Integration of ear and hearing care into primary health care in Malawi with special reference to task-sharing.

Wakisa Mulwafu

Thesis for the degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
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UNIVERSITY OF BERGEN

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Scientific environment

The project was performed in Malawi, College of Medicine while I was working as a consultant ENT Surgeon in the department of Surgery.

As a PhD candidate I received scientific supervision from the department of Clinical Medicine, University of Bergen and supervision from London School of Hygiene and Tropical Medicine.

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Acknowledgements

What really sparked my interest in ENT were the lectures delivered to us when I was in my fourth year at the College of Medicine in Malawi. The late Jessica Nakakande, a Ugandan national, taught us. I am so grateful to Dr Nakakande for starting that fire in me that has continued to burn up to this day. There was no ENT postgraduate training in the country then and so after my internship, I made several applications to different universities in South Africa. Professor Johan Fagan's department accepted my application and finished my ENT training at the University of Cape Town. Johan Fagan has been my mentor ever since. I am very grateful to his support and together we have written many papers, including Paper II that is part of this thesis. And Johan, you still hold the record of being the fastest person in responding to emails that I have known or come across.

I came back from training in 2007 to a country with virtually no ENT services. We needed to do something and whatever it was, we needed to do it fast. So over the last 10 years or so, we have built an ENT infrastructure in Malawi that is now capable of offering services, training and research. Without this infrastructure in place, my PhD would not have been possible. So I am very grateful to the people and organisations that have supported us to develop this infrastructure. Organisations like CBM, Sound Seekers, Michigan State University, Hearing Conversation Council and especially Lady Jean Wilson for believing in the Malawi dream. Professor Chris Prescott has been instrumental in formalising our task sharing services in Malawi.

Professor Hannah Kuper has been very instrumental in the growth of my research work. From when we did the Key Informant Method Study in Malawi to the time she became my PhD supervisor, I have benefitted a lot from her support and direction.

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To Asgaut Viste, you have been very supportive of the NORHED project that funded us to do this PhD and you were also one of my supervisors. Thank you for carefully reading my manuscripts and thesis. And I am also very grateful to Sven Young for establishing the links between Haukeland University Hospital and Malawi. They made our training go smoothly.

For you Omega, Lupa and Agnes

Abstract

Introduction

The prevalence of hearing impairment has increased rapidly over the last two decades. The burden is higher in Africa and South East Asia than in richer parts of the world. The majority of this hearing impairment is preventable and can be managed at primary care level. However, the primary care level is generally weak in the provision of ear and hearing services. In recognition of this gap, the overall aim of the present thesis is to investigate the need for and feasibility of integrating ear and hearing care into primary health care in Malawi, specifically through task-sharing.

Methods

The thesis is composed of five sub-studies. Apart from the first two studies which were trans-national, all the other studies took place in Malawi. The first study aimed to synthesise the available data on the prevalence and causes of hearing impairment in Africa through a systematic review of literature. The second study aimed at assessing availability and progress of ENT, Audiology and Speech Therapy services in Africa. It was a cross sectional study and a questionnaire was distributed by email to an ad hoc group of ENT Surgeons and Audiologists across Africa. The third study aimed at assessing the outcome of children with ear and hearing disorders, three years after diagnosis, in terms of uptake of referral to hospital, treatment given and satisfaction, and their participation in different aspects of life (school enrolment, ability to make friends, and ability to communicate needs). This was a longitudinal analysis of a population-based sample of children with hearing disorders, screened clinically and through questionnaires at baseline (2013) and follow-up (2016). The fourth study aimed to assess the uptake of and barriers to referrals to ear and hearing services for children in Thyolo District, Malawi. This was a mixed methods study, using both

quantitative and qualitative methods. The fifth study aimed at assessing the feasibility and accessibility of training community health workers in ear and hearing care and their ability to identify patients with ear and hearing disorders. This was a cluster randomised control trial. Community health workers (CHWs) were given a pre-test and post-test to assess the effect of training on their knowledge of ear and hearing care.

