-Retest Repeatability			
		Level of agreement	Cohen's Kappa Coefficient	Standard Error - Kappa	95% Confidence Interval (Lower limit – Upper Limit)
7	Baby born with hearing loss	Almost perfect	0.86	0.035	(0.79 – 0.93)
8	Causes of hearing loss	Almost perfect	0.89*	0.045	(0.80 – 0.98)
9	Detection in a newborn	Substantial	0.78	0.044	(0.69 – 0.86)
10	Develop HL after passing test	Almost perfect	0.89	0.031	(0.83 – 0.95)
11	Identifying a child with HL	Almost perfect	0.81*	0.050	(0.71 – 0.91)
12	Treatment for a child with HL	Almost perfect	0.86*	0.056	(0.75 – 0.97)

*pooled kappa

Attitude and Behaviour

The results of the kappa in the attitude scale reveal an almost perfect agreement. However, the CI width (margin of error – 0.36) of item 13a is so wide that it shows a large disagreement at the lower limit, even though the overall level of agreement shows reliability.

Table 3: Cohen's Kappa Coefficient of the Attitude scale construct (N=160)

Item	Assessment Criterion	Test-Retest Repeatability			
		Level of agreement	Cohen's Kappa Coefficient	Standard Error - Kappa	95% Confidence Interval

					(Lower limit – Upper Limit)
13	Screening acceptance	Almost perfect	1.00	0.00	(1.00 – 1.00)
13a	Reasons for not accepting screening	Almost perfect	0.83*	0.186	(0.47 – 1.00)
14	Reaction if baby found with HL	Almost perfect	0.83*	0.066	(0.70 – 0.96)
15	Gravity of HL impact on family and community	Almost perfect	0.97	0.018	(0.93 – 1.00)
16	Descriptions of the impact of HL	Almost perfect	0.84*	0.058	(0.73 – 0.96)
17	Community attitudes to deaf people	Almost perfect	0.98	0.013	(0.96 – 1.00)

*pooled kappa

Practice (Health care seeking and behaviour)

The level of agreement in the items of the practice scale construct varied from moderate to substantial as shown in Table 4 below. Please note item 20 where the level of agreement was moderate with the lowest kappa indicating that about half of the participant's responses disagreed with respect to the acceptance of further examination.

Table 4: Cohen's Kappa Coefficient of the Practice scale construct (N=160)

Item	Assessment Criterion	Test-Retest Repeatability			
		Level of agreement	Cohen's Kappa Coefficient	Standard Error - Kappa	95% Confidence Interval (Lower limit – Upper Limit)
18	Habitual health seeking behaviour	Substantial	0.79*	0.079	(0.64 – 0.95)
19	Action taken if child identified with HL	Almost perfect	0.87*	0.075	(0.72 – 1.00)
20	Acceptance of further examination	Moderate	0.50	0.277	(-0.04 – 1.00)
20a	Willingness to take a child for further examination	Almost perfect	0.97	0.019	(0.93 – 1.00)
21	Challenges that may hinder frequent visits to a health facility	Almost perfect	0.95*	0.033	(0.88 – 1.00)
22	Usual support when women take a child to the health facility	Substantial	0.66	0.051	(0.56 – 0.76)

*pooled kappa

Awareness of childhood hearing loss and newborn hearing screening

In terms of the awareness scale construct, five items were assessed by Cohen's kappa (Table 5).

Table 5: Cohen's Kappa Coefficient of the Awareness scale construct (N=160)

Item	Assessment Criterion	Test-Retest Repeatability			
		Level of agreement	Cohen's Kappa Coefficient	Standard Error - Kappa	95% Confidence Interval (Lower limit – Upper Limit)
23	First heard about newborn hearing screening	Substantial	0.73	0.057	(0.62 – 0.85)
24	Whether well informed about newborn hearing screening programme	Substantial	0.79	0.061	(0.67 – 0.91)
25	Current places to get health information	Almost perfect	0.91*	0.061	(0.79 – 1.00)
26	Information they would like to get if a child is at risk of HL	Almost perfect	0.96*	0.026	(0.91 – 1.00)
27	Effective sources of information that can reach the community regarding newborn hearing screening programme	Almost perfect	0.96*	0.029	(0.91 – 1.00)

*pooled kappa

Knowledge, Attitude, Practice and Awareness

A pooled Cohen's kappa was assessed for the four scale constructs. The pooled kappa result for knowledge was 0.86 (95% CI: 077, 0.95); for attitude it was 0.87 (95% CI: 0.76, 0.99); for practice it was 0.86 (95% CI: 0.75, 0.97) and for awareness it was 0.92 (95% CI: 0.83, 1.00) all indicating an almost perfect agreement.

The measured, pooled Cohen's kappa for all 23 items of the KAP survey tool was 0.87 (95% CI: (0.87, 0.87) indicating an almost perfect agreement. Hence, the test-retest repeatability evidently demonstrates a reliable KAP survey tool.

The feasibility of developing a KAP survey tool

It was important to develop this tool as it would encourage the community to share their perspectives regarding CHL and UNHSP. The development of the tool followed a rigorous

scientific approach which consisted of designing, refining, validating and assessing the reliability of the tool (Kumar, 2015). Since the study was part of the Amajuba UNHS research programme, the recruitment of participants at each stage of the development of the tool was possible, supported by subsidised incentives. This process also demanded a great deal of time, from the initial design stage to the validation of the tool and although tedious, most of the procedures were realistic and achievable. Another important factor was funding, which provided a budget to cover accommodation, transport and research team expenses.

Discussion

The development of the KAP survey tool was feasible given sufficient time, funds, motivation and a study population as demonstrated in this study. This study presents the stages of the development and validation of the KAP tool regarding childhood hearing loss and UNHS. The question was whether the proposed KAP measures were measuring what they were supposed to measure, in terms of accuracy or stability (Coughlan, Cronin & Ryan, 2007; Kumar, 2015). The results suggest that the tool which was developed is both theoretically sound and a valid measure of KAP regarding childhood hearing loss and UNHS.

The results of the validity assessments in the questionnaire indicated that it is an applicable measure for the phenomena of NHS and CHL, as it went through appropriate validation processes. Although face validity is understood as the weakest approach to validity due to its subjective nature (Drost, 2011), it is pragmatic in the context of acceptability (Bannigan & Watson, 2009). It has provided significant information that allowed the tool to be more understandable to participants in this study. Content validity results, on the other hand, demonstrated the KAP tool scale relevancy to the phenomena of newborn hearing screening and childhood hearing loss (Polit & Beck, 2010).

It could be argued that some of the generic concepts and measures of the KAP tool overlap with the previous KAP tool and these can be compared to yield additional evidence of the validity of the tool. For example, these could include measures that assessed knowledge about (1) a baby born with HL, (2) risk factors (e.g. noise, ear-discharge, medication, hereditary, traditional medicine), (3) hearing loss identified at birth, (4) treatment of CHL and (5) cultural beliefs (ancestral sins, bewitchment) as would measures that assessed attitude towards screening and whether parents would like more information. Clearly, we could have compared these measures at face value but we did not as context is important and varies between communities. The meaning of concepts can be unclear if they are interpreted within specific socio-cultural contexts and language differences as these factors can influence the outcome (Bowling, 2005; Boateng *et al.*, 2018). Our tool differed from the previous tool as the wording of the questions and the scale constructs captured the specific context and the concepts that were defined and which could readily be understood by the community of study. Further, this study also revealed that the interpretation of concepts in any content domain can be ambiguous (Bollen, 1989:p.185), as our own experience, through the repetitive process of content validity varied amongst the experts.

For various reasons, these results were not comparable to previous studies that measured similar variables. Some studies did not report validity (MacNeil & Stone, 2007; Mohd Khairi *et al.*, 2011; Scheepers, Swanepoel & Roux, 2014). Other studies adapted previous tools (Crockett *et al.*, 2006; Swanepoel & Almec, 2008; Suppiej *et al.*, 2013), while some studies modified these tools and conducted a pilot study but provided no evidence of validity (Rajagopalan *et al.*, 2014; Ravi *et al.*, 2016b). Nevertheless, it is hoped that the tool developed in this study will help initiate a new line of research which integrates and validates community perspectives of KAP with regard to childhood hearing loss and newborn hearing screening.

On the other hand, the test-retest repeatability exercise was undertaken to investigate whether or not the developed KAP survey tool of newborn hearing screening and childhood hearing loss was consistent and stable enough to be of value and to quantify its agreement and repeatability. The repeatability assessment of a measurement tool requires that it is undertaken at two points in time (Coughlan, Cronin & Ryan, 2007). In research practice, the degree of agreement between the two assessments is an indication of the quality of a single measurement, suggesting test-retest reliability for consistency and stability across time (Bannigan & Watson, 2009; Bartlett & Frost, 2008). The results of test-retest repeatability showed a Cohen's Kappa coefficient of 0.87 with almost perfect agreement indicating the consistency and stability of the tool and its constructs. The majority of items (22 of 23, 96%), with kappa values greater than 0.61, suggested a substantial to almost perfect agreement. However, there were two items that were incongruent with other items in their respective scale construct. In the knowledge scale construct, the level of agreement of one item was lower than the other five items. This could be interpreted to mean that items which assessed the general knowledge of childhood hearing loss such as causes, treatment etc., had clearly achieved better agreement than the early detection items. With the practice scale construct, the item "acceptance of further examination when offered to the child" achieved the lowest value of reliability leading to a negative value in confidence intervals. The kappa estimate claimed a moderate level of agreement with a 95% confidence interval that the true estimate was between -0.04 – 1. We can conclude from the negative CI in lower limits, based on the 95% confidence interval, that there is a disagreement with regard to the likely acceptance of further examination of a child if offered. This evidently demonstrates the limitation of kappa as the estimates of CI includes negative values of poor agreement to almost perfect agreement. In this

context, statistical significance signifies nothing when so much error exists in the results (McHugh, 2012).

These results are not in line with previous studies as the mode of analysis is different. As previously stated, the current study used Cohen's Kappa test-retest repeatability to account for chance agreement in order to achieve reliability of the KAP survey tool (Watson & Petrie, 2010). The assumptions of Cohen's kappa coefficient is that the nominal scales with an agreement are independent, mutually exclusive and exhaustive, showing stability at those two points in time. Previous studies that reported reliability used internal consistency with the Cronbach alpha coefficient, which reflects the coherence of the components of the scale of the measurement tool (Crockett *et al.*, 2006; Olusanya, Luxon & Wirz, 2006; Mohd Khairi *et al.*, 2011; Ravi *et al.*, 2016b). Although, the procedures undertaken to obtain reliability were not elaborated in these studies, the alpha coefficient is one way of assessing the internal consistency of a measuring scale (Kumar, 2015). This usually refers to the degree of homogeneity or the inter-relatedness of a set of items within a scale.

Overall, it can be argued that the validated KAP survey tool will be resourceful and versatile in addressing the needs of this community and other communities with similar characteristics.

Limitations and recommendations

There is a need for further validation of this tool using predictive validity to examine subsequent performance with regard to knowledge and attitude after UNHS programme implementation and health education.

To demonstrate further stability of the scale constructs, we recommend a cross-validation of the questionnaire across independent samples. This will strengthen the rigor of the questionnaire and broaden the generalisability.

Conclusion

Although the development of the tool was laborious it proved to be feasible and may offer valuable information for future interventions around childhood hearing loss and early detection. The KAP scale constructs showed a good validity with high I-CVI and S-CVI. The reliability of the KAP survey tool was good as the three constructs achieved an almost perfect agreement between the participants' two point results, after taking chance agreement into account. However, estimates of kappa can be ambiguous in certain contexts when the confidence intervals comprise the whole scale of kappa interpretation. Overall, the developed KAP survey tool may be useful in understanding rural communities that are similar to the community of study.

Acknowledgements

The authors wish to thank the women who participated in this study. Our gratitude to the experts, for their time and contributions to the development of the tool. We also thank the Department of Health and the Newcastle hospital staff for theirs support during the study.

References

Bannigan, K. & Watson, R. (2009) Reliability and validity in a nutshell. *Journal of Clinical Nursing*. [Online] 18 (23), 3237–3243. Available from: doi:10.1111/j.1365-2702.2009.02939.x.

Bartlett, J.W. & Frost, C. (2008) Reliability, repeatability and reproducibility: Analysis of measurement errors in continuous variables. *Ultrasound in Obstetrics and Gynecology*.

[Online] 31 (4), 466–475. Available from: doi:10.1002/uog.5256.

Boateng, G.O., Neilands, T.B., Frongillo, E.A., Melgar-Quiñonez, H.R., et al. (2018) Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. *Frontiers in Public Health*. [Online] 6, 149. Available from: doi:10.3389/fpubh.2018.00149.

Bollen, K.A. (1989) *Structural equations with latent variables*. [Online]. Available from: doi:10.1002/9781118619179.

Bowling, A. (2005) Mode of questionnaire administration can have serious effects on data quality. *Journal of Public Health VoI*. [Online] 27 (3), 281–291. Available from: doi:10.1093/pubmed/fdi031 [Accessed: 12 December 2019].

Coughlan, M., Cronin, P. & Ryan, F. (2007) Step ' by-step guide to critiquing research . Part 1 : quantitative research. *British Journal of Nursing*. 16 (11), 658–664.

Crockett, R., Wright, A.J., Uus, K., Bamford, J., et al. (2006) Maternal anxiety following newborn hearing screening: the moderating role of knowledge. *Journal of medical screening*. [Online] 13 (1), 20–25. Available from: doi:10.1258/096914106776179854.

DeVon, H. a., Block, M.E., Moyle-Wright, P., Ernst, D.M., et al. (2007) A psychometric toolbox for testing validity and reliability [Electronic Version]. *Journal of Nursing Scholarship*. [Online] 39 (2), 155–164. Available from: doi:10.1111/j.1547-5069.2007.00161.x.

DeVries, H., Europe, R., Elliott, M.N., Kanouse, D.E., et al. (2008) Using Pooled Kappa to Summarize Interrater Agreement across Many Items. *Field Methods*. [Online] 20 (3), 272–282. Available from: doi:10.1177/1525822X08317166.

Drost, E.A. (2011) Validity and Reliability in Social Science Research. *Education Research and Perspectives*. 38 (1), 105–123.

Engle, P.L., Black, M.M., Behrman, J.R., Cabral de Mello, M., et al. (2007) Strategies to avoid the loss of developmental potential in more than 200 million children in the developing world. *Lancet*. [Online]. 369 (9557) pp.229–242. Available from: doi:10.1016/S0140-

6736(07)60112-3.

Fitzpatrick, E., Graham, I.D., Durieux-Smith, A., Angus, D., et al. (2007) Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. *International journal of audiology*. [Online] 46, 97–106. Available from: doi:10.1080/14992020600977770.

Fox, R. & Minchom, S. (2008) Parental experiences of the newborn hearing screening programme in Wales: A postal questionnaire survey. *Health Expectations*. [Online]. 11 (4) pp.376–383. Available from: doi:10.1111/j.1369-7625.2008.00504.x.

Graham, C., Seeley, J., Gina, A. & Saman, Y. (2019) Mapping the content of mothers ' knowledge , attitude and practice towards universal newborn hearing screening for development of a KAP survey tool. *PloS one*. [Online] 14 (2), 1–20. Available from: doi:10.1371/journal.pone.0210764.

Institute of Translation Health Sciences (2017) *Research Study Feasibility Tool*. [Online]. 6 February 2017. Institute of Translational Health Sciences. Available from: https://www.iths.org/wp-content/uploads/ResearchStudyFeasibilityTool_V12017Feb6.pdf [Accessed: 1 August 2020].

Jack, L., Hayes, S., Jeanfreau, S., Stetson, B., et al. (2010) Appraising Quantitative Research in Health Education: Guidelines for Public Health Educators. *Health Promotion Practice*. [Online] 11 (2), 161–165. Available from: doi:10.1177/1524839909353023.Appraising.

Kumar, A. (2015) Review of the Steps for Development of Quantitative Research Tools. *Advanced Practices in Nursing*. [Online] 1 (1), 1–4. Available from: doi:10.4172/2573-0347.1000103.

Landis, J.R. & Koch, G.G. (1977) The Measurement of Observer Agreement for Categorical Data. *Biometrics*. [Online] 33 (1), 159. Available from: doi:10.2307/2529310.

Launiala, A. (2009) How much can a KAP survey tell us about people ' s knowledge , attitudes and practices ? Some observations from medical anthropology on malaria in pregnancy in Malawi Background : KAP surveys. *Anthropology Matters Journal*. 11 (1), 1–13.

MacNeil, J.R. & Stone, S. (2007) Evaluating Families' Satisfaction With Early Hearing Detection and Intervention Services in Massachusetts. *American Journal of Audiology* •. 16 (June).

Mazlan, R., Lee, T., Sarah, S.Z. & Abdullah, A. (2014) A questionnaire-based study on parental satisfaction with a universal newborn hearing screening program in Kuala Lumpur , Malaysia. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (2), 348–353. Available from: doi:10.1016/j.ijporl.2013.12.014.

McHugh, M.L. (2012) Interrater reliability : the kappa statistic. *Biochemia Medica*. [Online] 22 (3), 276–282. Available from: doi:10.11613/BM2012.031.

Mohd Khairi, M.D., Noor Rafidah, K., Affizal, A., Normastura, A.R., et al. (2011) Anxiety of the mothers with referred baby during Universal Newborn Hearing Screening. *International Journal of Pediatric Otorhinolaryngology*. [Online] 75 (4), 513–517. Available from: doi:10.1016/j.ijporl.2011.01.009.

Olusanya, B.O., Luxon, L.M. & Wirz, S.L. (2006) Maternal views on infant hearing loss in a developing country. *International journal of pediatric otorhinolaryngology*. [Online] 70 (4), 619–623. Available from: doi:10.1016/j.ijporl.2005.08.004.

Olusanya, B.O. & Newton, V.E. (2007) Global burden of childhood hearing impairment and disease control priorities for developing countries. *Lancet*. [Online] 369 (9569), 1314–1317. Available from: doi:10.1016/S0140-6736(07)60602-3.

Park, A.H., Warner, J., Sturgill, N. & Alder, S.C. (2006) A survey of parental views regarding their child's hearing loss: A pilot study. *Otolaryngology - Head and Neck Surgery*. [Online] 134 (5). Available from: doi:10.1016/j.otohns.2006.01.013.

Polit, D.F. & Beck, C.T. (2010) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice 7th Ed.* Seventh Ed. [Online]. Lippincott Williams & Wilkins. Available from: https://web2.aabu.edu.jo/tool/course_file/lec_notes/1001391_Essentials of Nursing Research Appraising Evidence for Nursing Practice Essentials of Nursing Research Polit.pdf.

Polit, D.F. & Beck, C.T. (2006) The Content Validity Index : Are You Sure You Know What ' s Being Reported ? Critique and Recommendations. *Research in Nursing & Health*. [Online] 29, 489–497. Available from: doi:10.1002/nur.

Rajagopalan, R., Selvarajan, H.G., Rajendran, A. & Ninan, B. (2014) Grandmothers ' perspective on hearing loss in children and newborn hearing screening. *Indian Journal of Otology*. [Online] 20 (1), 20–24. Available from: doi:10.4103/0971-7749.129803.

Ravi, R., Gunjawate, D.R., Yerraguntla, K., Rajashekhar, B., et al. (2016a) Knowledge and attitude of parents/caregivers towards hearing loss and screening in newborns – a systematic review. *International Journal of Audiology*. [Online] 2027 (August), 1–8. Available from: doi:10.1080/14992027.2016.1215560.

Ravi, R., Yerraguntla, K., Gunjawate, D.R., Rajashekhar, B., et al. (2016b) Knowledge and attitude (KA) survey regarding infant hearing loss in Karnataka , India. *International Journal of Pediatric Otorhinolaryngology*. [Online] 85, 1–4. Available from: doi:10.1016/j.ijporl.2016.03.012.

Scheepers, L.J., Swanepoel, D.W. & Roux, T. le (2014) Why parents refuse newborn hearing screening and default on follow-up rescreening-A South African perspective. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (4), 652–658. Available from: doi:10.1016/j.ijporl.2014.01.026.

Shulman, S., Besculides, M., Saltzman, A., Ireys, H., et al. (2010) Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics*. [Online] 126 Suppl (August), S19-27. Available from: doi:10.1542/peds.2010-0354F.

Suppiej, A., Cainelli, E., De Benedittis, M., Rizzardi, E., et al. (2013) Failure of hearing screening in high-risk neonates does not increase parental anxiety. *The journal of maternal-fetal & neonatal medicine*. [Online] 26 (9), 932–935. Available from: doi:10.3109/14767058.2013.766687.