Results

The thesis showed that sub-Saharan Africa bears a high burden of ear and hearing disorders and that there are gaps in resources available to address these ear and hearing disorders. In Africa, the estimated prevalence for hearing impairment in children was 7.7% (2.4%–21.3%) using a cut-off of 25 dB HL and 17% for the general population of all ages. Our study II indicated that there are between 0.1 and 4.6 ENT surgeons per million persons across the region. Apart from South Africa, there is less than one audiologist for every million persons in sub-Saharan African countries. The impact of ear and hearing disorders often goes unnoticed and has not been explored adequately in low and middle income countries (LMICs). Study III showed that school enrolment among children with hearing loss was associated with ability to communicate and ability to make friends. Among children with hearing loss, those with speech impairment were more likely to report difficulties in making friends and in communicating needs. Among children with hearing loss, older children, girls and those with an illiterate caregiver were less likely to be enrolled in school. Training of CHWs in ear and hearing disorders proved feasible and acceptable and that CHWs were able to identify patients with ear and hearing disorders, and make referrals to a tertiary hospital as appropriate. A follow-up study on the uptake of referrals showed that there was a low uptake and the thesis has highlighted that while caregivers appeared to be motivated to seek care for their child, several often-interacting factors prevented them from doing so. These included location of/distance to the hospital, indirect costs, lack of transportation, procedural challenges in camps, awareness and

understanding of ear and hearing issues, fear and uncertainty about the referral hospital, and lack of availability/visibility of hearing health services.

Conclusion

There is high prevalence of ear and hearing disorders in Africa. The majority of the causes are avoidable and these conditions have significant impact on the people affected. There are low levels of services available for people with ear and hearing disorders and low uptake due to difficulties with accessing services. Task-sharing at primary level is feasible and acceptable and could help to fill gaps in service provision.

Abbreviations

AOM	Acute otitis media
CHW	Community health worker
CSOM	Chronic suppurative otitis media
ENT	Specialist in Ear, Nose and Throat disease
GP	General practitioner
HSA	Health surveillance assistant
LMICs	Low and middle income countries
MEC	Middle ear cavity
OM	Otitis media
OME	Otitis media with effusion
ORL	Oto-rhino-laryngologists
WHO	World Health Organization
SNHL	Sensorineural hearing loss
ABR	Auditory brainstem response
PTA	Pure tone average
dB HL	Decibel hearing loss
EPI	Expanded program on immunisation
PEHC	Primary Ear Hearing Care
HDI	Human development index

GDP	Gross national product
HSAs	Health surveillance assistants
MOH	Ministry of Health
MCN	Managed clinical network
KIM	Key informant method
KI	Key informant
PHC	Primary health clinic
EHDSP	Ear and hearing disorders survey protocol
RAHL	Rapid assessment of hearing loss
QECH	Queen Elizabeth Central Hospital

Definitions

Task-shifting : has been described by WHO as a process of delegation or shifting of some tasks to less-specialized health workers with the advantage of allowing healthcare professionals to do more specialised tasks which could relieve congestion at the health units.

Task-sharing: a similar concept to task shifting, refers to a partnership in which different levels of providers do similar work, rather than having less-credentialed providers take over all provision of a service.

Health Surveillance Assistants : Formerly known as Cholera assistants , they are health workers who link the village to the health system in Malawi and have a defined job description but one which changes depending on the new interventions introduced into the health sector.

List of Publications

This thesis is based on the following papers:

Paper I:

Mulwafu W, Kuper H, Ensink RJ. Prevalence and causes of hearing impairment in Africa. *Trop Med Int Health*. 2016 Feb;21(2):158-65.

Paper II:

Mulwafu W, Ensink R, Kuper H, Fagan JJ. Survey of ENT services in Sub-Saharan Africa: Little progress between 2009 and 2015. *Global Health Action.* Volume 10, 2017 - Issue 1 *http://dx.doi.org/10.1080/16549716.2017.1289736*

Paper III:

Mulwafu W , Tataryn M, Polack S, Viste A, Goplen FK, Kuper H. Children with hearing impairment in Malawi, a cohort study. *WHO Bulletin*. 2019. Accepted for publication 27.03.2019

Paper IV:

Bright T, Mulwafu W*, Thindwa R, Zuurmond M, Polack S. Reasons for low uptake of referrals to ear and hearing services for children in Malawi. *PloS one*. 2017 Dec 19;12(12):e0188703.

Paper V

Mulwafu W, Kuper H, Viste A, Goplen FK. Feasibility and acceptability of training community health workers in ear and hearing care in Malawi: a cluster randomised controlled trial. *BMJ open*. 2017 Oct 1;7(10): e016457.

[*] *In Paper IV, Bright and Mulwafu are joint first authors*

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1 Introduction

1.1 Global prevalence of hearing loss

Over the last few decades, the global prevalence of hearing loss has continued to increase unabated and its prevalence is projected to increase from the estimated 466 million people in 2018 to 900 million people in 2050[1]. To make matters worse, these estimates are only for disabling hearing loss and exclude the mild hearing losses which certainly do not have mild consequences but can cause significant disability. The rise in the prevalance is partly due to population growth and population ageing. Disabling hearing loss, defined as a permanent unaided hearing threshold level in the better ear of ≥ 41 dB HL (for adults) and permanent unaided threshold level in the better ear of ≥31 dB HL (for children younger than 15 years old), is unequally distributed across the world. Hearing loss appears to be more common in Sub-Saharan Africa, South Asia and Asia Pacific than in richer parts of the world. Estimates suggest that the prevalence of hearing impairment (defined as hearing loss > 35dB) for adults aged > 15 years old is 15.7% in Sub-Saharan Africa as compared to 4.9% in high income countries. Even for children aged 5-14 years, the prevalence is higher in sub-Saharan Africa (1.9%) as compared to high income countries (0.4%)[2]. The majority of this hearing impairment is preventable and can be managed at primary care level. However, the primary care level is generally weak in the provision of ear and hearing services. This thesis presents an approach taken by our work in Malawi in addressing hearing loss and its causes. There are many causes of hearing impairment. It is important to think about cause as it guides prevention, treatment, rehabilitation strategies. The approach of our work in Malawi seeks to integrate ear and hearing care into primary health care through task sharing.

Throughout the introduction, I will briefly present the pathway for hearing so that it is clear to the reader where things can go wrong with hearing. I will discuss the importance of hearing especially as it affects communication and language development. I will discuss the measurement of hearing, grading and the definitions of

hearing loss. In order to plan programs for prevention, medical and supportive treatment, we need to understand the causes and identify the risk factors for hearing loss. Lastly, I will discuss the services available for people with hearing loss, globally and in Africa.

1.2 Structure and function of ear and hearing

The ear is divided into three parts, namely the outer ear, middle ear and inner ear as shown in Figure 1.

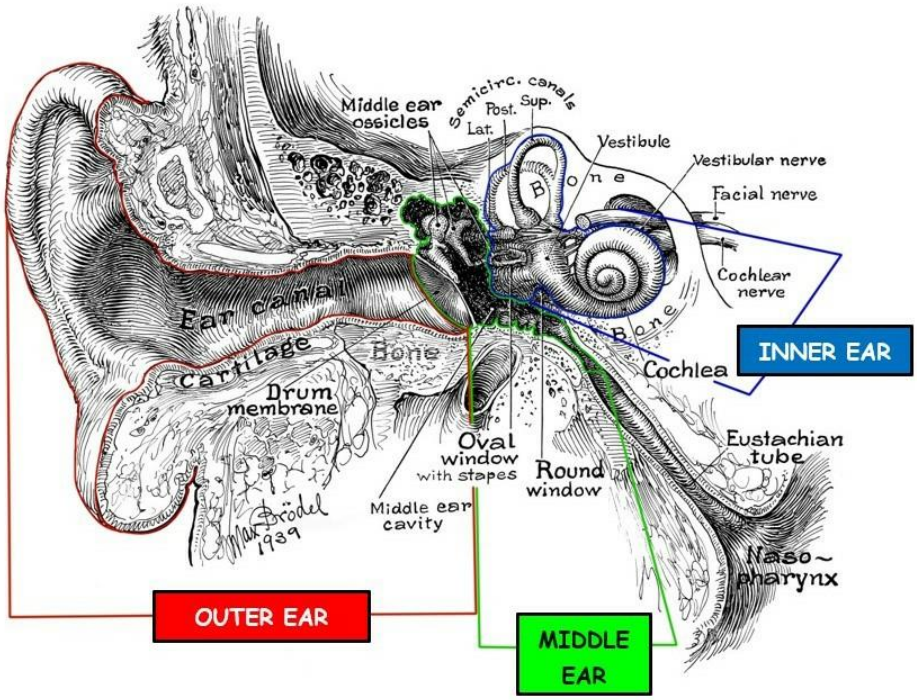


Figure 1: Anatomy of the ear [3]

Hearing takes place when sound, transported as pressure waves, moves from the outer ear to the inner ear and subsequently, through the process of transduction—the process of converting sound waves into electrochemical impulses—travel via the acoustic nerve to the brain where it is intepreted as e.g. speech, noise or music. Pressure waves are captured by the outer ear and cause the ear drum to vibrate. The external auditory canal acts as an acoustic resonator because it is closed at one end by the eardrum. It therefore contributes about 10 dB gain in pressure with a peak at 3 kHz. Vibrations of the ear drum are transmitted via the small bones (ossicles) of the middle ear to the inner ear. The transmission of sound from the outer ear to the inner ear requires sound to be converted from mechanical pressure waves into electrical signals. The middle ear acts like a bridge connecting the outer ear to the middle ear and has the important function of amplifying sound energy. This is possible due to the unique mechanical

properties of the eardrum and the ossicles. Firstly, due to the larger area of the tympanic membrane relative to the smaller area of the stapes footplate at the oval window, the pressure applied at the oval window by the stapes footplate is 17 times greater than the pressure at the tympanic membrane. Secondly, the larger size of the malleus exerting force on the shorter arm of the incus makes the ossicles act as a lever system thereby increasing the force applied by the stapes at the oval window by a factor of 1.3.[4] The middle ear matches the low impedance of the air medium—for sound energy within the ear canal—with the high impedance of the cochlear fluids. The hair cells of the organ of corti transform mechanical energy into electrical impulses. Ultimately, the impulses from the inner ear are transported by the acoustic nerves to the brain where they are perceived as sound. [5]