Swanepoel, D. & Almec, N. (2008) Maternal views on infant hearing loss and early intervention in a South African community. *International journal of audiology*. [Online] 47 Suppl 1,

S44-8. Available from: doi:10.1080/14992020802252279.

Waltz, C.F., Strickland, O. & Lenz, E.R. (2010) *Measurement in nursing and health research*. Fourth ed. Springer Pulbishing Company LLC.

Watson, P.F. & Petrie, A. (2010) Method agreement analysis : A review of correct methodology. *Theriogenology*. [Online] 73 (9), 1167–1179. Available from: doi:10.1016/j.theriogenology.2010.01.003.

WHO (2008) A Guide To Developing Knowledge , Attitude and Practice Surveys. *WHO Library Cataloguing-in-Publication Data*. [Online] Available from: http://whqlibdoc.who.int/publications/2008/9789241596176_eng.pdf.

WHO (2016) Childhood Hearing Strategies for prevention and care. *WHO Library Cataloguing-in-Publication Dat.* [Online] Available from: apps.who.int/iris/bitstream/10665/204632/1/9789241510325_eng.pdf.

WHO (2012) *Health education: theoretical concepts, effective strategies and core competencies*. [Online]. Cairo, Regional Office for the Eastern Mediterranean. Available from: https://apps.who.int/iris/handle/10665/119953?show=full.

WHO (2017) Prevention of deafness and hearing loss. *WHO Library Cataloguing-in-Publication Data*. [Online] Available from: http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_R13-en.pdf?ua=1 [Accessed: 2 April 2018].

Young, A. & Tattersall, H. (2007) Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*. [Online] 12 (2), 209–220. Available from: doi:10.1093/deafed/enl033.

Chapter 3 presented a detailed explanation of the process of developing the KAP tool from design to validation. In Chapter 4 the validated KAP tool was used with a community of expectant mothers to obtain a KAP baseline. This chapter addresses objective 5, which is to obtain a baseline of knowledge, attitude and practice of mothers regarding UNHSP process and childhood hearing loss and objective 6 which is to determine the compliance or non-compliance by mothers with UNHSP processes as influenced by knowledge and attitude.

CHAPTER 4

Mother's Knowledge, Attitude and Practice (KAP) towards Childhood Hearing Loss and a Universal Newborn Hearing Screening Programme (UNHSP) – Amajuba District

Submitted to International Journal of Integrated Care

Mother's Knowledge, Attitude and Practice (KAP) towards Childhood Hearing Loss and a Universal Newborn Hearing Screening Programme (UNHSP) – Amajuba District

Christine Graham[1]*; Janet Seeley[2] and Yougan Saman[1,3]

[1]Nelson Mandela School of Medicine, University of KwaZulu-Natal, Durban, South Africa; [2]Department of Global Development, London School of Hygiene and Tropical Medicine, London, UK; [3]Ear, Nose and Throat Department, University Hospitals of Leicester, Leicester, UK

*Corresponding author: cgtinagrm333@gmail.com

ABSTRACT

Background: The significance of a community knowledge, attitude and practice (KAP) study regarding childhood hearing loss (CHL) and newborn hearing screening (NHS), is the potential contribution it can make to improving early hearing detection programmes. The biggest challenge in these programmes is the loss to follow-up in children who require further hearing assessments and intervention.

Objective: To achieve a baseline KAP of mothers regarding childhood hearing loss and newborn hearing screening and to determine whether compliance or non-compliance with UNHSP is influenced by knowledge and attitude.

Methods: A descriptive cross-sectional survey was undertaken at the antenatal clinic in Newcastle provincial hospital, Amajuba district. A KAP survey questionnaire was self-administered to 450 randomly selected pregnant women.

Results: Knowledge of CHL was limited. 68% (n=304) of the participants did not know that a baby can be born with hearing loss. Well-known factors about the causes of hearing loss were ear disorders 56% (n=252) and hereditary 55% (n=248) and most of the participants knew little about other factors. 45% (n=203) of the participants reported cultural factors, such as non-adherence to birth and ancestral rituals, as causing hearing loss. Although 81% (n=366) had no knowledge about early hearing detection, the attitude towards NHS was positive with 97% (n=436) willing to accept the service if offered. However, participants may be discouraged from participating fully in the UNHSP processes due to a lack of finances (76%), time (16%) and a fear of equipment (20%). Most participants considered the health facility as the significant point of consultation (98%) and treatment (88%) for CHL. Based on KAP theory, the limited knowledge of participants did not affect their attitude to UNHSP but their attitude towards newborn hearing screening influenced their compliance with UNHSP processes.

Conclusion: The baseline KAP study demonstrated that over half of participants had knowledge of CHL and newborn hearing screening. Although UNHSP compliance seems feasible, various challenges may diminish the wider acceptance of these services. The evidence of this study will enable policymakers to consider KAP strengths and limitations in the delivery of UNHSP services, including health education and health promotion strategies.

Keywords: childhood hearing loss, newborn hearing screening, KAP

Introduction

Disabling hearing loss is defined as hearing loss greater than 40dB for adults and 30dB for children in the better hearing ear (WHO, 2020). In terms of the leading causes of years lived with disability, it is ranked third globally, fifth in sub-Saharan Africa and second in South Africa (Vos *et al.*, 2017). It remains a major public health issue affecting almost 6.1% (466 million) of the global population, with 7% (34 million) of this total accounted for by children (WHO, 2020). Public health strategies work towards Universal Newborn Hearing Screening Programmes (UNHSP) which enable early detection, treatment and the rehabilitation of childhood hearing loss (Muse *et al.*, 2013). These programmes promote the screening of newborns within one month of birth. When applicable, follow-up and diagnosis are organised within the first three months followed by an intervention within six months (Muse *et al.*, 2013). Although, these programmes are implemented widely in high-income countries, some mid-income and most of the low-income countries have not taken them on board.

Prevention strategies of UNHSP require families to be fully integrated into the programme as they are intrinsically connected to the success of the programme. UNHSP guidelines require families concerned to pursue several processes, whereby participation or non-participation can reduce or increase the burden of disabling hearing loss (Muse *et al.*, 2013). For over a decade, several studies have been carried out to analyse the knowledge, attitude and impact of newborn hearing screening (NHS) on families that participated in the intervention and those whose children were identified as deaf (Mohd Khairi *et al.*, 2011; MacNeil & Stone, 2007; Scheepers, Swanepoel & Roux, 2014; Young & Tattersall, 2005; Ravi *et al.*, 2016b). In these studies, an inadequacy of knowledge about NHS, childhood hearing loss (CHL) and its risk factors was observed amongst the study population (Olusanya, Luxon & Wirz, 2006; MacNeil & Stone, 2007; Swanepoel & Almec, 2008; Mohd

Khairi *et al.*, 2011; Akilan, Vidya & Roopa, 2014; Rajagopalan *et al.*, 2014; Ravi *et al.*, 2016b). Addressing this inadequacy of knowledge through public health interventions can inform and improve the effectiveness of the service delivery of UNHSP (Moeller *et al.*, 2013). Clearly, assessing the existing knowledge, attitudes and practices (KAP) relating to UNHSP and childhood hearing loss is crucial in understanding the challenges and optimising the experiences of families.

KAP studies are generally conducted to establish a baseline, assess the strengths and limitations of a health related issue within the community concerned as well as measuring changes in individuals or groups after intervention (Medicine Du Monde, 2011; Launiala, 2009). In this study our objective is to determine the levels of KAP regarding childhood hearing loss and NHS amongst expectant mothers in a semi-rural setting in KwaZulu-Natal Province, South Africa. The South African health system is complex with challenges in population health, health policy and service delivery, embedded in its history of racial and gender discrimination as well as income inequalities (Coovadia *et al.*, 2009). Inequities in health accessibility are shaped by various factors such as service provision/utilisation, financial affordability and the social and cultural acceptability that exists within and between provinces (Xu, Saksena & Evans, 2010; Coovadia *et al.*, 2009). Although UNHSP has been acknowledged as a public health strategy (The Health Professions Council of South Africa, 2018), there is no advanced policy for its roll-out nationally beyond pockets of screening conducted in a private hospitals, but rarely in public hospitals and community-based settings (Meyer & Swanepoel, 2011; Khoza-Shangase & Harbinson, 2015; De Kock, Swanepoel & Hall, 2016; Bezuidenhout *et al.*, 2018). KAP studies regarding childhood hearing loss and NHS amongst mothers that were undertaken in these settings have been influenced by the concepts of biomedical science (Swanepoel & Almec, 2008; Scheepers, Swanepoel & Roux, 2014). This has raised concerns that the populations studied are not aware of

the medical concepts (Ravi *et al.,* 2016a). This research has assessed KAP by using concepts that are embodied in the community's comprehension of CHL and UNHSP as obtained from our previous study (Graham *et al.,* 2019). These concepts were used for the development of a KAP tool which was later validated. This research has used the KAP tool to understand the participants' perceptions regarding childhood hearing loss and UNHSP which could influence their compliance or non-compliance. The results not only established a baseline but highlighted the needs of the community regarding childhood hearing loss and NHS. The outcome will also inform policy prior to establishing UNHSP.

Methods

Study area

Amajuba District is situated in the North-western part of KwaZulu-Natal bordering Mpumalanga and the Free State provinces of South Africa. It has an estimated population of over five hundred thousand with about out one third of the population being children (Amajuba District Municipality, 2018). The health needs of what is largely a rural community are catered for by 3 Provincial Hospitals (Madadeni, Newcastle and Niemeyer), 1 private hospital (Medi-clinic Newcastle), and close to 40 clinics. Newcastle Provincial hospital is a Regional Mother and Child Hospital which provides preventative, promotive, curative and rehabilitative health programmes for all women, newborns and children (Department of Health: Province of Kwazulu-Natal, 2018). The study was conducted in the ante-natal clinic of this provincial hospital as it covers pregnant mothers from all areas.

Study design

The study was a quantitative, cross sectional survey and is descriptive in design. A questionnaire was used as the instrument for data collection. This approach was suitable for this study as it allowed for the measurement of various variables and provided a snapshot of KAP regarding childhood hearing loss in the study population through a single-point data collection exercise. However, it is liable to non-response and information bias due to the inability of study participants to recall facts (Sedgwick, 2014).

Participants

A pre-requisite for participation in this study was being pregnant. Sample size was determined with the understanding that statistical precision increases as prevalence estimates approach 50%, we assumed the KAP among mothers to be approximately 20%. As no similar studies (in terms of data being collected from participant's concepts) have been conducted we assumed the limit of statistical significance to be 0.05 (95% confidence level) with an allowed error of 5%. The sample size before upward adjustment was 384 with an upward adjustment of 15% to allow for biases. We thus rounded the number up to 450 pregnant mothers who were selected for the study.

The recruitment was done at the ante-natal clinic at Newcastle Provincial Hospital. A simple random sampling was conducted so that all expectant mothers attending the clinic could have an equal chance to participate in the study (Creswell, 2013). Participants were recruited by first obtaining the number of women registered to attend the clinic on each day. The approximate sampling frame for each day was 70 – 80 registered pregnant women. Since the list was numbered, each number was written separately in a piece of paper, shuffled and then thirty numbers were randomly selected. We then identified the names from the registered list to obtain participants for

the study. Thereafter, we approached the mothers and invited them to participate in the study. A few refused to participate due to either being in a rush or not feeling well. Refusals were replaced by picking another number using the same selection process as described above.

Data Collection

The data was collected using a questionnaire developed from our previous study (Graham *et al.*, 2019). The Scale Content Validity Index (SCVI) and Item Content Validity Index (ICVI) for the questionnaire was 1. Test-retest repeatability for the questionnaire was Cohen's kappa 0.87 (95% CI: 0.87, 0.87). The questionnaire was administered to 450 participants for three weeks during the months of April and May, 2017. Two research assistants were recruited to assist in the quality control of the survey. They were first trained on the process of data collection in terms of sampling, how to approach participants and the distribution of the questionnaires. Prior to handing out the questionnaire, participants were given an information sheet about the study and were then asked for their written consent. Since it was a self-administered exercise, participants were asked to do this independently without discussing with the person next to them. However, some participants were accompanied by a mother, sister, etc. and we gave them a waiver for this restriction and advised them that it was acceptable to complete the questionnaire together. After completion they returned the questionnaire to either the researcher or research assistant. There was no intervention from the researcher/assistants at the time of completion of the questionnaire. Refreshments and snacks were provided to participants.

Data Analysis

KAP survey data was analysed using SPSS version 25. Responses were given values and descriptive analysis conducted. Since most of the items had variables that were dichotomous, the results were reported in frequencies and percentages.

The assessment of whether knowledge and attitude has influenced compliance or non-compliance towards UNHSP processes was determined by the linear narrative of KAP theory (Warwick, 1983; Launiala, 2009), based on the results of knowledge possessed by mothers' regarding CHL and UNHS and whether it has affected their attitudes which led to compliance or non-compliance.

Ethics

Ethical approval was obtained from Biomedical Research Ethical Committee at University of KwaZulu-Natal with protocol registration no. BFC261/16 (sub-study of BFC421/15). Voluntary informed written consent was administered for participation which included guaranteed confidentiality and anonymity within possible limits.

Results

Participants in the study were comprised of 450 expectant mothers from the Newcastle ante-natal clinic. Demographic data revealed that the ages of the participants ranged from 18 years to over 40 years. Demographic characteristics of the participants are shown in Table 1, including their marital status, religion, the level of education and employment status. The majority of the participants had completed high school with very few that had not been to school and some had tertiary education. The vast majority of participants were single and unemployed. The most common religion was Christianity followed by "African ancestral".

Table 1: Demographic characteristics of participants (N=450)

Characteristics	Frequencies and Percentages (N=450)				
	18-20yrs *N* (%)	21-30yrs *N* (%)	31-40yrs *N* (%)	Over 40yrs *N* (%)	Total *N* (%)
Marital status					
Married	8(2)	28(6)	26(6)	4(1)	66(15)
Single	70(16)	175(39)	97(22)	13(3)	355(79)
Divorced	0	1(.2)	0	1(.2)	3(.7)
Widow	0	0	1/(.2)	0	1(.2)
Living with partner	4(1)	8(2)	12(3)	2(.4)	25(6)
Religion					
Muslim	2(.4)	3(.6)	4(1)	0	9(2)
Christian	50(11)	132(29)	86(19)	14(3)	282(63)
African Ancestral	30(7)	77(17)	46(10)	6(1)	159(35)
Education					
No school	2(.4)	1(.2)	2(.4)	2(.4)	7(2)
Primary	21(5)	21(5)	34(8)	7(2)	83(18)
High School	57(13)	129(29)	72(16)	9(2)	267(59)
College	2(.4)	44(10)	19(4)	1(.2)	66(15)
Higher Education	0	17(4)	1(.2)	1(.2)	27(6)
Employment					
Employed	5(1)	45(10)	42(9)	5(1)	87(19)
Unemployed	41(9)	143(32)	92(20)	15(3)	291(66)
Student	36(8)	24(5)	2(.2)	0	62(15)

Knowledge about newborn hearing loss, its detection and its development in children

Although some participants had knowledge about newborn hearing loss and its development after birth, almost half of the participants did not know about newborn hearing loss (48%) and the development of hearing loss (44%) during a child's growth (Table 2). Similarly, over a half of the participants did not know about the detection of hearing loss (54%), with very few knowing about the issue (19%) and others disagreeing that detection was possible (27%).

Table 2: New-born, Detection and Development of Hearing Loss (N=450)

Measurements	Yes *N* (%)	No *N* (%)	I don't know *N* (%)
New-born hearing loss	146(32)	88(20)	216(48)
Detection of hearing loss	84(19)	121(27)	245(54)
Development of HL after birth	209(46)	45(10)	196(44)

Causes of childhood hearing loss

The top three causes of childhood hearing loss that were reported by participants were any form of ear disorder (wax, discharge, ear drum, nerve), hereditary causes and the impact of the non-adherence to birth and ancestral rituals (Figure 1).

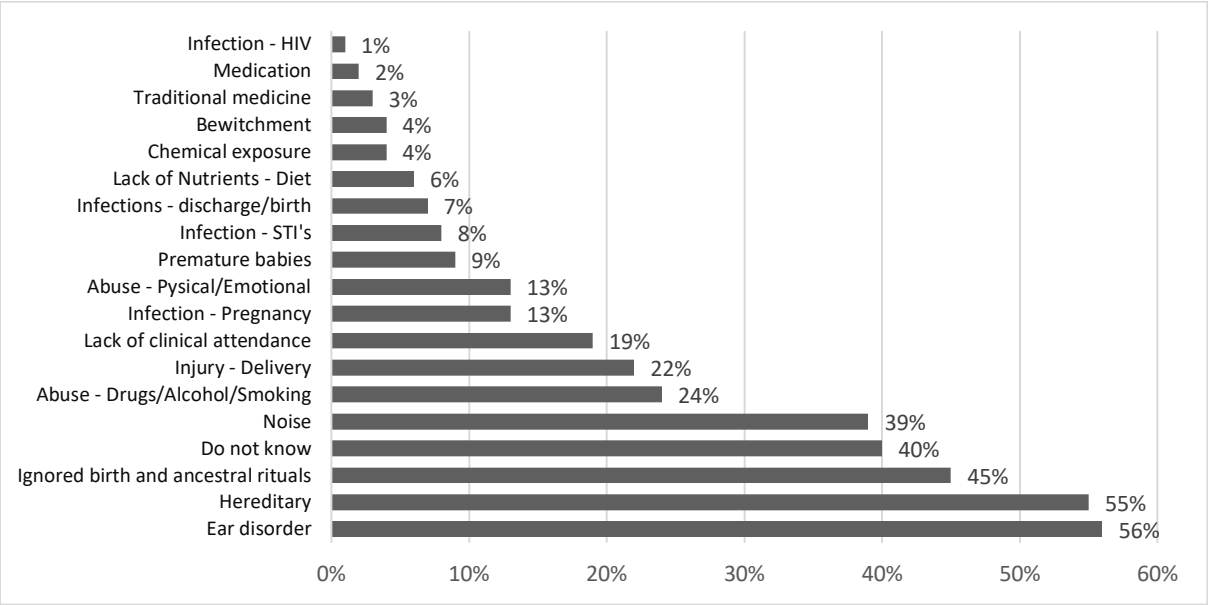
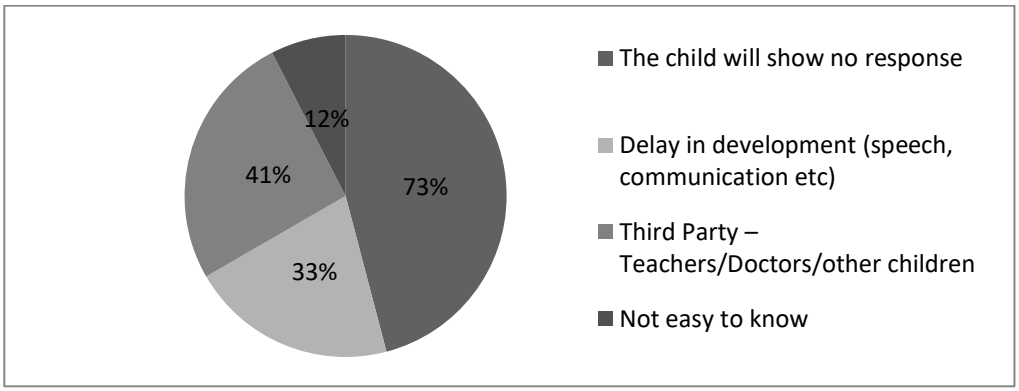


Figure 1: Participants knowledge about causes of hearing loss (N=450)

55% of the participants reported knowledge about the hereditary causes of childhood hearing loss, seemingly contradicting their previous responses regarding knowledge of newborn hearing loss (32%). We assumed that the percentage increase was due to some participants (46%) believing that hearing loss can develop after birth (Table 1). Over a third of the participants did not know the causes of hearing loss but 100% (N=159) of participants whose religion is African ancestral reported abandoning birth and ancestral rituals as the cause of childhood hearing loss as well as 42 additional participants from other religions (Fig. 1, Table 1).

Identification of childhood hearing loss

Participants knowledge about the ways in which one can identify a child with hearing loss was established in several ways (Figure 2), with a child showing no response to sounds as the most frequent answer.



` Figure 2: Participants knowledge about how to identify a child with hearing loss (N=450)

Treatment of childhood hearing Loss

Knowledge about the treatment of a child identified with hearing loss was demonstrated by 394 participants, stating that that treatment can be provided at the health facility. 165 participants mentioned hearing aids (Figure 3). Sixty eight participants said treatment can be provided by cultural means, using local herbs or conducting birth and ancestral rituals. This group was comprised of 37 participants whose religion is "African ancestral" and 28 participants who were Christians. Church as a place to get treatment was reported by 53 participants, of which 37 were Christians and 15 African ancestral.

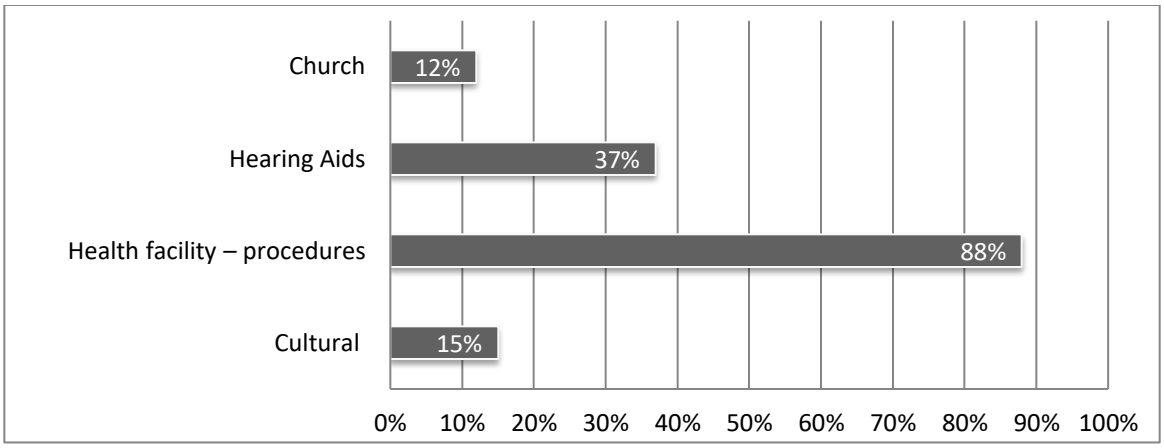


Figure 3: Participants knowledge about treatment of a child identified with hearing loss

Attitude towards hearing loss and newborn hearing screening

From the total participants, 97% (N=436) responded that they would accept newborn hearing screening when offered to them. The remaining 3% (N=14) said the opposite for a number of reasons such as the need to consult the family prior to accepting (N=8), scepticism about hearing loss being identified in newborns (N=6) and not having enough information about hearing screening to make a decision (N=5).

A total of 256 participants (57%) responded that they would be emotionally affected by hearing that one's baby had been diagnosed with hearing loss, with misery reported by 10% (N=47), disappointment 8% (N=38), stress 7% (N=31) whilst guilt, helplessness, and frustration accounted for 21% (N=21) of the participants. Although emotionally affected, 75% (N=339) of the participants responded that they would still want to learn more about the condition.

The participant's beliefs about the seriousness of childhood hearing loss were diverse. Whilst 36% (N=162) of participants believed that the condition of hearing loss was 'very serious' as it would deeply impact the family and community, a higher percentage of 46% (N=207) responded that the condition of hearing loss was `serious'. Other participants ranked it as `somewhat serious' 6%

(N=29) while 12% (N=52) claimed it `not to be serious at all'. In the social context, the impact of hearing loss was described in the following statements; the inability to communicate with others 64% (N=287), the deaf person's inability to hear danger warnings such as fire, vehicles on the road etc. (45% (N=201), the inability to socialise 14% (N=65), the person being vulnerable to sexual abuse 12% (N=54) and susceptible to suicide 2% (N=8). In the economic context, the participants reported that the deaf person will be unable to get a good education 21% (N=93), ultimately leading to unemployment and being dependent on the family 9% (N=40). However, 22% (N=97) reported not knowing of any impact on the family or community.

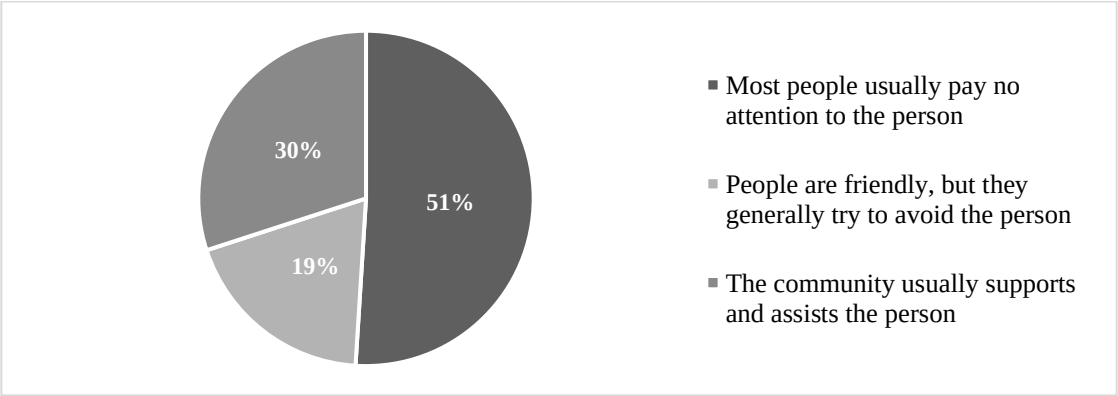


Figure 4: Community attitudes towards a deaf person

In the context of the community's general attitude towards deafness in their everyday environment the results showed that most people usually paid no attention to deaf people (Figure 4). The responses were equally distributed with approximately 50% of the participants in each age group (Table 1).

Habitual hearing care and childhood hearing loss treatment seeking patterns

Participants reported recourse to a health facility (95%) followed by a pharmacy (47%) as their first choice of consultation when they are not well (Figure 5). Additionally, there was a slight

increase of participants seeking health care at the health facility and the percentage doubled when a pharmacy was included as a place for referral when a child was identified with hearing problems.

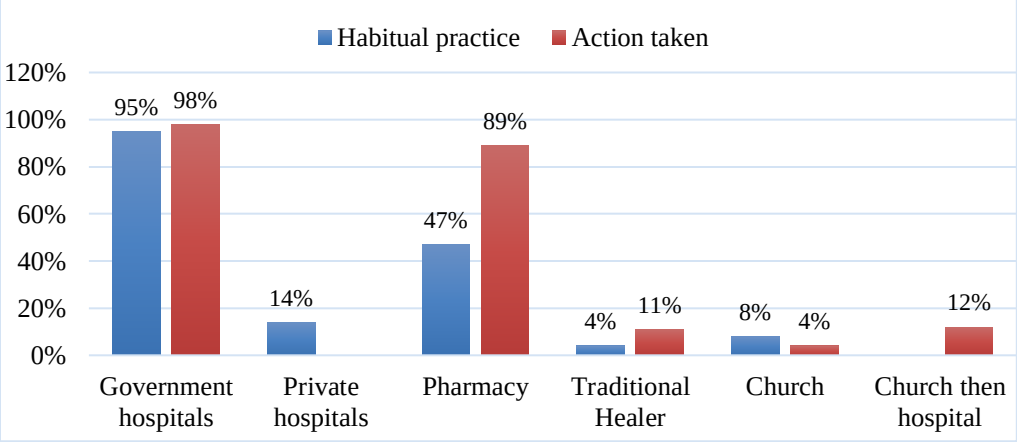


Figure 5: Health seeking behaviour

99% (N=444) of participants responded that they would honour any further examination offered to a child identified with hearing loss. However, the frequency of visits to health facilities for further examination varied widely from 59% (N=263) who said they would willingly visit once a month, whilst 27% (N=122) said once in three months, 12% (N=52) said once in six months and 2% (N=7) said once a year. The reasons given for occasional visits to the health facility are shown below (Figure 6). Financial concerns such as cost of transport, medical aid cover etc., were stated as the biggest challenge (76%, N=343) but 205 participants were still prepared to make monthly visits for further examination, followed by 97 participants who said quarterly visits. Being afraid of the equipment used for screening was another challenge reported by participants (20%, N=88) as they believed that the baby's ears may be affected by the equipment. Additional challenges included lack of time due to other responsibilities at home (16%, N=72) as they claimed visiting the clinic takes the whole day. For those who were employed, they said that the employer would not allow sick leave so often (4%, N=17), so it may be a challenge to visit the health facility

frequently. Other participants reported that frequent visits for further examination would not be a priority as hearing loss was insignificant (5%, N=22).

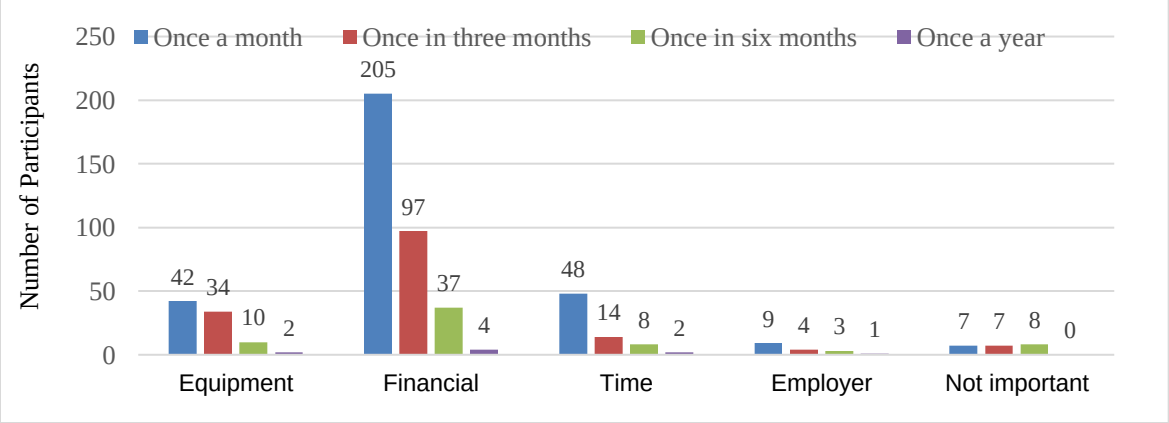


Figure 6: Reasons for infrequent visits to the health facility

In understanding how social support influences health seeking behaviour amongst participants when a child is unwell, responses were distributed unevenly. Sixty one percent (N=273) of the participants stated they would be going to the health facility alone, of which, 7% (N=32) of participants were married, 50% (N=226) were single and 3% (N=12) lived with a partner. Additionally, 21% (N=93) visit the health facility with a parent, 9% (40) with a spouse, 7% (N=30) with other relatives and 2% (N=11) with siblings.

Compliance or non-compliance

Considering the results of participant's knowledge, as demonstrated above, over two thirds had no knowledge that a child can be born with hearing loss. From the linear narrative of KAP theory this lack of knowledge could be viewed as affecting their attitudes toward UNHS. However, the majority of participants had positive attitudes towards UNHS and this translated into action taken, whereby the majority would comply with NHS and any follow-up examination. Accordingly, it could be argued that participants' knowledge of NHS did not influence their compliance whereas

their attitude towards NHS did influence their compliance although this compliance might be hindered by lack of finance.

Awareness

80% (N=360) of the participants reported that they did not have adequate information about newborn hearing screening. Newborn hearing screening was first heard about by 67% (N=303) of the participants at the clinic, 6% (N=25) in the radio/newspaper/brochures and 27% (N=121) had never heard about the concept at all. Furthermore, 66% (N=295) of the participants said they would like to get information about causes of hearing loss, whilst 62% (N=277) said they would prefer information about treatment and 61% (N=274) reported they would prefer to get more information about where to get help when a child is identified with hearing loss.

The current highest source of accessing health information, as per participants' responses, was the clinic followed by radio (Table 3). Nevertheless, to effectively reach the whole community the participants suggested clinics, television and radio.

Table 3: Sources of Information

Source of Information	Current N (%)	Effective in the community N (%)
Clinic	436(97)	426(95)
Newspaper	45(10)	149(33)
Radio	159(35)	375(83
Brochures and Posters	19(4)	93(21)
Family/friends/neighbours	24(5)	48(11)
Television	-	260(58

Discussion

The current study ascertained the knowledge, attitude and practice of mothers towards childhood hearing loss and UNHSP processes in the rural setting of Amajuba district of South Africa, which is partially comparable to previous studies of the same issue. Nonetheless, the approaches used to conduct this study were different, as previous studies were undertaken in established newborn hearing screening interventions and the current study was conducted prior the intervention.

Knowledge in families about childhood hearing loss is important given that preventable causes account for approximately 60% of all causes (WHO, 2016). Preventable childhood hearing loss encompasses various causes such as infections, birth complications, ototoxic medicines, etc. (Deltenre & Van Maldergem, 2013; Olusanya, Neumann & Saunders, 2014). The current study demonstrated that some participants had some knowledge about the factors that cause childhood hearing loss and this is consistent with previous studies (Olusanya, Luxon & Wirz, 2006; Swanepoel & Almec, 2008; Rajagopalan *et al.*, 2014; Ravi *et al.*, 2016b). However, the current study also revealed that some ear disorders, such as too much earwax, ear discharge or the accumulation of fluid inside the ear (Deltenre & Van Maldergem, 2013; WHO, 2016) were reported as higher than other factors as a cause of hearing loss. In line with previous studies, similar results of knowledge regarding ear discharge being a cause of infant hearing loss were observed (Olusanya, Luxon & Wirz, 2006; Swanepoel & Almec, 2008; Rajagopalan *et al.*, 2014; Ravi *et al.*, 2016b). The limited knowledge of preventable childhood hearing loss, as shown in this study, can be easily addressed through maternal education and the provision of healthy ear care and hygiene practices (WHO, 2016).

The awareness of families regarding childhood hearing loss and NHS will not only encourage and enhance hearing health but will increase opportunities for the child's cognitive development

(Gilliver, Ching & Sjahalam-King, 2013). General awareness regarding NHS in the current study was absent and 80% of the participants reported a lack of information. Although knowledge about early detection (54%) was lacking in the current study, participants' attitudes were inclined positively towards NHS (97%) and its processes, which includes further appointments (99%) and treatment (98%). This is consistent with previous studies that have demonstrated similar trends towards NHS and the usage of hearing aids (Olusanya, Luxon & Wirz, 2006; Swanepoel & Almec, 2008; Ravi *et al.*, 2016b; Rajagopalan *et al.*, 2014). Additionally, the present study also revealed challenges (financial, fear of screening equipment, time, social support), which participants may encounter that could constrain their engagement in the UNHSP processes. Nonetheless, the financial and time factors can be viewed as reflective of the socio-economic demographics of Amajuba district (Statistics South Africa, 2012) which has an unemployment rate of 39% of the functional group (15-64 years old) which itself comprises almost 62% of the total population (500,000). The majority of previous studies did not address these issues, other than one study which reported on financial challenges (Scheepers, Swanepoel & Roux, 2014). Another study which assessed challenges of follow-up in South Africa reported lack of time due to employment and appointment time being inconvenient (Kanji & Krabbenhoft, 2018). A second challenge observed in previous studies was the state of anxiety experienced by mothers who were called back for a child's rescreening or other follow-up examinations (Mohd Khairi *et al.*, 2011; Mazlan *et al.*, 2014) and this emotional state of mind was also reported by participants in this study. Nonetheless, participants were keen to get more information about the condition of hearing loss and NHS. Although information provided to mothers about newborn hearing screening increased their knowledge of the content of the UNHSP process and lowered the levels of anxiety (Bamford, Uus

& Davis, 2005; Mazlan *et al.*, 2014; Scheepers, Swanepoel & Roux, 2014), we must remain cautious in assuming that knowledge significantly moderates anxiety (Crockett *et al.*, 2006).

Addressing these gaps in ear health knowledge requires a supportive environment which acknowledges existing social-cultural factors in the community (WHO, 2018b). In previous studies, cultural factors (bewitchment, ancestral sins) were declared as non-determinants of hearing loss (Olusanya, Luxon & Wirz, 2006; Rajagopalan *et al.*, 2014), which is in contrast to the current study. Cultural factors such as non-adherence to birth and ancestral rituals were affirmed by 45% of the participants as one of the top three causes of hearing loss, most notably amongst those who believed in African ancestral religion, evoking specifically Zulu religious beliefs which are reinforced by historical factors and provides meaning which allows them to have some control over their environment (Lawson & McCauley, 1990; Kádár, 2013:pp.11–12). The Zulu religion is built upon indigenous beliefs that are dynamic with a fluid set of resources (God, ancestors, sacrifice, divination, political authority) that are informative, realistic and spirited (Chidester, 2008). Culturally, the presence of ancestors in the Zulu tribe is valued, as the dead are still viewed as belonging to the community. They remain an integral part of family relationships and are acknowledged through particular rites and rituals (Nel, 2007). In these rituals the ancestors are invoked and invited to participate during anxious times such as birth, puberty, marriage and death or during times of crisis, such as ill health (Nel, 2007). These entrenched beliefs of birth and ancestral rituals can inhibit parental uptake of NHS services. Accordingly, this context alludes to the importance of the integration of culturally sensitive notions for the effectiveness of UNHSP's service delivery (Muse *et al.*, 2013; Moeller *et al.*, 2013; Frieden, 2014).

The results of the current study can be easily integrated into UNHSP's 'Family Centred Early Intervention' (FCEI) principles of practice, such as 'family/provider partnerships', 'family, social

and emotional support' and 'informed choice and decision making' (Moeller *et al.*, 2013). Besides the provision of early hearing detection, the results will afford a space for an interaction between partners that guarantees family rights and allows them to take control of their ear health and hearing issues (WHO, 2016; Frieden, 2014). Similarly, the provision of effective support services may act as a dynamic force to motivate individuals to engage positively in early detection and ear health care as well as dealing with identified deaf children (Reblin & Uchino, 2008; Gascon-Ramos *et al.*, 2010). Additionally, a supportive community environment is required, as the current study revealed the pervasiveness of stigma associated with disabling hearing loss, whereby 70% said that deaf people are shunned by the community. These could be built upon in the planning phase of UNHSP (Young & Tattersall, 2005; Muse *et al.*, 2013), as the dynamics arising from participation are likely to form and change future beliefs and opinions. These results also underscore the need for policies that integrate ear health knowledge into maternal health education (Frieden, 2014; WHO, 2018a). Nonetheless, this will depend upon health promotion strategies which are aligned to their social, cultural or economic context (WHO, 2012).

Finally, the results of compliance and non-compliance towards UNHSP as being influenced by attitude but less affected by knowledge should be viewed with caution. Compliance refers to an individual consenting to a group outlook but privately following their own beliefs (Sowden *et al.*, 2018). Although participants self-administered the questionnaire anonymously, they were in a public setting (hospital) which may have influenced their responses regarding compliance.

Limitations and recommendations for future research

Although the results have provided a KAP representation of the community of study, we also need to consider some potential limitations prior to drawing conclusions. The nature of a cross-sectional

study such as this, characterised by one-point-in-time data, does reflect changes that are inevitable in another period of time, during everyday interactions. Another limitation can be observed in the usage of a self-administered questionnaire for data collection whereby the information given by the participants is taken at face value and may have shortcomings due to recall bias. Though anonymity and confidentiality were guaranteed, it is likely that some participants may have exaggerated or under-stated certain socially desirable responses that were pertinent to KAP.

We recommend that in future studies of childhood hearing loss and NHS KAP studies not only provide evidence in a biomedical context but also in interdisciplinary perspectives. Future research needs to look in depth at social, cultural and economic issues as this can provide tailor-made early detection interventions that have an influence on a child's health outcome. We also suggest that further research should be conducted to examine the KAP of health professionals in this setting, as this will not only increase the effectiveness of implementation of UNHSP but will also highlight issues that will inform future policy to promote reasonable UNHS interventions.

Conclusion

The results of the study demonstrated that participants' knowledge of childhood hearing loss and newborn hearing screening is lacking. Nevertheless, their attitude towards NHS was positive and they demonstrated a willingness to participate in the screening process. The study also revealed that participant's knowledge did not influence compliance with NHS but their attitude did. Conversely, some of their knowledge responses contradicted their willingness to participate and consequently their overall compliance with UNHSP may encounter challenges. The key results however, will assist policy makers to plan effective, complex interventions in establishing UNHS programmes within this community. This will include health promotion strategies such as: 1)

maternal ear health and hearing loss education, 2) public education programmes that involve different mediums and 3) social marketing and advocacy which will create a supportive environment in relation to hearing loss. These interventions need to assimilate all socio-cultural factors regarding childhood hearing loss and newborn hearing screening within the community and can provide a potential mechanism for the wider acceptance of UNHSPs.

Acknowledgements

The authors wish to thank all the women that participated in this study. Thanks to the Department of Health and the Newcastle hospital staff for their support during the study. We also thank the Amajuba Newborn Hearing Screening Research Programme for providing the opportunity to conduct this research.

References

Akilan, R., Vidya, R. & Roopa, N. (2014) Perception of ‘ mothers of beneficiaries ’ regarding a rural community based hearing screening service. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (12), 2083–2088. Available from: doi:10.1016/j.ijporl.2014.09.009.