1.3 Importance of early detection and treatment of hearing loss

Hearing is important for the development of the child's auditory brain and for language acquisition. The unborn child starts to hear from about six months as by this time the cochlea is fully developed [6]. Maternal sounds are an an important stimulus and contribute to the development of hearing in the unborn child. However, the central auditory pathways (from cochlea to brain) are not fully developed at birth. This system takes over a decade for its maturation, and auditory stimulation is important in this process [7]. Congenitally deaf children benefit most when cochlear implantation takes place within the first 3.5 years of life, when the central auditory pathways show maximal plasticity. By contrast, children who receive implants after the age of seven show abnormal cortical responses, even after many years of cochlear implant use [8]. This is why early detection and treatment of hearing loss is important. It is recommended that detection of hearing impairment in newborns should take place as early as 3 months and interventions started as early as 6 months after birth[9, 10].

Diagnosis of hearing loss in children at such an early age is possible through newborn infant screening programs[11]. However, newborn infant screening programs are currently not feasible in most low and middle income countries (LMICs).

Hearing is one of our most valuable senses. It connects us to the world. The most important use of hearing is communication[12]. We are able to connect with our family and friends through hearing and the communication skills that we have learned. Communication is also fundamental to education and, as children move towards adulthood, they need communication skills in order to participate and form relationships in all areas of life [13]. Despite the importance of hearing, we often take this sense for granted. This is largely because the ear does its job so well that we do not pay attention to it. Hearing is the only sensory system that allows us to know what is going on everywhere in our environment - we don't have to be looking at the dog barking to know there is something behind us in the dark [14].

Hearing loss may be caused by disorders of the ear or of the auditory pathways. There are two main categories of hearing loss: conductive and sensori-neural. Any problem in the outer or middle ear that leads to a reduction of the sound energy entering the inner ear leads to a conductive hearing loss. Many of these problems can be corrected either though medicine, surgery or rehabilitation with hearing aids that amplify sound energy. Any problem in the inner ear that leads to a reduction of the electrical signals entering the auditory brain cortex leads to a sensori-neural hearing loss (SNHL). Sensory hair cells are susceptible to damage from a variety of stresses, and since hair cells in the cochlea are not regenerated after they are lost, the resulting hearing loss is permanent [15]. The broad term "sensorineural hearing loss" is used because diagnostic tests may not always determine whether a lesion is in the sensory or the neural portion of the peripheral auditory system. The main causes of sensorineural hearing loss are degenerative processes associated with aging, genetic mutations, noise

exposure, exposure to therapeutic drugs that have ototoxic side effects, and chronic conditions. These conditions are more challenging to treat but can benefit from rehabilitation with hearing aids and cochlear implants. People may also experience mixed hearing loss, which includes both conductive and sensori-neural components. These are discussed in more detail later in the chapter.

Hearing loss has many negative consequencies. Hearing loss at any stage of life can compromise the communication process and influence an individual's quality of life[16]. The impact of hearing loss will be influenced by a number of factors including age at onset, degree and audiometric configuration of the hearing loss, therapeutic interventions and family and environmental influences[17]. The development of the child's ability to understand human speech and acquire language as well as the development of thinking capability is based on his/her ability to hear the speech of other people[18] [19] [20]). Therefore, hearing loss in childhood can cause delays in the development of speech, language, and cognition which may later lead to educational disadvantage, social isolation and economic disadvantage [21-23]. Children with hearing impairment on average have poorer school performance compared to children with normal hearing. For instance, a study among 1228 school children found that 3rd grade children with hearing impairment had significantly lower scores for reading vocabulary, language mechanics, word analysis and spelling than children with normal hearing, as well as lower scores on a range of functional tests. However, no differences were observed at 6th and 9th grade levels [24]. Other studies have suggested relationships between hearing impairment in children with worse school performance and language skills among children aged 11 years and 6-12 years [25].