Amajuba District Municipality (2018) *Amajuba District Municipality - Demographic*. [Online]. 2018. Available from: https://municipalities.co.za/demographic/116/amajuba-district-municipality [Accessed: 17 April 2018].

Bamford, J., Uus, K. & Davis, A. (2005) Screening for hearing loss in childhood: issues, evidence and current approaches in the UK. *Journal of medical screening*. [Online] 12 (3), 119–124. Available from: doi:10.1258/0969141054855256.

Bezuidenhout, J.K., Khoza-Shangase, K., De Maayer, T. & Strehlau, R. (2018) Universal newborn hearing screening in public healthcare in South Africa: Challenges to implementation. *SAJCH South African Journal of Child Health*. [Online] 12 (4), 159–163. Available from: doi:10.7196/SAJCH.2018.v12i4.1522.

Chidester, D. (2008) Dreaming in the contact zone: Zulu dreams, visions, and religion in nineteenth-century South Africa. *Journal of the American Academy of Religion*. [Online] 76 (1), 27–53. Available from: doi:10.1093/jaarel/lfm094.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., et al. (2009) The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*. [Online] 374 (9692), 817–834. Available from: doi:10.1016/S0140-6736(09)60951-X.

Creswell, J.W. (2013) *Research Design: Qualitative, Quantitative and Mixed Method Approaches 4th ed.* SAGE Publications Inc.

Crockett, R., Wright, A.J., Uus, K., Bamford, J., et al. (2006) Maternal anxiety following newborn hearing screening: the moderating role of knowledge. *Journal of medical screening*. [Online] 13 (1), 20–25. Available from: doi:10.1258/096914106776179854.

Deltenre, P. & Van Maldergem, L. (2013) Hearing loss and deafness in the pediatric population: causes, diagnosis, and rehabilitation. *Handbook of Clinical Neurology*. [Online] 113, 1527–1538. Available from: doi:10.1016/B978-0-444-59565-2.00023-X [Accessed: 25 May 2018].

Department of Health: Province of Kwazulu-Natal (2018) *Newcastle Provincial Hospital*. [Online]. 2018. Available from: http://www.kznhealth.gov.za/newcastlehospital.htm [Accessed: 17 April 2018].

Frieden, T.R. (2014) Six components necessary for effective public health program implementation. *American Journal of Public Health*. [Online] 104 (1), 17–22. Available from: doi:10.2105/AJPH.2013.301608 [Accessed: 2 August 2020].

Gascon-Ramos, M., Campbell, M., Bamford, J. & Young, A. (2010) Influences on parental evaluation of the content of early intervention following early identification of deafness: A study about parents' preferences and satisfaction. *Child: Care, Health and Development*. [Online] 36 (6), 868–877. Available from: doi:10.1111/j.1365-2214.2010.01092.x.

Gilliver, M., Ching, T.Y.C. & Sjahalam-King, J. (2013) When expectation meets experience: parents' recollections of and experiences with a child diagnosed with hearing loss soon after

birth. *International journal of audiology*. [Online] 52 Suppl 2 (S2), S10-6. Available from: doi:10.3109/14992027.2013.825051.

Graham, C., Seeley, J., Gina, A. & Saman, Y. (2019) Mapping the content of mothers ' knowledge , attitude and practice towards universal newborn hearing screening for development of a KAP survey tool. *PloS one*. [Online] 14 (2), 1–20. Available from: doi:10.1371/journal.pone.0210764.

Kádár, D.Z. (2013) *Relational rituals and communication : ritual interaction in groups*. [Online]. Available from: https://books.google.co.uk/books?hl=en&lr=&id=vRIhAQAAQBAJ&oi=fnd&pg=PP1&ots=SO4r5bJ0ys&sig=6NPVtrtMY0a3NSxxRa3Nxg77e_0#v=onepage&q&f=false [Accessed: 27 May 2018].

Kanji, A. & Krabbenhoft, K. (2018) Audiological follow-up in a risk-based newborn hearing screening programme: An exploratory study of the influencing factors. *South African Journal of Communication Disorders*. [Online] 65 (1), 1–7. Available from: doi:10.4102/sajcd.v65i1.587.

Khoza-Shangase, K. & Harbinson, S. (2015) Evaluation of universal newborn hearing screening in South African primary care. *African Journal of Primary Health Care and Family Medicine*. [Online] 7 (1), 1–12. Available from: doi:10.4102/phcfm.v7i1.769.

De Kock, T., Swanepoel, D.W. & Hall, J.W. (2016) Newborn hearing screening at a community-based obstetric unit: Screening and diagnostic outcomes. *International Journal of Pediatric Otorhinolaryngology*. [Online] 84, 124–131. Available from: doi:10.1016/j.ijporl.2016.02.031.

Launiala, A. (2009) How much can a KAP survey tell us about people ' s knowledge , attitudes and practices ? Some observations from medical anthropology on malaria in pregnancy in Malawi Background : KAP surveys. *Anthropology Matters Journal*. 11 (1), 1–13.

Lawson, E.T. & McCauley, R.N. (1990) *Rethinking religion : connecting cognition and culture*. Cambridge University Press.

MacNeil, J.R. & Stone, S. (2007) Evaluating Families' Satisfaction With Early Hearing Detection and Intervention Services in Massachusetts. *American Journal of Audiology* •. 16 (June).

Mazlan, R., Lee, T., Sarah, S.Z. & Abdullah, A. (2014) A questionnaire-based study on parental satisfaction with a universal newborn hearing screening program in Kuala Lumpur , Malaysia. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (2), 348–353. Available from: doi:10.1016/j.ijporl.2013.12.014.

Medicine Du Monde (2011) *The Kap Survey model - Knowledge attitude and practices | Médecins du Monde*. [Online]. Available from: https://www.medecinsdumonde.org/en/actualites/publications/2012/02/20/kap-survey-model-knowledge-attitude-and-practices [Accessed: 21 May 2018].

Meyer, M.E. & Swanepoel, D.W. (2011) Newborn hearing screening in the private health care sector - A national survey. *South African Medical Journal*. [Online] 101 (9), 665–667. Available from: doi:10.7196/SAMJ.5003.

Moeller, M.P., Carr, G., Seaver, L., Stredler-brown, A., et al. (2013) Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing : An International Consensus Statement. *Journal of Deaf Studies and Deaf Education*. [Online] 18 (4). Available from: doi:10.1093/deafed/ent034.

Mohd Khairi, M.D., Noor Rafidah, K., Affizal, A., Normastura, A.R., et al. (2011) Anxiety of the mothers with referred baby during Universal Newborn Hearing Screening. *International Journal of Pediatric Otorhinolaryngology*. [Online] 75 (4), 513–517. Available from: doi:10.1016/j.ijporl.2011.01.009.

Muse, C., Harrison, J., Yoshinaga-Itano, C., Grimes, A., et al. (2013) Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing. *Pediatrics*. [Online] 131 (4), e1324–e1349. Available from: doi:10.1542/peds.2013-0008.

Nel, M.J. (2007) *The Ancestors and Zulu Family Transitions: A Bowen Theory and Practical Theological Interpretation*. [Online]. University of South Africa. Available from:

https://core.ac.uk/download/pdf/43165099.pdf.

Olusanya, B.O., Luxon, L.M. & Wirz, S.L. (2006) Maternal views on infant hearing loss in a developing country. *International journal of pediatric otorhinolaryngology*. [Online] 70 (4), 619–623. Available from: doi:10.1016/j.ijporl.2005.08.004.

Olusanya, B.O., Neumann, K.J. & Saunders, J.E. (2014) The global burden of disabling hearing impairment: a call to action. *Bulletin of the World Health Organization*. [Online] 92 (5), 367–373. Available from: doi:10.2471/BLT.13.128728.

Rajagopalan, R., Selvarajan, H.G., Rajendran, A. & Ninan, B. (2014) Grandmothers ' perspective on hearing loss in children and newborn hearing screening. *Indian Journal of Otology*. [Online] 20 (1), 20–24. Available from: doi:10.4103/0971-7749.129803.

Ravi, R., Gunjawate, D.R., Yerraguntla, K., Rajashekhar, B., et al. (2016a) Knowledge and attitude of parents/caregivers towards hearing loss and screening in newborns – a systematic review. *International Journal of Audiology*. [Online] 2027 (August), 1–8. Available from: doi:10.1080/14992027.2016.1215560.

Ravi, R., Yerraguntla, K., Gunjawate, D.R., Rajashekhar, B., et al. (2016b) Knowledge and attitude (KA) survey regarding infant hearing loss in Karnataka , India. *International Journal of Pediatric Otorhinolaryngology*. [Online] 85, 1–4. Available from: doi:10.1016/j.ijporl.2016.03.012.

Reblin, M. & Uchino, B.N. (2008) Social and emotional support and its implication for health. *Current Opinion in Psychiatry*. [Online]. 21 (2) pp.201–205. Available from: doi:10.1097/YCO.0b013e3282f3ad89.

Scheepers, L.J., Swanepoel, D.W. & Roux, T. le (2014) Why parents refuse newborn hearing screening and default on follow-up rescreening-A South African perspective. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (4), 652–658. Available from: doi:10.1016/j.ijporl.2014.01.026.

Sedgwick, P. (2014) Cross sectional studies: advantages and disadvantages. *BMJ : British Medical Journal*. [Online] 348 (2276). Available from: doi:10.1136/bmj.g2276 [Accessed:

17 April 2018].

Sowden, S., Koletsi, S., Lymberopoulos, E., Militaru, E., et al. (2018) Quantifying compliance and acceptance through public and private social conformity. *Consciousness and Cognition*. [Online] 65, 359–367. Available from: doi:10.1016/j.concog.2018.08.009 [Accessed: 4 August 2020].

Statistics South Africa (2012) *Census 2011 Census in brief*. [Online]. Available from: http://www.statssa.gov.za/census/census_2011/census_products/Census_2011_Census_in_brief.pdf [Accessed: 11 December 2019].

Swanepoel, D. & Almec, N. (2008) Maternal views on infant hearing loss and early intervention in a South African community. *International journal of audiology*. [Online] 47 Suppl 1, S44-8. Available from: doi:10.1080/14992020802252279.

The Health Professions Council of South Africa (2018) Professional Board For Speech, Language and Hearing Professions Early Hearing Detection and Intervention Programmes in South Africa - Guidelines. *Children*. [Online] Available from: http://www.hpcsa.co.za/Uploads/editor/UserFiles/downloads/speech/Early_Hearing_Detection_and_Intervention_(EHDI)_2018.pdf [Accessed: 18 June 2018].

Vos, T., Alemu Abajobir, A., Hassen Abate, K., Abbafati, C., et al. (2017) Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet*. [Online] 390, 1211–1259. Available from: doi:10.1016/S0140-6736(17)32154-2 [Accessed: 4 May 2018].

Warwick, D.P. (1983) *The KAP survey : dictates of mission versus demands of science /*. Cambridge, MA :, Harvard Institute for International Development, Harvard University,.

WHO (2018a) Addressing The Rising Prevalence of Hearing Loss. *WHO*. [Online]. Available from: doi:10.1080/09687599.2011.589198.

WHO (2016) Childhood Hearing Strategies for prevention and care. *WHO Library Cataloguing-in-Publication Dat*. [Online] Available from:

apps.who.int/iris/bitstream/10665/204632/1/9789241510325_eng.pdf.

WHO (2020) *Deafness and hearing loss: Fact Sheet*. [Online]. 2020. Media Centre. Available from: https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss [Accessed: 23 July 2020].

WHO (2018b) *Health 2020 priority area four: creating supportive environments and resilient communities A compendium of inspirational examples*. Erio Ziglio (ed.). [Online]. Denmark, WHO Regional Office for Europe. Available from: http://www.euro.who.int/pubrequest [Accessed: 2 August 2020].

WHO (2012) *Health education: theoretical concepts, effective strategies and core competencies*. [Online]. Cairo, Regional Office for the Eastern Mediterranean. Available from: https://apps.who.int/iris/handle/10665/119953?show=full.

Xu, K., Saksena, P. & Evans, D.B. (2010) Health financing and access to effective interventions. *World Health Organization*. [Online] 18. Available from: http://www.who.int/healthsystems/topics/financing/healthreport/8Accesstocare.pdf [Accessed: 18 June 2018].

Young & Tattersall, H. (2005) Parents ' of Deaf Children Evaluative Accounts of the Process and Practice of Universal Newborn Hearing Screening. *Journal of Deaf Studies and Deaf Education*. [Online] 10 (2). Available from: doi:10.1093/deafed/eni014.

Chapter 4 reported the KAP baseline of mothers regarding childhood hearing loss and newborn hearing screening. In Chapter 5 a synthesis of the research is presented together with a conclusion and implications for future research.

CHAPTER 5

SYNTHESIS, CONCLUSION AND IMPLICATIONS FOR FUTURE RESEARCH

SYNTHESIS, CONCLUSION AND IMPLICATIONS FOR FUTURE RESEARCH

5.1 Synthesis

In this thesis I have covered the full process of developing a KAP survey tool regarding childhood hearing loss and universal newborn hearing screening programme (UNHSP) procedures amongst mothers that can be used with parents, families and the community. The importance of developing this tool is due to UNHSP procedures that require families to have frequent consultations at various stages of the intervention, specifically when a child has failed screening tests or been identified with hearing loss (Muse *et al.*, 2013). Further, the challenges observed in many programmes have been loss to follow-up examinations (Stich-Hennen & Bargen, 2008; Olusanya, 2009, 2011) due to families lack of knowledge about NHS and the false positive outcome of pursuing screening procedures (Scheepers, Swanepoel & Roux, 2014). To a certain extent it also raises questions about their level of acceptance of the programme and their participation in the procedures of these programmes. Contextual literature indicated that working in collaborative partnership with families with regard to childhood hearing care and the early detection of hearing loss initiatives may decrease the burden of disabling hearing loss (Muse *et al.*, 2013; Olusanya, Neumann & Saunders, 2014). The literature on hearing care suggests that in order to increase the accessibility and culturally appropriateness of service delivery which foster beneficial health outcomes and encourage the uptake of services it is important for families' general perception of hearing loss in children to be understood by service providers (Preston, Waugh & Taylor, 2009; Ntsoane & Oduntan, 2010).

This thesis is the outcome of research undertaken in South Africa, where the health system is complex, with challenges in population health, health policy and service delivery, embedded in its history of racial and gender discrimination as well as income inequalities (Coovadia *et al.*, 2009). Inequities in health accessibility are shaped by various factors such as service provision and utilisation, financial affordability and the social and cultural acceptability that exists within and between provinces (Xu, Saksena & Evans, 2010; Coovadia *et al.*, 2009). Although UNHSP has been acknowledged as a strategy of public health (The Health Professions Council of South Africa, 2018), there is no advanced policy for its roll-out nationally beyond pockets of screening conducted in a few hospitals. In recent developments, the private sector health provider (Netcare) launched UNHSP in its hospitals. However these services would not be accessible to the larger communities that utilises services in the public sector (Netcare, 2019). The thesis has thus linked three sub-projects sequentially whereby each chapter provides for community involvement, in varying degrees of responsibility, in terms of defining, evaluating and imparting meaning to the content used in the tool. These chapters discussed the evidence of developing and validating the tool, as well as the baseline KAP of the community of study which could inform policy and health promotion strategies.

The key findings generated from this thesis are outlined below.

5.1.1 Devising the content area of childhood hearing loss and Universal Newborn Hearing Screening

In chapter 2, I described the content area for developing the questionnaire regarding childhood hearing loss and UNHSP by conducting a study of expectant mothers in Amajuba district, South Africa. The study evoked the Alma-Ata 1978 vision of health as a human right whilst increasing community participation, with the aim of enhancing individuals' self-reliance and social awareness of their health issues that may lead to better health outcomes (World Health Organization, 2000). The context for undertaking the study was acquired from the literature on hearing loss, whereby certain key ideas enabled the development of the guiding questions used in the interviews (Olusanya, 2008; Muse *et al.*, 2013; WHO, 2016). The study, undertaken in the participants own setting, enabled us to identify nine themes that were meaningful for the development of a KAP survey tool. With regards to **Knowledge**, I determined four themes which included, 1) the perception of hearing loss, 2) the causes of hearing loss, 3) the identification of hearing loss and 4) the detection and treatment of hearing loss. These themes represented the general perspectives of participants and their understanding of childhood hearing loss and early hearing detection.

In terms of **Attitude**, two themes were identified, 5) beliefs and 6) feelings. These themes reflected the beliefs of participants about childhood hearing loss which were expressed in the context of their familiar dogmas about childhood hearing loss. They also represented a mother's stance towards newborn hearing screening procedures which was expressed either positively or negatively. The responses of participants further explained the likely impact at the personal level so that when a child is identified with hearing loss it could eventually lead to potentially negative emotional attitudes.

With respect to **Practice** three themes were established comprising 7) health seeking behaviour; 8) follow-up examination and 9) support. The health seeking behaviour theme was manifested through efforts to understand the health seeking patterns of the participants. Since UNHSP obligates mothers/families to make frequent hospital visits for further assessments or referrals when a child is identified with hearing loss, the responses of participants with regard to this issue resulted in an additional theme of follow-up examinations. I also tried to understand the assistance received from family and community when a child is not well. The responses showed the importance of the theme of support.

The results of this study provided a detailed and contextualised understanding of childhood hearing loss and newborn hearing screening. This understanding produced the themes that were used to develop a questionnaire as demonstrated in Chapter 3.

5.1.2 Development of the tool, assessment of validity and test-retest repeatability

In chapter 3, I demonstrated how I used the themes obtained in chapter 2 to develop a KAP survey tool. I designed a tool that had five sections, with twenty-nine items. Three sections represented the three KAP constructs whereby Knowledge had six items, Attitude had six items and Practice had six items. The remaining two sections consisted of Demography with six items and Awareness with five items. It is a requirement of any new tool to demonstrate its validity, in terms of whether the measurements are measuring what they are supposed to measure and reliability, where the consistency/stability of the measurement over a period of time is assessed (Coughlan, Cronin & Ryan, 2007; Drost, 2011). The assessments of the validity and reliability of the developed tool were done in stages. The first stage involved the assessment of the comprehensiveness and representativeness of the content of each item in the tool and the entire tool. The results revealed an item content validity index (ICVI) of 1 and content validity index (CVI) of 1 for the three constructs indicating a sufficient coverage of the content domain. In the second stage, the study presented the face validity of the tool with a high percentage of participants reporting that the tool was appropriate in terms of clarity and logic. Lastly, the study exhibited reliability through a test-retest repeatability, achieving a Cohen's Kappa coefficient of 0.87, demonstrating that the tool as stable over different periods in time. I also argued that the process of developing a KAP survey tool was feasible by addressing three assessment criteria; science, population and resources.

Overall, the KAP survey tool demonstrated that it will consistently assess what it is supposed to measure over a period of time. The tool was then used for a KAP baseline of mothers which is described in chapter 4.

5.1.3 Baseline of mothers' Knowledge, Attitude and Practice

The results of the assessment of knowledge, attitude and practice of the mothers were presented in chapter 4. By using the validated KAP tool, limited knowledge about newborn hearing loss and its advancement into childhood, as well as early hearing detection was observed amongst participants. Similar observations were reported in previous studies but with respect to maternal knowledge about infant hearing loss (Olusanya, Luxon & Wirz, 2006; Swanepoel & Almec, 2008; Ravi *et al.*, 2016b). Also in support of previous studies (Swanepoel & Almec, 2008; Rajagopalan *et al.*, 2014; Ravi *et al.*, 2016a), the current study confirmed that participants understood ear disorders to be a cause of hearing loss but with limited knowledge of other risk factors. Additionally, with respect to the causes of hearing loss, non-adherence to birth and ancestral rituals was reported by almost half of the participants. This affirmed that cultural factors are perceived by participants in the study area to be amongst the determinants of childhood hearing loss,

which is in contrast with previous studies where they were scarcely observed (Swanepoel & Almec, 2008; Rajagopalan *et al.*, 2014).

In terms of health seeking behaviour, health facilities were largely seen as the first point of consultation and treatment, even though general support for a mother is considered to be scarce when a child is unwell. On the other hand, the general attitudes of participants towards early UNHSP procedures were favourable in terms of their willingness to accept newborn hearing screening if offered but with differing attitudes to follow-up tests which require regular visits to the health facility. The barriers to follow-up were identified as financial (transport, medical aid cover, etc.), fear of the equipment used for screening/further tests and lack of time, which may lead UNHSP procedures being unfavourable. To a certain extent, general attitudes towards hearing loss presented issues of stigma as participants stated that deaf persons are usually ignored and people avoid them in their community.