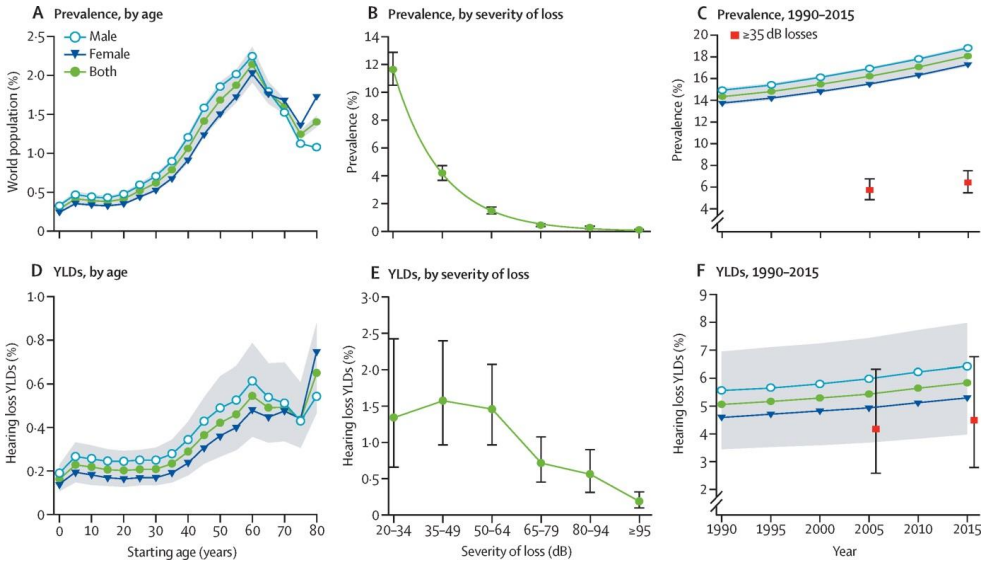
There are broader impacts of hearing loss, beyond communication problems. In adults, untreated hearing loss has been linked to depression, anxiety and other psychological

disorders, poorer social functioning, as well as an increased risk of dementia [26-29]. Therefore, treatment of hearing loss might help to prevent cognitive decline, depression, and dementia, each of which is strongly associated with hearing loss.

The economic impact of hearing loss must not be underestimated. WHO estimates that unaddressed hearing loss constitutes an annual global cost of US$ 750 billion. This includes health sector costs (excluding the cost of hearing devices), costs of educational support and societal costs[1] . The largest part of these societal costs are lost work productivity.

The importance and impact of hearing loss is sometimes overlooked because it is a hidden disabilty. This is despite the fact that it currently ranks fourth on the global index of causes of years lived with disability, higher than other chronic diseases such as diabetes or dementia[30, 31]. We have witnessed the prevalence of hearing loss rise as the population is aging. Males tend to be affected more than females. (See Figure 2).

Figure 2: Prevalence of hearing impairment from the GBD 2015[31]



1.4 Measurement and grading of hearing loss

There are many ways to measure hearing and to quantify hearing loss, but each method can be classified as objective or subjective. Objective measurements include otoacoustic emissions (OAEs) and auditory brainstem response audiometry (ABR). For these measures, the client does not need to actively participate, and so results are not influenced by behavioural performance. For instance ABR involves recording of ongoing electrical activity in the brain recorded via electrodes placed on the scalp in response to auditory stimuli. ABR is still considered the gold standard for estimating hearing threshold in very young and non-cooperative children.[32]. A more commonly used practice in the subjective measurement category is pure-tone audiometry[33]. This method involves presenting the client with pure tones (sinusoids) of different frequencies and intensities and the client indicating to the tester when the sound can be heard. The hearing thresholds to pure-tones of varying frequencies are determined and plotted on an audiogram as decibel hearing level (dB HL)[34]. Using a questionnaire to estimate self-reported hearing loss is quick and cheap, but this method often underestimates the prevalence of hearing loss as it fails to identify those with mild hearing loss[35]. It is recommended that a combination of subjective and objective measurement be done to allow a complete view of a client's hearing. However, subjective methods are difficult to undertake in clients who are not able to cooperate (e.g. small children, or people with cognitive impairments) and so objective methods are recommended for these groups.

In both objective and subjective methods hearing is often assessed by the average of thresholds for hearing sinusoids at the frequencies of 0.5 kHz, 1 kHz, 2 kHz, and 4 kHz; the thresholds are measured in decibels (dB HL) relative to the thresholds of unimpaired hearing [36]. Hearing loss is classified by type, degree and configuration based on the audiometric results. Hearing loss can either be assessed for a single ear, or for a person, and if the latter, it is usually defined on the basis of the better ear. Three classifications of hearing loss are widely used: the classifiacions by the American Speech-Language-Hearing Association (ASHA), by the WHO and the Global Burden of Disease Study.