Overall, the study presented us with a baseline KAP of mothers which assumes their compliance with newborn hearing screening programmes. The study also showed that mother's knowledge did not affect their attitudes, but their attitudes did influence their practice/behaviour in terms of compliance and non-compliance with UNHSP processes. However, the data also shows that the level of compliance with the follow-up process is reduced due to various challenges faced by mothers. Accordingly, the study provided an insightful description of the KAP of mothers which can shape the opinions of policy makers in promoting strategies that affect child hearing health positively and overall wellbeing.

5.2 General conclusion

This research has demonstrated that it is feasible to develop a KAP survey tool regarding childhood hearing loss and newborn hearing screening. It has demonstrated the content used to develop the tool which was obtained from the community of study. It also achieved a validated tool through assessment of face validity and content validity as well as confirming reliability through test-retest repeatability. The baseline KAP study has shown that socio-cultural, economic and environmental factors are likely to determine knowledge, attitudes and health seeking behaviour with regard to childhood hearing loss. The study also demonstrated that compliance with UNHSP processes is influenced by mother's attitudes but that a variety of circumstances can render this possibility unrealistic. However, the results should be viewed from my position as a researcher, as someone who contextualised the research on established knowledge of CHL and UNHS. The research agenda, from project design to implementation was influenced by existing literature and the results should be understood from that perspective. Additionally, we should note the fact that the studies were based at health facilities and that the participants' perception of the setting could have influenced the information provided. Overall, this research has largely contributed to the literature,

specifically for how countries without UNHS programs may proceed with the implementation of a UNHS program which addresses socio-cultural factors and which could sensitize the voluntary parental uptake of the services.

5.3 Implications for future research

Overall, the research has identified certain aspects in its individual studies which require further consideration to improve on the objectives of study. These would include:

1. Further validation of the tool using predictive validity to examine performance on knowledge, attitude and behaviour after UNHSP implementation and health education.
2. Cross validation of the KAP tool across independent samples as it can improve the stability of the scale construct.
3. Consideration, in future KAP studies, with regard to childhood hearing loss and newborn hearing screening, to focus not only on the biomedical context but also to undertake in-depth assessments of social, cultural and economic issues in the community.
4. A study of the KAP by health professionals, regarding childhood hearing loss and newborn hearing screening programmes may improve service delivery.
5. Further study to investigate appropriate health promotion strategies that can increase the understanding of childhood hearing loss, influence positive attitudes towards hearing loss and newborn hearing screening, as well as encourage the child's health outcomes through healthy behaviours.

References

Akilan, R., Vidya, R. & Roopa, N. (2014) Perception of ' mothers of beneficiaries ' regarding a rural community based hearing screening service. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (12), 2083–2088. Available from: doi:10.1016/j.ijporl.2014.09.009.

Azjen, I. (2005) *Attitudes, Personality And Behaviour 2nd Ed.* [Online]. Open University Press. Available from: doi:10.1037/e418632008-001.

Badran, I.G. (1995) Knowledge, attitude and practice the three pillars of excellence and wisdom: a place in the medical profession. *Eastern Mediterranean Health Journal*. [Online] 1 (1), 8–16. Available from: https://apps.who.int/iris/bitstream/handle/10665/116905/emhj_1995_1_1_8_16.pdf?sequence=1&is

Allowed=y [Accessed: 2 August 2020].

Bezuidenhout, J.K., Khoza-Shangase, K., De Maayer, T. & Strehlau, R. (2018) Universal newborn hearing screening in public healthcare in South Africa: Challenges to implementation. *SAJCH South African Journal of Child Health*. [Online] 12 (4), 159–163. Available from: doi:10.7196/SAJCH.2018.v12i4.1522.

Bornstein, M.H., Jager, J. & Putnick, D.L. (2013) Sampling in Developmental Science: Situations, Shortcomings, Solutions, and Standards. *Dev Rev*. [Online] 33 (4), 357–370. Available from: doi:10.1016/j.dr.2013.08.003 [Accessed: 1 August 2020].

Chien-Yun, D., Wan-Fei, C., Yu-Hsi, Y. & Chia-Hung, Y. (2012) A Study on Modification of Knowledge, Attitude and Practice on Vocational High School Electronics Courses Integrated with Nanotechnology Concept. *Int. J. of Thermal & Environmental Engineering*. [Online] 4 (1), 73–79. Available from: doi:10.5383/ijtee.04.01.011.

Coovadia, H., Jewkes, R., Barron, P., Sanders, D., et al. (2009) The health and health system of South Africa: historical roots of current public health challenges. *The Lancet*. [Online] 374 (9692), 817–834. Available from: doi:10.1016/S0140-6736(09)60951-X.

Coughlan, M., Cronin, P. & Ryan, F. (2007) Step ' by-step guide to critiquing research . Part 1 : quantitative research. *British Journal of Nursing*. 16 (11), 658–664.

Creswell, J.W. (2013) *Research Design: Qualitative, Quantitative and Mixed Method Approaches 4th ed.* SAGE Publications Inc.

Crockett, R., Baker, H., Uus, K., Bamford, J., et al. (2005) test and newborn hearing screening. *Journal of Medical Screening*. 12 (2), 78–83.

Drost, E.A. (2011) Validity and Reliability in Social Science Research. *Education Research and Perspectives*. 38 (1), 105–123.

Fishbein, M. & Ajzen, I. (1975) Belief, Attitude, Intention and Behaviour: An Introduction to Theory and Research. *Reading MA AddisonWesley*. [Online]. Available from: doi:10.2307/2065853.

Fitzpatrick, E., Graham, I.D., Durieux-Smith, A., Angus, D., et al. (2007) Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. *International journal of audiology*. [Online] 46, 97–106. Available from: doi:10.1080/14992020600977770.

Fox, R. & Minchom, S. (2008) Parental experiences of the newborn hearing screening programme in Wales: A postal questionnaire survey. *Health Expectations*. [Online]. 11 (4) pp.376–383. Available from: doi:10.1111/j.1369-7625.2008.00504.x.

Fox, S.E., Levitt, P. & Nelson, C.A. (2010) How the timing and quality of early experiences influence the development of brain architecture. *Child Development*. [Online]. 81 (1) pp.28–40. Available from: doi:10.1111/j.1467-8624.2009.01380.x.

Frieden, T.R. (2014) Six components necessary for effective public health program implementation. *American Journal of Public Health*. [Online] 104 (1), 17–22. Available from: doi:10.2105/AJPH.2013.301608 [Accessed: 2 August 2020].

Gaffney, M., Eichwald, J., Gaffney, C. & Alam, S. (2014) Early Hearing Detection and Intervention Among Infants — Hearing Screening and Follow-up Survey, United States, 2005–2006 and 2009–2010. *Center for Disease Control and Prevention. MMWR Surveill Summ.* [Online] 63 (2), 20–26. Available from: https://www.cdc.gov/mmwr/preview/mmwrhtml/su6302a4.htm [Accessed: 7 December 2019].

Greene, J.C. (2008) Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods Research*. [Online] 2 (1), 7–22. Available from: doi:10.1177/1558689807309969 [Accessed: 31 July 2020].

Hazell, T. (2006) Newborn hearing screening. *Paediatric nursing*.18 (5) p.9.

Holdershaw, J. & Gendall, P. (2008) Understanding and predicting human behaviour. *Manu-Ao.Ac.Nz*. [Online] (July), 1–15. Available from: http://www.manu-ao.ac.nz/massey/fms/Colleges/College of Business/Communication and Journalism/ANZCA 2008/Refereed Papers/Holdershaw_Gendall_ANZCA08.pdf.

Huang, H.-M., Chiang, S.-H., Shiau, Y.-S., Yeh, W.-Y., et al. (2013) The universal newborn hearing screening program of Taipei City. *International journal of pediatric otorhinolaryngology*. [Online] 77 (10), 1734–1737. Available from: doi:10.1016/j.ijporl.2013.08.004.

Hyde, M.L. (2005) Newborn hearing screening programs: overview. *The Journal of otolaryngology*. 34 Suppl 2 (August), S70–S78.

Jack, L., Hayes, S., Jeanfreau, S., Stetson, B., et al. (2010) Appraising Quantitative Research in Health Education: Guidelines for Public Health Educators. *Health Promotion Practice*. [Online] 11 (2),

161–165. Available from: doi:10.1177/1524839909353023.Appraising.

Johnson, R.B., Onwuegbuzie, A.J. & Turner, L.A. (2007) Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*. [Online] 1 (2), 112–133. Available from: doi:10.1177/1558689806298224.

Kalra, S., Pathak, V. & Jena, B. (2013) Qualitative research. *Perspectives in Clinical Research*. [Online] 4 (3), 192. Available from: doi:10.4103/2229-3485.115389.

Kanji, A. (2016) *Early Detection of Hearing Loss : Exploring Risk-Based Hearing Screening Within a Developing Country Context*. [Online]. University of the Witwatersrand. Available from: http://wiredspace.wits.ac.za/bitstream/handle/10539/22321/PhD THESIS A KANJI.pdf?sequence=2&isAllowed=y%0D%0A%0D%0A.

Kanji, A. & Krabbenhoft, K. (2018) Audiological follow-up in a risk-based newborn hearing screening programme: An exploratory study of the influencing factors. *South African Journal of Communication Disorders*. [Online] 65 (1), 1–7. Available from: doi:10.4102/sajcd.v65i1.587.

Karaca, C.T., Oysu, C., Toros, S.Z., Naiboğlu, B., et al. (2014) Is hearing loss in infants associated with risk factors? Evaluation of the frequency of risk factors. *Clinical and experimental otorhinolaryngology*. [Online] 7 (4), 260–263. Available from: doi:10.3342/ceo.2014.7.4.260.

Kennedy, C., Kimm, L., Thornton, R. & Davis, A. (2000) False positives in universal neonatal screening for permanent childhood hearing impairment. *Lancet*. [Online] 356 (table 1), 1903–1904. Available from: doi:10.1016/S0140-6736(00)03267-0.

Khoza-shangase, K. & Harbinson, S. (2015) Evaluation of universal newborn hearing screening in South African primary care. *Afr J Prm Health Care Fam Med*. [Online] 7 (1), 1–12. Available from: doi:10.4102/phcfm.v7i1.769.

De Kock, T., Swanepoel, D.W. & Hall, J.W. (2016) Newborn hearing screening at a community-based obstetric unit: Screening and diagnostic outcomes. *International Journal of Pediatric Otorhinolaryngology*. [Online] 84, 124–131. Available from: doi:10.1016/j.ijporl.2016.02.031.

Korver, A.M.H., Admiraal, R.J.C., Kant, S.G., Dekker, F.W., et al. (2011) Causes of permanent childhood hearing impairment. *Laryngoscope*. [Online] 121 (2), 409–416. Available from: doi:10.1002/lary.21377.

Launiala, A. (2009) How much can a KAP survey tell us about people ' s knowledge , attitudes and

practices ? Some observations from medical anthropology on malaria in pregnancy in Malawi Background : KAP surveys. *Anthropology Matters Journal*. 11 (1), 1–13.

Lebeko, K., Bosch, J., Noubiap, J.J.N., Dandara, C., et al. (2015) Genetics of hearing loss in Africans: Use of next generation sequencing is the best way forward. *Pan African Medical Journal*. [Online]. 20 pp.1–14. Available from: doi:10.11604/pamj.2015.20.383.5230.

Levin, K. (2006) 'I am what I am because of who we all are': international perspectives on rehabilitation: South Africa. *Pediatric rehabilitation*. [Online] 9 (3), 285–292. Available from: doi:10.1080/13638490500293358.

MacNeil, J.R. & Stone, S. (2007) Evaluating Families' Satisfaction With Early Hearing Detection and Intervention Services in Massachusetts. *American Journal of Audiology* •. 16 (June).

Mayosi, B.M., Flisher, A.J., Lalloo, U.G., Sitas, F., et al. (2009) The burden of non-communicable diseases in South Africa. *The Lancet*. [Online] 374 (9693), 934–947. Available from: doi:10.1016/S0140-6736(09)61087-4.

Mazlan, R., Lee, T., Sarah, S.Z. & Abdullah, A. (2014) A questionnaire-based study on parental satisfaction with a universal newborn hearing screening program in Kuala Lumpur , Malaysia. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (2), 348–353. Available from: doi:10.1016/j.ijporl.2013.12.014.

McHugh, M.L. (2012) Interrater reliability : the kappa statistic. *Biochemia Medica*. [Online] 22 (3), 276–282. Available from: doi:10.11613/BM2012.031.

Meyer, M.E. & Swanepoel, D.W. (2011) Newborn hearing screening in the private health care sector - A national survey. *South African Medical Journal*. [Online] 101 (9), 665–667. Available from: doi:10.7196/SAMJ.5003.

Moeller, M.P., Carr, G., Seaver, L., Stredler-brown, A., et al. (2013) Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing : An International Consensus Statement. *Journal of Deaf Studies and Deaf Education*. [Online] 18 (4). Available from: doi:10.1093/deafed/ent034.

Moeller, White, K.R. & Shisler, L. (2006) Primary care physicians' knowledge, attitudes, and practices related to newborn hearing screening. *Pediatrics*. [Online] 118 (4), 1357–1370. Available from: doi:118/4/1357 [pii]\r10.1542/peds.2006-1008 [doi].

Mohd Khairi, M.D., Noor Rafidah, K., Affizal, A., Normastura, A.R., et al. (2011) Anxiety of the mothers with referred baby during Universal Newborn Hearing Screening. *International Journal of Pediatric Otorhinolaryngology*. [Online] 75 (4), 513–517. Available from: doi:10.1016/j.ijporl.2011.01.009.

Morgan, D.L. (2018) Living Within Blurry Boundaries: The Value of Distinguishing Between Qualitative and Quantitative Research. *Journal of Mixed Methods Research*. [Online] 12 (3), 268–279. Available from: doi:10.1177/1558689816686433 [Accessed: 31 July 2020].

Muse, C., Harrison, J., Yoshinaga-Itano, C., Grimes, A., et al. (2013) Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing. *Pediatrics*. [Online] 131 (4), e1324–e1349. Available from: doi:10.1542/peds.2013-0008.

Neille, J., George, K. & Khoza-Shangase, K. (2014) A study investigating sound sources and noise levels in neonatal intensive care units. *SAJCH South African Journal of Child Health*. [Online] 8 (1), 6–10. Available from: doi:10.7196/SAJCH.676.

Nelson, H.D., Bougatsos, C. & Nygren, P. (2008) Universal newborn hearing screening: systematic review to update the 2001 US Preventive Services Task Force Recommendation. *Pediatrics*. [Online] 122 (1), e266-76. Available from: doi:10.1542/peds.2007-1422.

Netcare (2019) *Netcare launches first national newborn hearing screening programme in South Africa*. [Online]. 2019. Netcare Limited. Available from: https://www.netcare.co.za/News-Hub/Articles/netcare-launches-first-national-newborn-hearing-screening-programme-in-south-africa [Accessed: 24 July 2020].

Netcare (2011) *Public Private Partnership*. [Online]. 2011. Netcare Limited. Available from: https://www.netcare.co.za/InvestorReport/ar_2011/sa_public.php [Accessed: 30 July 2020].

Ntsoane, M.. & Oduntan, O.. (2010) A review of factors influencing the utilization of eye care services. *The South African Optometrists*. 69 (4), 182–192.

Olusanya, B. (2015) Screening for neonatal deafness in resource-poor countries: challenges and solutions. *Research and Reports in Neonatology*. [Online] 5, 51. Available from: doi:10.2147/RRN.S61862 [Accessed: 30 April 2018].

Olusanya, B.O. (2009) Follow-up default in a hospital-based universal newborn hearing screening programme in a low-income country. *Child: Care, Health and Development*. [Online] 35 (2), 190–

198. Available from: doi:10.1111/j.1365-2214.2008.00923.x.

Olusanya, B.O. (2011) Highlights of the new WHO Report on Newborn and Infant Hearing Screening and implications for developing countries. *International Journal of Pediatric Otorhinolaryngology*. [Online] 75 (6), 745–748. Available from: doi:10.1016/j.ijporl.2011.01.036.

Olusanya, B.O. (2010) Intrauterine growth restriction in a low-income country: Risk factors, adverse perinatal outcomes and correlation with current WHO Multicenter Growth Reference. *Early human development*. [Online] 86 (7), 439–444. Available from: doi:10.1016/j.earlhumdev.2010.05.023.

Olusanya, B.O. (2008) Priorities for early hearing detection and intervention in sub-Saharan Africa. *International Journal of Audiology*. [Online] 47 (s1), S3–S13. Available from: doi:10.1080/14992020802287143.

Olusanya, B.O., Luxon, L.M. & Wirz, S.L. (2006) Maternal views on infant hearing loss in a developing country. *International journal of pediatric otorhinolaryngology*. [Online] 70 (4), 619–623. Available from: doi:10.1016/j.ijporl.2005.08.004.

Olusanya, B.O., Neumann, K.J. & Saunders, J.E. (2014) The global burden of disabling hearing impairment: a call to action. *Bulletin of the World Health Organization*. [Online] 92 (5), 367–373. Available from: doi:10.2471/BLT.13.128728.

Olusanya, B.O., Swanepoel, D.W., Chapchap, M.J., Castillo, S., et al. (2007) Progress towards early detection services for infants with hearing loss in developing countries. *BMC health services research*. [Online] 7, 14. Available from: doi:10.1186/1472-6963-7-14.

Olusanya, B.O., Wirz, S.L. & Luxon, L.M. (2008) Community-based infant hearing screening for early detection of permanent hearing loss in Lagos, Nigeria: A cross-sectional study. *Bulletin of the World Health Organization*. [Online] 86, 956–963. Available from: doi:10.2471/BLT.07.050005.

Padilla, C.D. (2008) Towards universal newborn screening in developing countries: obstacles and the way forward. *Annals of the Academy of Medicine, Singapore*. [Online] 37 (12 Suppl), 6–4. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19904464.

Park, A.H., Warner, J., Sturgill, N. & Alder, S.C. (2006) A survey of parental views regarding their child's hearing loss: A pilot study. *Otolaryngology - Head and Neck Surgery*. [Online] 134 (5). Available from: doi:10.1016/j.otohns.2006.01.013.

Patel, H. & Feldman, M. (2011) Universal newborn hearing screening. *Paediatrics Child health*. [Online]

16 (5), 301–305. Available from: doi:10.1055/s-0031-1285900.

Polit, D.F. & Beck, C.T. (2010) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice 7th Ed.* Seventh Ed. [Online]. Lippincott Williams & Wilkins. Available from: https://web2.aabu.edu.jo/tool/course_file/lec_notes/1001391_Essentials of Nursing Research Appraising Evidence for Nursing Practice Essentials of Nursing Research Polit.pdf.

Preston, R., Waugh, H. & Taylor, J. (2009) The benefits of community participation in rural health service development: where is the evidence? *Proceedings of the 10th National Rural Health Conference In: 10th National Rural Health Conference,*. [Online] 17-20 May, 1–20. Available from: http://eprints.jcu.edu.au/5316/.

Pugel, E.P. & Cekinovic, D. (2011) Pathogenesis of congenital cytomegalovirus infection of the central nervous system. *PERIODICUM BIOLOGORUM*. [Online] 113 (1), 51–60. Available from: http://hrcak.srce.hr/file/100630.

Rajagopalan, R., Selvarajan, H.G., Rajendran, A. & Ninan, B. (2014) Grandmothers ' perspective on hearing loss in children and newborn hearing screening. *Indian Journal of Otology*. [Online] 20 (1), 20–24. Available from: doi:10.4103/0971-7749.129803.

Ravi, R., Gunjawate, D.R., Yerraguntla, K., Lewis, L.E., et al. (2016a) Follow-up in newborn hearing screening – A systematic review. *International Journal of Pediatric Otorhinolaryngology*. [Online]. 90 pp.29–36. Available from: doi:10.1016/j.ijporl.2016.08.016.

Ravi, R., Gunjawate, D.R., Yerraguntla, K., Rajashekhar, B., et al. (2016b) Knowledge and attitude of parents/caregivers towards hearing loss and screening in newborns – a systematic review. *International Journal of Audiology*. [Online] 2027 (August), 1–8. Available from: doi:10.1080/14992027.2016.1215560.

Scheepers, L.J., Swanepoel, D.W. & Roux, T. le (2014) Why parents refuse newborn hearing screening and default on follow-up rescreening-A South African perspective. *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (4), 652–658. Available from: doi:10.1016/j.ijporl.2014.01.026.

Shulman, S., Besculides, M., Saltzman, A., Ireys, H., et al. (2010) Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics*. [Online] 126 Suppl (August), S19-27. Available from: doi:10.1542/peds.2010-0354F.

Statistics South Africa (2012) *Census 2011 Census in brief*. [Online]. Available from: http://www.statssa.gov.za/census/census_2011/census_products/Census_2011_Census_in_brief.pdf [Accessed: 11 December 2019].

Statistics South Africa (2014) *Provincial profile : KwaZulu-Natal*. [Online]. Available from: http://www.statssa.gov.za/?page_id=1854&PPN=Report-03-01-74.

Stich-Hennen, J. & Bargen, G.A. (2008) Risk Monitoring for Delayed-Onset Hearing Loss. In: *A Resource Guide for Early Hearing Detection & Intervention*. [Online]. National Center for Hearing Assessment and Management. Utah State University. pp. 1–20. Available from: http://www.infanthearing.org/ehdi-ebook/2015_ebook/10-Chapter10RiskMonitoring2015.pdf.

Suppiej, A., Cainelli, E., De Benedittis, M., Rizzardi, E., et al. (2013) Failure of hearing screening in high-risk neonates does not increase parental anxiety. *The journal of maternal-fetal & neonatal medicine*. [Online] 26 (9), 932–935. Available from: doi:10.3109/14767058.2013.766687.

Swanepoel, D. (2009) Early detection of infant hearing loss in South Africa. *SAMJ: South African Medical Journal*. [Online] 99 (3), 2–3. Available from: doi:10.1016/j.ijporl.

Swanepoel, D. & Almec, N. (2008) Maternal views on infant hearing loss and early intervention in a South African community. *International journal of audiology*. [Online] 47 Suppl 1, S44-8. Available from: doi:10.1080/14992020802252279.

Swanepoel, D., Hugo, R. & Louw, B. (2006) Infant hearing screening at immunization clinics in South Africa. *International Journal of Pediatric Otorhinolaryngology*. [Online] 70 (7), 1241–1249. Available from: doi:10.1016/j.ijporl.2006.01.002.

Swanepoel, D., Johl, L. & Pienaar, D. (2013) Childhood hearing loss and risk profile in a South African population. *International Journal of Pediatric Otorhinolaryngology*. [Online] 77 (3), 394–398. Available from: doi:10.1016/j.ijporl.2012.11.034.

Swanepoel, D., Störbeck, C. & Friedland, P. (2009) Early hearing detection and intervention in South Africa. *International journal of pediatric otorhinolaryngology*. [Online] 73 (6), 783–786. Available from: doi:10.1016/j.ijporl.2009.01.007.

Swanepoel, D.W., Scheepers, L. & le Roux, T. (2014) Why parents refuse newborn hearing screening in South Africa? *International Journal of Pediatric Otorhinolaryngology*. [Online] 78 (7), 1197–1198. Available from: doi:10.1016/j.ijporl.2014.04.047.

Tanon-Anoh, M.J., Sanogo-Gone, D. & Kouassi, K.B. (2010) Newborn hearing screening in a developing country: results of a pilot study in Abidjan, Côte d'ivoire. *International journal of pediatric otorhinolaryngology*. [Online] 74 (2), 188–191. Available from: doi:10.1016/j.ijporl.2009.11.008.

The Health Professions Council of South Africa (2018) Professional Board For Speech, Language and Hearing Professions Early Hearing Detection and Intervention Programmes in South Africa - Guidelines. *Children*. [Online] Available from: http://www.hpcsa.co.za/Uploads/editor/UserFiles/downloads/speech/Early_Hearing_Detection_and_Intervention_(EHDI)_2018.pdf [Accessed: 18 June 2018].

Theunissen, M. & Swanepoel, D.W. (2008) Early hearing detection and intervention services in the public health sector in South Africa. In: *International Journal of Audiology*. [Online]. 2008 Int J Audiol. p. Available from: doi:10.1080/14992020802294032 [Accessed: 30 July 2020].

Thompson, S.K. (2012) *Sampling*. Third. [Online]. New Jersey, John Wiley & Sons, Inc. Available from: https://ebookcentral.proquest.com/lib/ukzn-ebooks/reader.action?docID=818503 [Accessed: 1 August 2020].

Timans, R., Wouters, P. & Heilbron, J. (2019) *Mixed methods research: what it is and what it could be*. [Online] Available from: doi:10.1007/s11186-019-09345-5 [Accessed: 31 July 2020].

United Nations Population Division (2019) *World Population Prospects*. [Online]. 2019. United Nations World Population Prospects Report. Available from: www.un.org.

Vos, T., Alemu Abajobir, A., Hassen Abate, K., Abbafati, C., et al. (2017) Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet*. [Online] 390, 1211–1259. Available from: doi:10.1016/S0140-6736(17)32154-2 [Accessed: 4 May 2018].

Warwick, D.P. (1983) *The KAP survey : dictates of mission versus demands of science /*. Cambridge, MA :, Harvard Institute for International Development, Harvard University,.

WHO (2008) A Guide To Developing Knowledge , Attitude and Practice Surveys. *WHO Library Cataloguing-in-Publication Data*. [Online] Available from: http://whqlibdoc.who.int/publications/2008/9789241596176_eng.pdf.

WHO (2018a) Addressing The Rising Prevalence of Hearing Loss. *WHO*. [Online]. Available from:

doi:10.1080/09687599.2011.589198.

WHO (2016) Childhood Hearing Strategies for prevention and care. *WHO Library Cataloguing-in-Publication Dat*. [Online] Available from: apps.who.int/iris/bitstream/10665/204632/1/9789241510325_eng.pdf.

WHO (2020) *Deafness and hearing loss: Fact Sheet*. [Online]. 2020. Media Centre. Available from: https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss [Accessed: 23 July 2020].

WHO (2013) *Multi-country assessment of national capacity to provide hearing care*. [Online] 1–49. Available from: www.http://www.who.int/pbd/deafness/en.

WHO (2009) Newborn and infant hearing screening: Current Issues and Guiding principles for action. *WHO Library Cataloguing-in-Publication Data*. [Online] (November), 9–10. Available from: http://www.who.int/blindness/publications/Newborn_and_Infant_Hearing_Screening_Report.pdf.

WHO (2004) The global burden of disease 2004. *Update*. [Online] 1, 160. Available from: doi:10.1038/npp.2011.85.

WHO (2014) WHO | Deafness and hearing loss. *World Health Organization*. [Online]. Available from: doi:/entity/mediacentre/factsheets/fs300/en/index.html [Accessed: 22 March 2016].

WHO (2018b) *WHO Global estimates on prevalence of hearing loss*. [Online]. 2018. WHO. Available from: http://www.who.int/deafness/estimates/en/ [Accessed: 30 July 2020].

World Health Organization (2000) *Declaration of Alma-Ata*. [Online] (September 1978), 6–8. Available from: www.who.int/publications/almaata_declaration_en.pdf.

World Health Organization (2005) Resolution WHA58.33. Sustainable health financing, universal coverage and social health insurance. In: *Fifty-eight World Assembly, Geneva, 16-25 May, 2005*. Geneva. pp. 139–140.

World Health Organization (2010) The World Health Report: Health Systems Financing - The path to universal coverage. *WHO Library Cataloguing-in-Publication Data*. [Online]. Available from: doi:17 July 2012.

Xu, K., Saksena, P. & Evans, D.B. (2010) Health financing and access to effective interventions. *World Health Organization*. [Online] 18. Available from:

http://www.who.int/healthsystems/topics/financing/healthreport/8Accesstocare.pdf [Accessed: 18 June 2018].

Young & Tattersall, H. (2005) Parents ' of Deaf Children Evaluative Accounts of the Process and Practice of Universal Newborn Hearing Screening. *Journal of Deaf Studies and Deaf Education*. [Online] 10 (2). Available from: doi:10.1093/deafed/eni014.

Young, A. & Tattersall, H. (2007) Universal newborn hearing screening and early identification of deafness: Parents' responses to knowing early and their expectations of child communication development. *Journal of Deaf Studies and Deaf Education*. [Online] 12 (2), 209–220. Available from: doi:10.1093/deafed/enl033.

6 Appendices

6.1 Appendix 1 - Ethics Approval

19 October 2016

Ms C Graham
Discipline of Audiology
School of Health Sciences
cgtinagrm333@gmail.com

Protocol: Development of an assessment tool that measures change of knowledge, attitude, practice and behaviour of mothers towards a universal new-born hearing screening programme following health education intervention.
Degree: PhD
BREC reference number: BFC261/16 (sub-study of BFC421/15)

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application at a meeting held on 14 June 2016.

The study was provisionally approved by BREC pending appropriate responses to queries raised. Your responses dated 11 October 2016 to queries raised on 28 September 2016 have been noted and approved by a sub-committee of the Biomedical Research Committee. The conditions have now been met and the study is given **full ethics approval** and may begin as from 19 October 2016.

This approval is valid for one year from **19 October 2016.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

Pg. 2/...

Biomedical Research Ethics Committee
Professor J Tsoka-Gwegweni (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2486 Facsimile: +27 (0) 31 260 4609 Email: brec@ukzn.ac.za

The following Committee members were present at the meeting that took place on 14 June 2016:

Prof J Tsoka-Gwegweni	Chair
Rev. S D Chili	External - Community member
Dr R Harrichandparsad	Neurosurgery
Dr T Hardcastle	Surgery
Dr M Khan	Obstetrics and Gynaecology
Prof TE Madiba	General Surgery
Dr T Maistry	External - Microbiology
Ms T Makhanya	External - Community member
Dr G Nair	HIV Medicine
Dr S Paruk	Psychiatry
Dr A Noorbhai	Surgery
Prof V Rambiritch	Pharmacology (Deputy Chair)
Dr D Singh	Critical Care
Prof D Wassenaar	Psychology (Deputy Chair)

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

PROFESSOR JOYCE TSOKA-GWEGWENI
Chair: Biomedical Research Ethics Committee

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

27 January 2016

Dr Y Saman
Discipline of Otorhinolaryngology
School of Clinical Medicine
samany@ukzn.ac.za

Dear Dr Saman

Protocol: The Amajuba new-born hearing screening programme: An assessment of the feasibility and effectiveness of a Universal New-born Hearing Screening (UNHSP) Programme in a semi-rural community in KwaZulu-Natal.
Degree: Non-degree
BREC reference number: BFC421/15

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application at a quorate meeting held on 10 November 2015.

Your responses received on 11 January 2016 to queries raised on 25 November 2015 have been noted and approved by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given **full ethics approval** and may begin as from 27 January 2016.

This approval is valid for one year from **27 January 2016.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

Pg. 2/...

The following Committee members were present at the meeting that took place on 10 November 2015:

Prof J Tsoka-Gwegweni	Chair
Rev. S D Chili	External – Community Representative
Dr T Hardcastle	Surgery
Dr R Harrichandparsad	Neurosurgery
Mr H Humphries	Research Psychology and Public Health
Dr Z Khumalo	KZN Health (External) General Medicine
Dr M Khan	Obstetrics and Gynaecology
Prof TE Madiba	General Surgery
Ms T Maistry	External – Microbiology
Mrs T Makhanya	External – Community Representative
Dr G Nair	HIV Medicine
Dr S Paruk	Psychiatry
Prof V Rambiritch	Pharmacology (Deputy Chair)
Prof C Rout	Anaesthetics
Dr S Singh	Dentistry

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

This approval will be **ratified** at the next BREC meeting to be held on 09 February 2016.

Yours sincerely

PROFESSOR J TSOKA-GWEGWENI
Chair: Biomedical Research Ethics Committee

6.2 Appendix 2 - Qualitative study – Interview guides – English and Zulu version

Group Interviews – Guide questions

1. What do you understand with hearing Loss or deafness?
2. What is your opinion about babies born with hearing loss? What makes you think that way? What stands out in your mind about the issue?
3. How does a baby get a condition of hearing loss? What are the causes? Why do you think it happens?
4. In your opinion, what kind of babies are more likely to have hearing loss? Who can have hearing loss?
5. How would you know that your child has a hearing loss condition?
6. In your opinion, how serious is a condition of hearing loss? What sort of impact does it have at family and community level?
7. Do you think that doctors at the hospital can identify hearing loss on a newborn baby?
   - Why do you think they can do it and why not?
8. If you are offered a screening for your newborn baby, will you accept it? Why would you decide that way? What are the reasons for your decisions?
9. What would you do if your baby has been identified with a condition that might lead to hearing loss? What would you decide? How would you feel? Why would you feel that way?
10. How would you feel if your child has been detected with hearing loss?
11. If your child is offered more examination for hearing, how many times are you willing to come in a year? Why
12. If your child is found with hearing loss, what would you do?
13. What help would you seek, if you thought your child had a hearing problem?
14. What do you think can be done when a child has a hearing loss?
15. What do you think are the treatments for hearing loss?
16. If provided with opportunities for treatment so that your child can hear better, would you accept it? Why and why not?
17. Where do you usually go if you are not well, or for treatment of general health problem?
18. How often do you generally seek health at the clinic or hospital?
19. When a child is not well, do women usually go to a health care facility alone or are they accompanied by their relatives?
20. If you had a child who is not responding to your communications or difficulty in learning what would you do?
21. What has been your primary source of information about health issues?

Groups Interviews – Guide Questions

1. Yini oyaziyo ngokulahlekelwa ukuzwa?
2. Luthini uvo lwakho ngezingane ezizalwa zilahlekelwe ukuzwa? Yini ekwenza ucabange ngaleyondlela? Yini gqamayo emqondweni wakho ngalesisimo?
3. Kwenziwa yini umntwana agcine enenkinga yokungezwa ezindlebeni? Kudalwa yini ukungezwa? Uma ucabanga, yini imbangela?
4. Ngokombono wakho abanjani abantwana abangahle bebenenking yokulahlekelwa ukuzwa? Ubani ongalahlekelwa ukuzwa?
5. Ungazi kanjani ukuthi umntwana wakho unenkinga yokuzwa ezindlebeni
6. Ngokombono wakho kubucayi kangakanani ukulahlekelwa ukuzwa? Kungawuthinta kanjani umndeni nophakathi wakho ukulahlekelwa ukuzwa?
7. Uma ucabanga, kungenzeka yini odokotela esibhedlela bakhone ukubona inkinga yokungezwa ezindlebeni ezinganeni ezizelwe? Yebo noma Cha? Yini ucabange ukuthi bangakwazi noma bangekwazi?
8. Uma unganikwa ithuba lokuhlolelwa umntwana wakho amadlebe, ungavuma yini? Yini engakwenza uthathe lesosinqumo? Yiziphi izizathu ezikwenze wathatha lesosinqumo?
9. Ungenzenjani uma ungathola ukuthi umntwana wakho unenkinga engamenza agcine engezwa? isiphi isinqumo ongasithatha? Ungaphatheka kanjani? Sizathu sini esingenza uphatheke kanjalo?
10. Ungaphatheka kanjani uma umthwana wakho ungatholakala enenkinga yokungezwa ezindleni.
11. Uma untwana wakho engathola ithuba lokuxilongwa kabanzi, uzimisele ukumuletha kangakhi onyakeni? Ngobani?
12. Ungenzenjani uma uthola ukuthi umntwana wakho akezwa ezindlebeni?
13. Iluhi usizo ongalufuna uma ucabanga ukuthi umntwana wakho akezwa ezindlebeni?
14. Yini ocabanga ukuthi ingenziwa uma umntwana wakho enenkinga yokungezwa ezindlebeni?
15. Ucabanga ukuthi angalashwa kanjani?
16. Uma unganikwa amathuba okulashelwa umntwana wakho ezozwa kancono, unjalimulela yini? Ngobani?
17. Unokuyaphi uma ungaphathekile kahle, noma ukulashelwa ukugula?
18. Unokuya kangakhi ukuyofuna usizo, lwempilo emitholampilo noma esibhedlela?
19. Uma untwana uphathekile, abantu besifazane bavamise ukuya emitholampilo bebodwa noma baphelezelwa abomndeni?
20. Uma unengane engakhombisi ukiyizwa inkulumo yakho, noma enenkinga yokufunda, ungenzenjani?
21. Ulithole kuphi ulwazi ngokuhlolwa kwamadebe, kwezingane eziqeda kuzalwa?

6.3 Appendix 3 – Qualitative study - Statement of Verbal Consent

Statement of Verbal Consent

My name is [full name] and I have been appointed by the Universal Newborn Hearing Screening programme research team to conduct the discussions/survey on their behalf. The focus of this research is to understand knowledge, attitude and practice of UNHSP processes and childhood hearing loss. The research will thus explore the existing knowledge, attitude and practices towards UNHS programmes and it is seems vital for us to speak directly with persons who are going through that experience with their babies. We are approaching you because we understand that as mothers every experience of having a baby is different.

Thank you for agreeing to take part in this study. Your participation in this research is entirely voluntary and you are free to participate or you can decide not to take part. If you find any of the questions we ask upsetting, please inform us and we will stop discussing them immediately. You have the right to withdraw from this study at any time and you can refuse to answer any question. You can ask me or other members of the team for more detail on how the information will be used, where it will be stored etc. We will ensure that your name and personal details are not shared.

6.4 Appendix 4 – Repeatability study – Experts content review form

CONTENT REVIEW QUESTIONNAIRE

Content Domain

Hearing loss: any inability of hearing which varies from mild, moderate, severe to deafness

UNHSP processes (being measured): The early detection of hearing loss in newborns, this comprises screening and follow-ups.

Scale Construct

Knowledge: Knowledge about childhood hearing loss and early detection

Attitude: Beliefs, Feelings, Opinions towards hearing loss at individual, family and community level

Practice: Action taken by mothers for seeking health care in general and in hearing as well as support received from family or community

Instructions

Please complete the questionnaire as follows.

Column 1: Read the question number from the tool provided

Column 2: Representative – Please rate by circling according to the content domain above and the scale provided below

Column 3: Clarity – Please rate by circling in terms of Layout; Wording; Directions of using the tool; Response Scale; Readability

Column 4: Comment if rated "2 – the item is not clear" in column 3

Question No.	**REPRESENTATIVE** 1. Not Relevant 2. Somewhat Relevant 3. Relevant 4. Very Relevant	**CLARITY** 1. The item is clear 2. The item is not clear	**Comments**
7	1 2 3 4	1 2	
8	1 2 3 4	1 2	
9	1 2 3 4	1 2	
10	1 2 3 4	1 2	
11	1 2 3 4	1 2	
12	1 2 3 4	1 2	

13	1	2	3	4	1	2	
13a	1	2	3	4	1	2	
14	1	2	3	4	1	2	
15	1	2	3	4	1	2	
16	1	2	3	4	1	2	
17	1	2	3	4	1	2	
18	1	2	3	4	1	2	
19	1	2	3	4	1	2	
20	1	2	3	4	1	2	
20a	1	2	3	4	1	2	
21	1	2	3	4	1	2	
22	1	2	3	4	1	2	
23	1	2	3	4	1	2	
24	1	2	3	4	1	2	
25	1	2	3	4	1	2	
26	1	2	3	4	1	2	
27	1	2	3	4	1	2	

Comprehensiveness: Are the items in this KAP Survey Tool sufficient to represent KAP and Behaviour of the UNHSP processes and Hearing Loss. (Please circle accordingly)

1. Yes, the items are sufficient to represent KAP and Behaviour of UNHSP processes and Hearing loss
2. No, the items are not sufficient to represent KAP and Behaviour of UNHSP processes and Hearing Loss

Recommendations for Comprehensiveness:

.....

.....

Suggestions for additions or deletions of items: (please specify the Ques. no. and why)

.....

.....

6.5 Appendix 5 – Face Validity - Mothers evaluation form

FACE VALIDITY

Evaluation of a KAP Survey Questionnaire

Kindly complete this evaluation form. We are keen to receive your views on the completed questionnaire. The feedback you provide allows us to improve the questionnaire to a better understanding.

Please tick one on each row

	Criteria			
	Strongly Disagree	Disagree	Agree	Strongly Agree
Instructions were clear and understandable	O	O	O	O
Words used are appropriate and clear to understand	O	O	O	O
Reading level is suitable	O	O	O	O
Content is well organised and easy to follow	O	O	O	O
The language used is natural and real	O	O	O	O
Layout is attractive and interesting	O	O	O	O

Additional Comments:.....

.....

THANK YOU

6.6 Appendix 6 – KAP Study Questionnaire – English and Zulu

KAP SURVEY QUESTIONNAIRE

Aim: To explore mothers' knowledge, attitude, practice and behaviour of Universal Newborn Hearing Screening programme processes and hearing loss.

Baseline data collection Date: ...../...../.....

Follow-Up data collection Clinic: .....

Information to read before completing the questionnaire:

We would like to learn about your knowledge, attitudes and practices regarding Newborn Hearing Screening Programme (NHSP) and childhood hearing loss/deafness. We believe that we can understand your needs and challenges encountered in relation to NHSP process and childhood deafness. The information provided by you will be used to inform policy.