The American Speech-Language-Hearing Association recommends the scale of hearing impairment devised by Goodman in 1965 [37] and modified by Clark in 1981[38] which describes slight (15 - 25 dBHL), mild (26 - 40 dBHL), moderate (41 - 55 dBHL), moderately-severe (56 - 70 dBHL), severe (71 - 90 dBHL) and profound (≥ 91 dBHL) degrees of hearing impairment.

The WHO defines disabling hearing impairment as a permanent unaided hearing threshold level in the better ear of ≥ 41 dB HL (for adults) and permanent unaided threshold level in the better ear of ≥31 dB HL (for children younger than 15 years old)[1]. One of the limitations of this classification is that it is dependent on pure tone audiometry. Therefore, patients unable to undergo this test, e.g. small children with hearing loss based on OAE failure, cannot be classified. In this thesis, the WHO classification (table 1) is used [36].

Table 1: **WHO grades of hearing impairment[36]**

Grade of Impairment	Audiometric ISO value (average of 500, 1000, 2000, 4000 Hz)	Impairment description
0 (no impairment)	25 dBHL or less (better ear)	No or very slight hearing problems. Able to hear whispers
1 (Slight impairment)	26-40 dBHL (better ear)	Able to hear and repeat words spoken in normal voice at 1 metre
2 (Moderate impairment)	41-60 dBHL (better ear)	Able to hear and repeat words using raised voice at 1 metre
3 (severe impairment)	61-80 dBHL (better ear)	Able to hear some words when shouted into better ear
4 (Profound impairment including deafness)	81 dBHL or greater (better ear)	Unable to hear and understand even a shouted voice

The Global Burden of Disease Study proposed a different classification linked to the impact of hearing loss on activities [2]. This classification also employs the better-ear hearing threshold, in decibels, averaged over frequencies of 0.5, 1, 2 and 4 kHz. It defines the threshold for disabling hearing impairment to 35 dB for all age groups. It also recalibrates the hearing scale in equal steps of 15 dB in an attempt to reflect crucial shifts in hearing perception more accurately. The categories are Mild (20–34 dB), Moderate (35–49 dB), Moderately severe (50–64 dB), Severe (65–79 dB), Profound (80–94 dB), and complete losses (≥ 95dB).

The use of different systems for classification and grading of hearing impairment makes it difficult to estimate the prevalence of hearing impairment as well as to compare results by region or over time.

1.5 Causes of hearing impairment

Hearing loss is one of the main symptoms of ear disorders. However, many ear disorders may present with other symptoms such as ear pain (otalgia), ear discharge (otorrhea), dizziness and balance problems. Some ear disorders such as cholesteatoma, mastoiditis and otogenic meningitis may be life-threatening. This thesis will focus on common ear disorders that cause significant hearing loss in a primary health care setting, leaving out certain conditions that are uncommon in our region, including otosclerosis and vestibular schwannoma.

As described above, hearing loss may be classified as conductive – also known as peripheral hearing loss (caused by impairment of the outer or middle ear) – sensorineural (caused by dysfunction in the cochlea or spiral ganglion), or mixed (hearing loss that has both conductive and sensorineural components). Hearing loss can be either stable or progressive. According to the time of onset it may be described

as congenital or acquired (or late-onset). Etiology is broadly divided into genetic (hereditary) or non-genetic (environmental) causes[39]. The types of hearing loss will vary geographically, and overall globally – in high income countries sensorineural hearing loss is more common while conductive loss is more common in lower resource settings **[40].** For instance, studies of children in Nigeria, Zimbabwe and South Africa showed that conductive hearing loss was the most common type.[41-43]

Some of the most important causes of conductive and sensorineural hearing loss are described below:

1.5.1 Conductive hearing loss

1.5.1.1 Cerumen Impaction

Earwax or cerumen is produced naturally by the ear canal. It serves a protective function for the skin in the external auditory canal and therefore, a little bit of cerumen is healthy and necessary. Its acidic pH gives it antimicrobial properties. Cerumen is also naturally eliminated: new earwax forms continuously, and the older cerumen is moved toward the opening of the external ear canal by the outward movement of epithelial cells[44].

In some circumstances, the ear canal produces too much wax or wax is not eliminated properly and can accumulate until it blocks the ear canal. This is referred to as impacted wax.

Cerumen impaction is a common ear disorder, though the some groups are affected more often than others and these groups include children: e.g. studies conducted in Kenya and Tanzania found that 8.6% and 15.7%, respectively, of surveyed school children had impacted wax[45, 46]; workers using ear protectors and hearing aid users (use of a hearing aid mould may cause wax impaction). Some people accumulate earwax because of the nature and shape of their external auditory canal.

It is important to identify and treat wax impaction, for the following reasons:

Wax impaction can cause hearing loss in adults and children by obstructing the ear canal and interfering with sound transmission. This hearing loss is reversible.

Wax may occlude hearing aid moulds, which reduces the effectiveness of the aid and can exacerbate uncomfortable feedback noise.

Wax impaction may mask a more severe underlying condition such as chronic suppurative otitis media causing hearing loss[47].

Cerumen impaction can easily be managed by trained primary health care workers. Every effort should be made to prevent, identify and manage it, especially in children [48] as any hearing impairment, even temporary, will have an impact on their learning and development. Traditional ways to remove cerumen are mechanical removal with instruments, oily detergents to soften the cerumen, water irrigation and removal with suction equipment under an otomicroscope. Furthermore, it is important to have an experienced assistant, who can keep the person´s head in a soft but steady grip.

1.5.1.2 Acute Otitis Media (AOM)

Otitis media is a general term for middle ear inflammation. In most cases, AOM precedes an viral upper respiratory tract infection, which causes inflammation of the mucosa of the upper respiratory tract, including the nasopharynx and eustachian tube. Failure by the eustachian tube to drain middle ear fluid establishes an environment that is conducive to bacterial growth [49]

AOM is reported as one of the most common respiratory illnesses affecting pre-school children, children under five years old[50]. As with many infectious diseases, the nature of the burden of AOM differs greatly between high income countries and LMICs[51]. The main differences seem to be the frequency of complications and sequelae such as hearing loss due to chronic suppurative otitis media (defined by WHO as 2 weeks of persistent ear discharge, rather than the incidence of AOM[52].

Clinical diagnosis of AOM is difficult because signs and symptoms might overlap with symptoms of other respiratory infections. Ear pain is the most specific symptom but often seems absent in children with AOM. The American Academy of Paediatrics states that clinicians should diagnose AOM in children who present with moderate to severe bulging of the tympanic membrane (TM) or new onset of otorrhea not due to

acute otitis externa [53-55]. Moreover, diagnosis relies on visualisation (otoscopy) and functional testing of the eardrum (pneumatic otoscopy, tympanometry, acoustic reflectometry), which is done inconsistently. Diagnosis needs training, good instruments, removal of cerumen from the external auditory canal, and cooperation from medical staff, children, and parents. Use of antibiotics in the treatment of AOM is an issue that remains unresolved. Prevention is also possible, and the introduction of the pneumococcal vaccine has resulted in reduction of risk of up to 34% for children to develop AOM [56, 57].

1.5.1.3 Otitis Media with Effusion (OME)

OME, also known as middle ear effusion, 'glue ear' or secretory otitis media, is defined as the presence of fluid in the middle ear (behind the eardrum) without signs or symptoms of acute ear infection (no fever or pain). It is primarily the appearance of the eardrum that will help diagnose OME. The eardrum is not perforated but you may find air bubbles behind the eardrum translucent eardrum normal when you shine a light on it, dull and indrawn ear drum. The fluid can vary from a watery (serous) liquid (in which case air bubbles may be present and/or a fluid level seen) to a sticky mucus (when air bubbles and a fluid level are not present). OME is more common in children than adults and may affect one or both ears, with both ears being the most common.

In USA, nine in every ten children at the age of two years have had at least one episode of OME which can be transient or can persist for several months[58] . The prevalence may be even higher in a developing countries with large sections of disadvantaged communities since OME has been associated with poor socioeconomic circumstances[59] .

The 2016 clinical practice guidelines recommend that management of the child with OME who is not at risk should be with watchful waiting for 3 months from the date of effusion onset (if known) or 3 months from the date of diagnosis (if onset is unknown)[60] . Those at increased risk for speech, language, or learning problems from middle ear effusion because of baseline sensory, physical, cognitive, or behavioral factors should be recommended for tympanostomy tubes when surgery is performed for OME in a *child <4 years old or* should be recommended for ventilation

tubes, adenoidectomy, or both when surgery is performed for OME in a *child ≥4 years old.*

1.5.1.4 Chronic suppurative otitis media (CSOM)

CSOM is persistent inflammation of the middle ear or mastoid cavity. Synonyms include "chronic otitis media", chronic mastoiditis, and chronic tympanomastoiditis. CSOM is characterised by recurrent or persistent ear discharge (otorrhoea) over 2 to 6 weeks through a perforation of the tympanic membrane[61, 62]. CSOM usually begins as a complication of persistent AOM with perforation in childhood. WHO's estimates suggest that worldwide 65 million to 330 million individuals develop chronic suppurative otitis media, 60% of whom will suffer from hearing impairment[63].