We will ensure that your personal details are not shared and will remain anonymous. Your participation in this research is entirely voluntary and you are free to participate or you can decide not to take part.

Thank you for agreeing to take part in this study.

Demographics

Please tick one box of selected answers

1. **How old are you?**
   - ☐ 18 - 20 years
   - ☐ 21 – 30 years
   - ☐ 31 – 40 years
   - ☐ Over 40 years

2. **What is your Gender?**
   - ☐ Male
   - ☐ Female

3. **What is your Marital Status?**
   - ☐ Married
   - ☐ Single
   - ☐ Divorced
   - ☐ Widow
   - ☐ Living with partner

4. **What is your Religious belief?**
   - ☐ Muslim
   - ☐ Christian
   - ☐ Hindu
   - ☐ African Ancestral
   - ☐ Other (Please specify): .....

5. **What is your highest level of completed education?**
   - ☐ No school
   - ☐ Primary
   - ☐ High School
   - ☐ College
   - ☐ Higher Education (University)
   - ☐ Other – (Please specify): .....

6. **What is your current employment status?**
   - ☐ Employed
   - ☐ Unemployed
   - ☐ Student
   - ☐ Retired/Pensioner

Knowledge

7. Do you think a baby can be born deaf/born with a hearing loss condition? *(Tick one)*

- ☐ Yes
- ☐ No
- ☐ I don't know

8. What can cause newborns and children to have deafness/hearing loss? *(Tick all that apply)*

- ☐ Noise
- ☐ Infection during pregnancy
- ☐ Infection after birth
- ☐ Hereditary
- ☐ Disease of the ear
- ☐ Premature babies
- ☐ Injury during delivery
- ☐ Non-nutritional diet
- ☐ Physical abuse
- ☐ Not attending clinic
- ☐ Attending clinic late
- ☐ Emotional abuse
- ☐ HIV positive pregnant mothers
- ☐ Smoking, alcohol and drug abuse
- ☐ Use of traditional medicine (izihalambezo)
- ☐ Non adherence to ancestral rituals
- ☐ Non adherence to birth rituals
- ☐ Bewitched
- ☐ STI's pregnant mothers
- ☐ Do not know
- ☐ Chemical exposures
- ☐ Medications
- ☐ Others (*please specify*).....

9. Can deafness/hearing loss be detected in a newborn baby? *(Tick one)*

- ☐ Yes
- ☐ No
- ☐ I don't know

10. Can a newborn pass the hearing test at birth and still develop a hearing loss later? *(Tick one)*

- ☐ Yes
- ☐ No
- ☐ I don't know

11. How can you know that a child is deaf/hard of hearing? *(Tick all that apply)*

- ☐ The child will show no response on sounds
- ☐ Delay in development (communication, speech, talking)
- ☐ Teachers will inform the parent
- ☐ Other children will inform the parent
- ☐ Doctors will inform the parent
- ☐ Not easy to know
- ☐ Others (*please specify*):.....

12. A child identified with deafness or hearing loss can be treated by *(Tick all that apply)*

- ☐ Traditional healers
- ☐ Specific procedures provided at the health facility
- ☐ Local Herbs/treatments
- ☐ Cultural rituals (ancestral and birth rituals)
- ☐ Prayers – Church
- ☐ Hearing aids
- ☐ Other (please specify): .....

Attitudes and Behaviour

13. If your newborn baby was offered screening for hearing loss would you accept it? *(Tick one)*

- ☐ Yes
- ☐ No (*Go to Ques. 13a*)

13 a) Why not? *(Tick all that apply)*

- ☐ I need to consult the family first
- ☐ I do not trust the devices used and tests done
- ☐ Do not know
- ☐ I do not believe that hearing loss can be identified in newborns, only when the child is older
- ☐ I do not have enough information about hearing screening to make a decision
- ☐ It depends on how much it costs
- ☐ Other (*please specify*): .....

14. What would be your reaction, if your baby was found with a condition of hearing loss/deafness? *(Tick all that apply)*

- ☐ Stressed
- ☐ Miserable
- ☐ Frustrated
- ☐ Helpless
- ☐ Hurt
- ☐ Guilty
- ☐ Disappointed
- ☐ Would want to know more

15. In your opinion, how seriously does the condition of deafness/hearing loss impact the family and community? *(Tick one)*

- ☐ Very Seriously
- ☐ Seriously
- ☐ Somewhat seriously
- ☐ Not seriously

16. Which statement explains more about the impact of deafness/hearing loss? (*Tick all that apply*)

- ☐ Unable to get good education
- ☐ Unemployed hence dependent on family
- ☐ lack of communication with others
- ☐ Unable to hear danger warnings – fire, vehicles etc.
- ☐ Vulnerable to sexual abuse
- ☐ Unable to socialise
- ☐ Suicidal
- ☐ Other (*please specify*):.....

17. What is the attitude of the community towards a deaf person? *(Tick one)*

- ☐ Most people usually pay no attention to the person
- ☐ People are friendly, but they generally try to avoid the person
- ☐ The community usually supports and assists the person
- ☐ Other (*please specify*): .....

Health care seeking and Behaviour

18. Where do you usually go if you are not well or for treatment of a general health problem? *(Tick all that apply)*

- ☐ Government clinic or hospital
- ☐ Private clinic or hospital
- ☐ Pharmacy/chemist
- ☐ Traditional healer
- ☐ Church
- ☐ Other *(please specify)*: .....

19. What would you do if your child has been identified with a condition of hearing loss? (*Tick all that apply*)

- ☐ Go to a health facility
- ☐ Go to a pharmacy/chemist
- ☐ Go to a traditional healer
- ☐ Go to church
- ☐ Go to church then Doctor
- ☐ Other *(please specify)*: .....

20. If your child is offered further examination for hearing would you accept it? *(Tick one)*

- ☐ Yes (*Go to Ques. 20a)*
- ☐ No

20a. How many times are you willing to take the child for further examination to the health facility in a year? *(Tick one)*

- ☐ Once a month
- ☐ Once in three months
- ☐ Once in six months
- ☐ Once a year
- ☐ Other (*please specify*): .....

21. What are the challenges you experience to visit the health facility less frequently? *(Tick all that apply)*

- ☐ Afraid of the equipment used as they may affect baby's ears
- ☐ Financial matters – e.g. transport, medical aid cover, etc.
- ☐ Lack of time – other responsibilities at home and clinics take the whole day
- ☐ My employer will not allow
- ☐ It is not so important
- ☐ Other (*please specify):* .....

22. When a child is sick, women usually take the child to the health facility... *(Tick one)*

- ☐ Alone
- ☐ with a Spouse
- ☐ with a Parent
- ☐ with Siblings
- ☐ with a Friend
- ☐ Other relatives

Awareness

23. Where did you first hear about Newborn Hearing Screening? *(Tick one)*

- ☐ At the clinic/Health workers
- ☐ Brochures and Posters
- ☐ Newspapers
- ☐ Family/Friends/Neighbours
- ☐ Radio
- ☐ Have not heard
- ☐ Other (*please specify*):.....

24. Do you think you are well informed about Newborn Hearing Screening Programme and Hearing loss condition? *(Tick one)*

- ☐ Yes
- ☐ No

25. Where do you currently get health information from? *(Tick all that apply)*

- ☐ At the clinic/Health workers
- ☐ Brochures and Posters
- ☐ Newspapers
- ☐ Family/Friends/Neighbours
- ☐ Radio
- ☐ Other (*please specify*):.....

26. If your child is at risk for hearing loss what other information would you like to have? *(Tick all that apply)*

- ☐ Information about causes
- ☐ Information about treatment
- ☐ Information about where to go for help
- ☐ Other (*please specify*): .....

27. What sources of information that you think can most effectively reach people like you and others in your community with information on Newborn Hearing Screening Programme and Hearing loss condition? (*Tick three most accepted sources*)

- ☐ At the clinic/Health workers
- ☐ Brochures and Posters
- ☐ Newspapers
- ☐ Family/Friends/Neighbours
- ☐ Radio
- ☐ TV
- ☐ Other (*please specify*):.....

Any additional comments: .....

.....

Thank you for participating in this survey

UHLAMIBUZO LWESAVEYI YE-KAP

Inhloso: Ukuhlola ulwazi, isimo, indlelakwenza nokuziphatha kukamama ohlelweni i-Universal Newborn Hearing Screening Programme Processes and Hearing Loss.

Ukuqoqwa kolwazi okokuqala Usuku: ...../...../.....

Ukuqoqwa kolwazi okwesibili Iklinikhi: .....

Ulwazi okumele lufundwe anduba kuphendulwe uhlamibuzo :

Singathanda ukwazi ngokwaziyo, isimo nendlelakwenza mayelana nohlelo i-Newborn Hearing Screening Programme (NHSP) nokulahleka kokuzwa noma ukungezwa ebantwaneni. Sikholwa ukuthi singaziqonda kangcono izidingo nezinselelo zakho obhekana nazo eziphathelene ne-NHSP nokungezwa komntwana. Ulwazi osihlinzeka ngalo luzosetshenziswa ekwakhiweni kwenqubomgomo.

Sizoqinisekisa ukuthi imininingwane yakho ayitholakali futhi iyimfihlo. Ukubamba kwakho iqhaza kuzahlala kuyimfihlo. Ukubamba kwakho iqhaza kulolu cwaningo akluphoqelekile futhi ungaqhubeka noma ukhethe ukuyeka ukubamba iqhaza.

Siyabonga ngokuvuma ukubamba iqhaza kulolu cwaningo.

Imininingwane Yomphakathi

Sicela ukhethe ibhokisi elilodwa lezimpendulo

1. **Uneminyaka emingaki?**
   - ☐ 18 - 20 eminyaka
   - ☐ 21 – 30 eminyaka
   - ☐ 31 – 40 eminyaka
   - ☐ Ngaphezu 40 eminyaka

2. **Ubulili?**
   - ☐ Owesilisa
   - ☐ Owesifazane

3. **Isimo sezokushada?**
   - ☐ Ushadile
   - ☐ Awushadile
   - ☐ Uhlukanisile
   - ☐ Umfelokazi
   - ☐ Uhlala nozwana naye

4. **Ukholelwa kweyiphi inkolo?**
   - ☐ Isulumane
   - ☐ Umkhrestu
   - ☐ UmHindu
   - ☐ Amadlozi
   - ☐ Okunye *(Sicela ucacise):*

     .....

5. **Yiliphi ibanga lezemfundo owagcina kulo?**
   - ☐ Alikho
   - ☐ Ibanga eliphansi
   - ☐ Ibanga eliphezulu
   - ☐ Ikolishi
   - ☐ Imfundo ephakeme(Inyuvesi)
   - ☐ Okunye – *(Sicela ucacise)*: .....

6. **Sinjani isimo sakho kwezomsebenzi njengamanje?**
   - ☐ Uyasebenza
   - ☐ Awusebenzi
   - ☐ Umfundi
   - ☐ Umhlalaphansi/ impesheni

Ulwazi

7. Ucabanga ukuthi ingane ingazalwa ingezwa/nesimo esibangela ukungezwa? *(khetha okukodwa)*

- ☐ Yebo
- ☐ Cha
- ☐ Angazi

8. Yini engabangela izinsana nabantwana ukuba bangezwa/balahlekelwe ukuzwa? *(khetha konke okuthintekayo)*

- ☐ Umsindo
- ☐ Ukutheleleka ngesifo ngesikhathi sokukhulelwa
- ☐ Ukutheleleka ngesifo emva kokuzalwa
- ☐ Ufuzo
- ☐ Isifo sendlebe
- ☐ Abantwana abazalwa kungakabi yisikhathi
- ☐ Ukulimala ngesikhathi kuzalwa
- ☐ Ukudla okungenamsoco
- ☐ Ukuhlukumezeka emzimbeni
- ☐ Ukungayi eklinikhi
- ☐ Ukuya eklinikhi sekuhambe isikhathi
- ☐ Okunye (*Sicela ucacise*):.....
- ☐ Ukuhlukumezeka imizwa
- ☐ Abesifazane abakhulelwe abanengculazi
- ☐ Ukubhema, utshwala nezidakamizwa
- ☐ Imithi yesintu (izihlambezo)
- ☐ Ukungalandeli isiko
- ☐ Ukungalandeli okwenziwa uma kubelethwa
- ☐ Ukuthakathwa
- ☐ Izifo ezisuleleka ngocansi kwabakhulelwe
- ☐ Angazi
- ☐ Ukungavikeleki kumakhemikhali
- ☐ Imithi

9. Ingabe ukungezwa/ukulahleka kokuzwa vela emntwaneni osanda kuzalwa? *(khetha okukodwa)*

- ☐ Yebo
- ☐ Cha
- ☐ Angazi

10. Ingane esanda kuzalwa ingakwazi ukuphumelela uma ixilongwa ukuzwa kodwa ilahlekelwe ukuzwa emva kwesikhathi? *(khetha okukodwa)*

- ☐ Yebo
- ☐ Cha
- ☐ Angazi

11. Ungabona kanjani ukuthi umntwana uyezwa/ akezwa kahle?*(khetha konke okuthintekayo)*

- ☐ Umntwana angeke alandele imisindo
- ☐ Uthatha kade ukuthuthuka (ukuxhumana, ukusebenzisa iphimbo, ukukhuluma)
- ☐ Othisha abazisa umzali
- ☐ Abanye abantwana bazokwazisa umzali
- ☐ Odokotela abazokwazisa umzali
- ☐ Akulula ukwazi
- ☐ Okunye *(sicela ucacise)*.....

12. Umntwana ongezwa noma olahlekelwa ukuzwa angalashwa ngalezi zindlela *(khetha konke okuthintekayo)*

- ☐ Izinyanga
- ☐ Ngezindlela ezithize ezihlinzekwa emtholampilo
- ☐ Amakhambi esintu
- ☐ Ukwenziwa kwemisebenzi eyisiko
- ☐ Imithandazo – isonto
- ☐ Okulekelela ukuzwa
- ☐ Okunye *(sicela ucacise)*: .....

Isimo Nokuziphatha

13. **Uma umntwana wakho osanda kuzalwa enikwa ithuba lokuhlolwa ukuzwa ungavuma?** *(khetha okukodwa)*

- ☐ Yebo
- ☐ Cha (Dlulela kumbuzo *13a*)

13 a) Kungani? *(khetha konke okuthintekayo)*

- ☐ Kumele ngibonisane nomndeni wami kuqala
- ☐ Angikwethembi abakusebenzisayo kanye nokuhlola abakwenzayo
- ☐ Angazi
- ☐ Angikholwa ukuthi ukulahleka kokuzwa kungatholakala emntwaneni osanda kuzalwa, kutholakala kwasebekhulile
- ☐ Anginalo ulwazi olwanele ngokuhlola okwenziwayo ukuze ngithathe isinqumo
- ☐ Kuncike ekutheni kubiza kangakanani
- ☐ Okunye sicela ucacise):……

14. **Kungakuphatha kanjani ukutholakala kokuthi umntwana wakho unokungezwa noma ulahlekelwa ukuzwa?** *(khetha konke okuthintekayo)*

- ☐ Ingcindezi
- ☐ Usizi
- ☐ Ukukhungatheka
- ☐ Ukuthothobala
- ☐ Ubuhlungu
- ☐ Unecala
- ☐ Ukudumala
- ☐ Ungafisa ukwazi kangcono

15. **Ngokubona kwakho, ukungezwa /ukulahlekelwa ukuzwa kunomthelela ongakanani emndenini nasemphakathini?** *(khetha okukodwa)*

- ☐ Omkhulu kakhulu
- ☐ Omkhulu
- ☐ Ongemkhulu kakhulu
- ☐ Ongemkhulu

16. **Isiphi isitatimende esichaza kahle ngomthelela wokungezwa/ukulahlekelwa ukuzwa?** *(khetha konke okuthintekayo)*

- ☐ Ukungabi nemfundo efanele
- ☐ Awusebenzi ngakho uthembule emndenini
- ☐ Ukungakwazi kukuxhuman nabanye
- ☐ Awkuwazi ukuzwa izexwayiso ngengozi – umlilo, izimoto njl
- ☐ Usengozini yokuhlukunyezwa ngokocansi
- ☐ Awakuwazi ukuhlalisana nabanye
- ☐ Unomqondo wokuzibulala
- ☐ Angazi
- ☐ Okunye (*Sicela ucacise*): ……

17. **Umphakathi umthatha kanjani umuntu ongezwa?** *(khetha okukodwa)*

- ☐ Abantu abaningi bayaye bangamnaki
- ☐ Abantu banobungani kodwa bayazama ukuziqhelanisa naye
- ☐ Umphakathi uvamise ukumesekela futhi umelekelele
- ☐ Okunye (Sicela ucacise): ……

Ukufuna usizo lwezempilo nokuziphatha

18. **Uvamise ukuya kuphi uma ungaphilile noma udinga ukwelashwa okujwayelekile?** *(khetha konke okuthintekayo)*

- ☐ Esibhedlela noma eklinikhi kahulumeni
- ☐ Esibhedlela noma iklinikhi yangasese
- ☐ Ekhemisi
- ☐ Enyangeni
- ☐ Esontweni
- ☐ Okunye (*Sicela ucacise*):.....

19. Ungenzenjani uma umntwana wakho kutholakala ukuthi unesimo sokulahlekelwa ukuzwa? (*khetha konke okuthintekayo*)

- ☐ Ungaya emtholampilo
- ☐ Ungaya ekhemisi
- ☐ Ungaya enyangeni
- ☐ Ungaya esontweni
- ☐ Ungaya esontweni anduba uye kudokotela
- ☐ Okunye (*Sicela ucacise*):.....

20. **Uma umntwana wakho enikwa ithuba lokuhlolwa futhi ungalithatha?** *(khetha okukodwa)*

- ☐ Yebo (*dlulela kumbuzo 20a)*
- ☐ Cha

20a. Uzimisele ukumyisa kangaki umntwana ukuyohlolwa kabanzi emtholampilo enyakeni owodwa? *(khetha okukodwa)*

- ☐ Kanye ngenyanga
- ☐ Kanye ezinyangeni ezintathu
- ☐ Kanye ezinyangeni eziyisithupha
- ☐ Kanye ngonyaka
- ☐ Okunye (*sicela ucacise*):.....

21. **Yiziphi izinselelo obhekana nazo ezikwenza ungakwazi ukuya umtholampilo kambalwa?** *(khetha konke okuthintekayo)*

- ☐ Ukwesaba ukuthi imishini esesthenziswayo ingalimaza umntwana ezindlebeni
- ☐ Ezezimali – okokuhamba, okokukhokhela ukwelashwa, njl.
- ☐ Ukungabi nesikhathi – okunye okukudingayo ekhaya futhi amaklinikhi athatha usuku lonke
- ☐ Umqashi wami akavumi
- ☐ Akubalulekile kangako
- ☐ Okunye (sicela ucacise):.....

22. **Uma umntwana egula, abesifazane abayaye bamhambise emtholampilo…** *(khetha okukodwa)*

- ☐ Bodwa
- ☐ Nomkhwenyanae
- ☐ Nomzali
- ☐ Nezelamani
- ☐ Nomngani
- ☐ Nezinye izihlobo

Ukwazi

23. **Waqala ukuzwa kephi nge-Newborn Hearing Screening?** *(khetha okukodwa)*

- ☐ Eklinikhi/ngonompilo
- ☐ Ngamaphephandaba
- ☐ Umsakazo
- ☐ EmabhukwaneninakumaPhosta
- ☐ Emndenini/Abangani/Nomakhelwane
- ☐ Angikweza
- ☐ Okunye (sicela ucacise) .....

24. **Ucabanga ukuthi unolwazi olwanele ngohlelo i-Newborn Hearing Screening Programme Nesifo sokulahlekelwa ukuzwa?** *(khetha okukodwa)*

- ☐ Yebo
- ☐ Cha

25. **Ulutholaphi ulwazi lwezempilo lwakho njengamanje?** *(khetha konke okuthintekayo)*

- ☐ Eklinikhi/ngonompilo
- ☐ Emaphephandabeni
- ☐ Emsakazweni
- ☐ EmabhukwaneninakumaPhosta
- ☐ Emndenini/Abangani/ Nomakhelwane
- ☐ Okunye(sicela ucacise):.....

26. Uma umntwana wakho esengcupheni yokulahlekelwa ukuzwa, yiluphi uhlobo lolwazi ongathanda ukuba nalo? *(khetha konke okuthintekayo)*

- ☐ Ulwazi ngezimbangela
- ☐ Ulwazi ngezindlela zokwelapha
- ☐ Ulwazi ngezindawo ongaya kuzo ukuze usizakale
- ☐ Okunye (Sicela ucacise):.....

27. Yimiphi imithombo yolwazi ocabanga ukuthi ungafinyelela kangcono kubantu abafana nawe nabanye emphakathini wakho yolwazi nge-Newborn Hearing Screening Programme nokulahlekelwa ukuzwa? (*khetha okuthathu okwamukeleke kakhulu*)

- ☐ Eklinikhi/ngonompilo
- ☐ Ngamaphephandaba
- ☐ Umsakazo
- ☐ EmabhukwaneninakumaPhosta
- ☐ Emndenini/Abangani/ Nomakhelwane
- ☐ Umabonakude
- ☐ Okunye (Sicela ucacise):.....

Okunye ofisa ukukusho: .....

.....

Siyabonga ngokubamba iqhaza kulolu cwaningo

6.7 Appendix 7 – Participant Information sheet and Consent Form – English and Zulu version

PARTICIPANT INFORMATION SHEET

Dear Mother,

My name is Christine Graham, a research student at University of KwaZulu-Natal. I am currently conducting a study in development of a tool that can assess knowledge, attitude and practice towards Universal Newborn Hearing Screening programme and Hearing loss. This study is part of the Universal Newborn Hearing Screening research programme that is being conducted in Amajuba District and led by Dr. Y. Saman. The study intends to explore the existing knowledge, attitude and practices towards UNHS programmes and hearing loss. We are approaching you because we understand that as mothers you are the main persons in contact with the child at infancy.

STUDY TITLE:

Development of an assessment tool that measures change of knowledge, attitude, practice and behaviour of mothers towards a universal new-born hearing screening programme following health education intervention.

We would like to invite you to participate in the study, which is concerned with understanding the existing knowledge, attitude and practices of mothers towards Universal Newborn Hearing Screening programme and hearing loss. Before you decide, it is important for you to understand why the research is being done and what it involves. Please take your time to read the information clearly. You can also discuss with others if you wish.

Why am I doing this study?

It is estimated that 32 million children under the age of 15 are affected with hearing loss globally. Childhood hearing loss if not detected early especially after birth may result in delays in speech and language development. Universal Newborn Hearing Screening programme provides opportunity for early detection of hearing loss. Evidence from the UNHS programmes shows that children that have been identified with problems and called back for re-screening sometimes they are not going back. In order to understand why this happens, we have decided to study the community that will experience this intervention and identify the underlying systems that shapes knowledge and behaviour.

Why have you been invited?

You have been asked to participate in this study because you are a mother that could be involved in the existing newborn hearing screening that is being implemented in Amajuba District. All expectant mother that will be attending ante/postnatal clinics during the intervention of UNHSP will be approached.

What will happen if you agree to take part in the study?

There are several parts of the study that you be asked to participate

1. You may be asked to take part in focus group interviews which will be done in the clinic where you usually receive your antenatal check-ups. You will be asked questions regarding the UNHS programme and hearing loss during the focus group interviews and the session is expected to last no longer than forty five minutes to one hour and it is a one-off event.
2. You may be asked to participate in a survey while you are attending ante/postnatal clinics, this will involve being presented with a questionnaire and being asked to complete it. This is also a one off event.
3. You may asked to participate in a survey while attending the ante/postnatal clinic that involves to complete a questionnaire complete the questionnaire and repeat the same exercise in two weeks' time.
4. You may be asked to complete the questionnaire and then evaluate how easy or difficult it was to complete it.
5. When the study is completed, we will produce a summary of the findings which we will be happy to send you if you are interested.
6. You will be required to sign the consent form before participation in the study

Your participation in this research is entirely voluntary and you are free to participate or you can decide not to take part. During focus group interview if you find any of the questions we ask upsetting, please inform us and we will stop discussing them immediately. You have the right to withdraw from this study at any time and you can refuse to answer any question.

You can ask me or other members of the team for more detail on how the information will be used, where it will be stored etc. All information shared by you will be strictly confidential. We will ensure that your name and personal details are not shared.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee.

You must feel free to contact us or the UKZN Biomedical Research Ethics Committee (details below) for any problems or questions relating to the study.

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus,
Govan Mbeki Building
University of KwaZulu-Natal
Private Bag X54001, Durban, 4000
KwaZulu-Natal, South Africa
Tel: 27 31 2602486 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Consent Form

CONSENT FORM

Date: _____

STUDY TITLE:

Development of an assessment tool that measures change of knowledge, attitude, practice and behaviour of mothers towards a universal new-born hearing screening programme following health education intervention.

I, the undersigned, confirmed that

1. I have read and understood the Participant Information Sheet
2. I am taking part in this study voluntarily
3. All questions about my participation in this study have been answered satisfactorily
4. I understand that I can withdraw from the study at any time without giving any reasons
5. All terms of confidentiality and anonymity of the information I have given to the study has been explained clearly

_____ _____

Participant's Name (*Printed*) Participant's signature

_____ _____

Name of person obtaining consent (*Printed*) Signature of person obtaining consent

IKHASI LOLWAZI NGOKUBAMBA IQHAZA

Mzali,

Igama lami ngu-Christine Graham,ongumfundi owenza ucwaningo waseNyuvesi YaKwaZulu-Natali. Ngenza ucwaningo ngokuthuthukiswa kwethuluzi lokuthola ulwazi, imicabango nendlelakwenza mayelana nohlelo i-Universal Newborn Hearing Screening and Hearing loss. Lolu cwaningo luyingxenye yohlelo locwaningo i-Universal Newborn Hearing Screening olwenziwa esifundeni saseMajuba oluholwa uDkt Y. Saman. Ucwaningo luhlose ukuhlola ulwazi olukhona imicabango kanye nendlelakwenza ebhekiswe ohlelweni i-UNHS nokulahlekelwa ukuzwa. Sixhumana nawe ngoba siyakuqonda ukuthi njengomama yini abantu abaxhumana kakhulu nomntwana uma esakhula.

Ukuthuthukiswa kwethuluzi lokuthola ulwazi, imicabango nendlelakwenza mayelana nohlelo i-Universal Newborn Hearing Screening and Hearing loss ngokulandela uhlelo lwezempilo

Sithanda ukukumema ukuba ubambe iqhaza kulolu cwaningo olumayelana nokuqonda ngolwazi imicabango nendlelakwenza yomama mayelana nohlelo i-Universal Newborn Hearing Screening and Hearing loss . Ngaphambi kokuthatha isinqumo kubalulekile ukuthi uqonde ukuthi lolu cwaningo lwenziwelwani futhi luthintani. Sicela uzinike isikhathi sokuthi ufundisise ulwazi oluhlinzekiwe. Ungaludingida nabanye uma uthanda.

Ngilwenzelani Lolu cwaningo?

Balinganiselwa ezigidini ezingama-32 abantwana abangaphansi kweminyaka eyi-15 abanenkinga yokulahlekelwa ukuzwa emhlabeni jikelele. Ukulahleka kokuzwa ebantwaneni kubangela nokungathuthuki ngokufanele kokukhuluma nolimi uma kungatholakalanga umntwana esamncane. Uhlelo i-Universal Newborn Hearing Screening luhlinzeka ngethuba lokusheshisa ukutholakala kokulahleka kokuzwa. Ubufakazi balolu hlelo bukhombisa ukuthi abantwana ababonakala ukuthi banenkinga yokuzwa bese bebizwa ukuze bahlolwe kabusha ababuyeli ngezinye izinkathi. Ukuze kuqondakale ukuthi kwenziwa yini lokhu, sithathe isinqumo sokucwaninga imiphakathi lapho kusebenza khona lolu hlelo ukuze Sithole okwakha ulwazi nokuziphatha.

Kungani umenyiwe?

Umenywe ukuthi ubambe iqhaza kulolu cwaningo ngoba ungumama onggaba yingxenye yohlelo olukhona lokuhlola ukuzwa ezinsaneni olusebenza esifundeni saseMajuba. Bonke omama abakhulelwe ababahamba iklinikhi yabakhulelwe ngesikhathi sokusebenza kohlelo i-UNHSP bazothintwa.

Kuzokwenzekani uma uvuma ukubamba iqhaza kulolu cwaningo?

Kunezingxenye ezimbalwa ozocelwa ukuthi ubambe iqhaza kuzo

1. Ungacelwa ukuthi ubambe iqhaza emaqenjini ezingxoxo azokwenzeka eklinikhi lapho uxilongwa khona. Uzobuzwa imibuzo mayelana nohlelo i-UNHS uma sekunezingxoxo zamaqembu futhi lezi zingxoxo ngeke zeqe emizuzwini engamashumi amane nanhlanu kuya ehoreni ubude futhi zibanjwa kanye.
2. Ungacelwa ukuthi ubambe iqhaza kusaveyi ngenkathi useklinikhi lokhu kuzohlanganisa ukunikezwa uhlu lwemibuzo ozocelwa ukuthi uluphendule. Nalokhu kuzokwenzeka kanye.
3. Ungacelwa ukuthi ubambe iqhaza kusaveyi ngokuphendula uhlu lwemibuzo eklinikhi uphinde wenze lokhu emva kwamasonto amabili.
4. Ungacelwa ukuthi uphendule uhlu lwemibuzo bese uhlaziya ubulula noma ubunzima bokuphendula loluhlu.
5. Uma ucwaningo seluphothuliwe siyoshicilela umbhalo ofingqiwe ngokutholakele ocwaningweni futhi uyowuthola nawe uma uwudinga.
6. Uzodinga ukusayina ifomu lokugunyaza ngaphambi kokubamba iqhaza kulolu cwaningo.

Ukubamba kwakho iqhaza kulolucwaningo akuphoqelekilefuthi uvumelekile ukubamba iqhaza noma ungalibambi uma uthanda. Ngesikhathi sezingxoxo zamaqembu uma kunemibuzo ongayithandi sicela usazise ukuze siyeke ukuxoxa ngayo ngokushesha. Unelungelo lokuhoxa kulolu cwaningo noma yinini futhi unganqaba nokuphendula

Ungabuza mina noma amanye amalungu eqembu ngeminye imininingwane yokuthi ulwazi olutholakele luzosetshenziswa kanjani, luzogcinwa kephi njl. Lonke ulwazi oluzotholakala luzoba yimfihlo. Sizoqinisekisa ukuthi igama nemininingwane yakho akunikezelwa kwabanye. Lolu cwaningo lubuyekezwe lwaphinde lwagunyazwa yikomidi lase-UKZN i-Biomedical research ethics committee.

Unhaxhumana nathi noma i-UKZN Biomedical Research Ethics Committee (imininngwane ingezansi) uma kunezinkinga noma imibuzo mayelana nocwaningo.

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus,
Govan Mbeki Building
University of KwaZulu-Natal
Private Bag X54001, Durban, 4000
KwaZulu-Natal, South Africa
Ucingo: 27 31 2602486 - Fax: 27 31 2604609
Imeyili: BREC@ukzn.ac.za

IFOMU LOKUGUNYAZA

Usuku: _____

ISIHLOKO SOCWANINGO:

Ukuthuthukiswa kwethuluzi lokuthola ulwazi, imicabango nendlelakwenza mayelana nohlelo i-Universal Newborn Hearing Screening and Hearing loss ngokulandela uhlelo lwezempilo

Mina, osayine ngezansi, ngiyaqinisekisa ukuthi

1. Ngilifundile ngaliqonda ikhasi lolwazi
2. Ngibamba iqhaza kulolu cwaningo ngokuzikhethela
3. Yonke imibuzo mayelana nokubamba kwami iqhaza ocwaningweni iphendulwe ngendlela egculisayo
4. Ngiyaqonda ukuthi ngingahoxa noma yinini ocwaningweni ngale kokubeka izizathu
5. Yonke imibandela yobumfihlo nokugodlwa kolwazi engilunikezile icacisiwe ngokugcwele

_____ _____

Igama Lobamba Iqhaza (*libhalwe ngokuhlukanisa*) Ukusayina

_____ _____

Igama lowamukela ukugunyazwa (*libhalwe ngokuhlukanisa*) Ukusayina

6.8 Appendix 8 – Supplement literature review

Reported Reliability and Validity of Measurements Tools – Quantitative studies

Year	Country	Urban/ Rural	Measurement Tool	Outcome measure	Reliability	Validity
2006	England	Urban	Questionnaire	Maternal anxiety of NHS Knowledge about UNHSP Worry about baby' hearing Certainty about baby's hearing	alpha=0.81 alpha=0.57	None
2006	Nigeria	Urban	Questionnaire	Maternal knowledge and attitude on infant hearing loss and NHS	K – alpha=0.84 A – alpha=0.83	None
2006	United States	Urban	Questionnaire	Parental perception of the process to diagnose and treatment of child hearing loss	None	None *****
2007	United States	Urban	Questionnaire	Levels of family satisfaction and anxiety – EHDI process	None	None
2008	Wales	Urban	Questionnaire	Mother experiences &levels of satisfaction with UNHSP	None**	None**
2008	South Africa	Urban	Questionnaire	Maternal knowledge and attitude towards infant hearing loss and UNHS	None**	None
2011	Malaysia	Urban	Questionnaire	Mothers anxiety – failed test result – NHS	alpha=0.96	None
2013	Italy	Urban	Questionnaire	Parental anxiety - infants failed hearing screening	None***	None***
2014	India	Urban	Questionnaire	Grandmothers knowledge and attitude on hearing loss & NHS	None**	None******
2014	Malaysia	Urban	Questionnaire	Parents satisfaction of UNHSP process	None**	None**
2014	South Africa	Urban	Tele-Interviews/ Questionnaire	Caregivers perceptions of NHS and its process	None	None
2016	India	Rural	Questionnaire	Mothers knowledge and attitude towards infant hearing loss	alpha=0.84	None**

Reported methods used to enhance the quality of data collection

Year	Country	Urban/ Rural	Measurement Tool	Outcome measure	Criteria for Quality	
					Data Collection	Trustworthiness
2005	England	Urban	Interviews	Parents perspective of UNHS and Intervention	PE; AVT; Tri/data	Cred.; Auth.; Dep.
2007	Canada	Urban	Semi-structured Interviews	Parents perceptions of early/late detection	PO; CFN; AVT;	Cred.; Auth.; Trans
2007	England	Urban	Interviews	Parents descriptions of significance and impact of knowing early	PE; PO; AVT; Tri/data	Cred.; Auth.; Dep.;
2010	Belgium	Urban	Interviews	Parental experiences of deafness and UNHS	CFN; AVT;	Cred.; Auth.; Trans
2014	India	Rural	Focus Group Discussion	Caregiver perceptions regarding NHS service delivery	PO; CFN; AVT	Cred.; Auth.; Trans

The criteria from Lincoln and Guba (1985, 1996) framework - PE (Prolonged Engagement); PO (Persistent Observation); CFN (Comprehensive Field Notes); AVT (Audiotaping & Verbatim transcription); Tri/data (Triangulation/data); Cred. (Credibility); Auth. (Authenticity); Dep. (Dependability); Trans (Transferability) (cited from Polit & Beck, 2010)

Summary of the Parental knowledge and attitudes regarding UNHS and childhood hearing loss

Year	Country	Study design	Participants	Sample	Outcome Measure	Findings	Recommendations
2005	England	Qualitative	Families	45	Parents perspective of NHS & Intervention	• Good professionalism • Interpretation of results and limited knowledge created anxiety • Screening process unsatisfactory	• Ensuring means that verify the understanding of information provided to parents • Further consideration of practice required to minimise parents misunderstandings and maximise the protective effects of knowledge
2006	England	Descriptive	Mothers	344	Maternal anxiety of NHS	• Anxiety highest to those referred • More tests – increased anxiety • Not understanding the meaning of recall and more tests increased anxiety	• Further studies – to validate this findings and other NHS programmes
2006	Nigeria	Survey	Mothers	101	Mothers knowledge and attitude on infant hearing loss and NHS	• Limited knowledge – a few risk factors were above average • Positive attitudes towards screening and intervention	• Further studies to ascertain whether parental attitude can be modified by the knowledge of risk associated to screening such as false-positive results.
2006	United States	Survey	Families	108	Parental perception of hearing loss	• NHS is a difficult and intimidating process • Communication in conveying results of screening was inadequate • Information was insufficient • Intervention services were inadequate • Desire for support groups	• More involvement of Otolaryngologist is required • A critical analysis of infant hearing loss evaluation and treatment is needed
2007	Canada	Qualitative	Parents	17	Parents perceptions of early/late detection	• Early detection beneficial – long-term prognosis & child development • UNHS process – contributes to the knowledge about child's hearing loss • Not knowing early – positive, give time for bonding • The process can create anxiety, frustration and confusion	• Further research on the impact of larger health care system on child and family outcomes
2007	England	Qualitative	Families	45	Parents descriptions of knowing early	• Parents positive about knowledge of knowing early that led to grief • Knowing early – reassurance of being in control	• There is a need to create space for parents to feel their responses to their child's deafness.
2007	United States	Survey	Families	1106	Levels of families satisfaction and anxiety – EHDI process	• Families satisfied with screening and intervention services • Adequate information was provided • Anxiety increased with more tests	• A need for additional education of both parents and professionals about newborn hearing screening and follow-ups.
2008	Wales	Survey	Women	177	Parental experiences and satisfaction of NHS	• Satisfaction with NHS were high • Less satisfaction on information provided • More anxiety for parents who had to go for more test	
2008	South Africa	Survey	Mothers	100	Maternal knowledge and attitude on Infant hearing loss and NHS	• Limited knowledge about the risk factors and early detection • Positive attitude towards UNHSP process	• A need to for increased maternal awareness on infant hearing loss and readiness of EHDI programmes
2010	Belgium	Qualitative	Parents	17	Parental experiences of deafness and NHS	• Confusion – screening procedures • Disbelief – health professional acts • Uncertainty – diagnostic procedures; between the testing and communication; expectations	• Adequate support to parents is necessary – clarity on screening, testing and further care

2011	Malaysia	Cross-sectional	Mothers	50	Mothers anxiety – failed test result – NHS	• Limited knowledge on screening prior screening • Positive with screening • Majority felt mild anxiety experienced during the initial screening then decrease before re-screening • Few felt moderate anxiety on both the initial screening and rescreening • Symptoms of anxiety included:- worst expectations, inability to relax, heart pounding and feeling of choking	• Further study to compare the anxiety level in different ethnic groups with different cultures. • Actions required to reduce the false-positive result • Improve the understanding of mothers regarding the meaning of the results
2013	Italy	Survey	Parents	288	Parental anxiety – infants failed hearing screening	• An average group of mothers were not worried about the screening process • Less mothers were worried about the outcome of screening • A few mothers – knowledge about rescreening would be better	• Lack of parental anxiety to be considered when evaluating the costs and benefits of tests for UNHS
2014	India	Qualitative	Mothers	83	Caregiver perception regarding NHS service delivery	• Sufficient awareness of screening programme services • Adequate knowledge of the devices used for tests and its performance • Adequate knowledge on the requirements of screening • Adequate knowledge about the screening results and rescreening • Positive attitudes towards screening • Adequate information provided	• Findings can be used to adjust NHS strategies in order to improve service delivery and facilitate compliance from the community
2014	India	Survey	Grand-mothers	102	Opinions of mothers on NHS	• Limited knowledge on caused of hearing loss • Low knowledge on early detection and NHS • Positive attitude towards UNHSP process	• Attentive during awareness creation and counselling towards the limited knowledge and negative attitude • The whole family should be involved during counselling services
2014	Malaysia	Survey	Mothers	119	Levels of parents satisfaction of UNHS process	• Majority of parents satisfied with UNHSP • Parents not satisfied by communication about test procedures and results • Information received was insufficient • Knowledge about UNHSP – sufficient • Half of the group knew the results of the baby and very few did not know	• The family-centred approach during screening should be considered
2014	South Africa	Survey telephonic interviews	Caregivers	25	Caregiver knowledge of NHS and its process	• Limited knowledge of NHS • Information provided insufficient • Few caregivers – NHS reliable • Majority – uncertain about NHS	
2016	India	Cross-sectional Survey	Mothers	219	Mothers knowledge and attitude towards infant hearing loss	• Limited knowledge of risk factors • Knowledge about early detection limited • Positive attitude towards screening but concern raised towards intervention	• A need for public awareness programmes to improve knowledge and attitude among the population
2016	-	Systematic Review	-	-	To review knowledge and attitude of parents/caregivers infant hearing loss and NHS	• Ear discharge, measles, drugs/medication, family history, congenital causes and noise exposure identified as a risk factors for hearing loss • mixed results for knowledge about newborn hearing screening • positive attitudes towards hearing screening and intervention options	• the need for more studies of knowledge and attitude of parents/caregivers • develop antenatal training and public awareness program