Risk factors for CSOM vary in different settings. Frequent upper respiratory tract infections and poor socioeconomic conditions (e.g. overcrowded housing and poor hygiene and nutrition) are often associated with the development of CSOM[64]. In LMICs, the rate of complications from chronic suppurative otitis media is still high, due to factors associated with poverty [51, 65, 66]. In high income countries and advantaged populations, previous insertion of tympanostomy tubes is now probably the single most important risk factor for the development of CSOM[67].

In Africa, CSOM represents the most frequent cause of moderate hearing loss (40–60 dB). Persistent hearing loss during the first 2 years of life may increase learning disabilities and poor scholastic performance[68, 69] . Progressive hearing loss may occur among those in whom infection persists and discharge recurs. Less frequently, the spread of infection may lead to life-threatening complications such as intracranial infections and acute mastoiditis. Early identification of the disease is key to improving treatment outcomes[70] .The aims of treatment of CSOM are to avoid serious complications (such as mastoiditis and meningitis), improve symptoms (like otorrhea, ear pain, tinnitus, dizziness and ear fullness) and finally to improve hearing function..

1.5.2 Sensorineural hearing loss

1.5.2.1 Congenital causes

Congenital hearing loss is defined as hearing loss that is present at birth. Diagnosis of this type of hearing loss has been made possible in developed countries because of neonatal hearing screening programmes. In developing countries, prevalence estimates of congenital hearing loss vary between 19 per 1,000 newborns in sub-Saharan Africa up to 24 per 1,000 in South Asia as compared to 1.33 per 1,000 live births in developed countries [71]. Risk factors for congenital hearing loss include a positive family history, intensive care unit admission, genetic defects and infections such as cytomegalovirus and rubella. In most cases, it is difficult to establish the cause of congenital hearing loss. In developed countries, cochlear implants are now the gold standard in the restoration of hearing for children with profound bilateral congenital hearing loss.

1.5.2.2 Age-related hearing loss

Age-related hearing loss occurs because of environmental and genetic factors that contribute to degeneration of cochlear cells[72] . Age-related hearing loss (presbycusis) is usually bilateral and symmetric and is most pronounced at higher frequencies (≥2000 Hz). It is the leading cause of adult-onset hearing loss, and it has been estimated that adult onset hearing impairment will be within the top 15 leading global causes of burden of disease by 2030 [73, 74].In Africa, the prevalence of age related hearing loss is not known but in Europe, approximately 30% of men and 20% of women have been found to have a hearing loss of 30 dB HL or more by age 70 years, and 55% of men and 45% of women by age 80 years[75]. In low-resource countries, where exposure to environmental risk factors such as noise and ototoxic drugs (aminoglycosides are used without serum-level monitoring in treatment of tuberculosis and of severe pneumonia in children) may be greater, and potentiate the development of age-related hearing loss[76].

1.5.2.3 Noise induced hearing loss

Noise induced hearing loss (NIHL) is thought to be one of the major causes of preventable hearing loss[77, 78]. Workplaces such as factories are associated with exposure to high noise levels; however, even people who do not work in these environments have a risk of noise exposure in daily life that they often underestimate.

Loud sounds and noise exposure can occur in a variety of seemingly innocuous settings, such as concerts, movie theaters, and fitness classes with loud music, and through engagement in a range of activities, such as listening to music at home. Noise-induced hearing loss can be temporary or permanent, depending on the intensity and duration of exposure [79]. Worldwide, 16% of the disabling hearing loss in adults (over 4 million disability adjusted life years [DALYs]) is attributed to occupational noise, ranging from 7% to 21% in the various subregions[80] . Occupational NIHL burden is much heavier in the developing world, with over 3.8 million DALYs , and only about 0.3 million in the developed world[80]. Through the "make listening safe" initiative, WHO hopes to reduce the incidence of NIHL [81]

1.5.2.4 Ototoxicity

Epidemiological data on ototoxic deafness are lacking for developing countries, and the public health aspect of ototoxicity is often overlooked, to the detriment of the individual patient [82]. Ototoxicity can result in permanent hearing loss, which is accompanied by degeneration of hair cells and neurons in the cochlea. An iron–aminoglycoside complex is believed to potentiate Reactive Oxygen Species (ROS)-induced cellular degeneration in the cochlea. The ROS trigger the cell death pathways (Apoptosis) [83]. The apoptosis employs caspase-dependent pathways [84]. Ototoxicity appears to be related to specific mitochondrial DNA mutations. Two mutations in the mitochondrial 12S ribosomal RNA gene have been previously reported to predispose carriers to aminoglycoside-induced ototoxicity[85]. Despite their adverse effects, aminoglycosides are commonly used as short-course antibiotics in developing countries such as South Africa and are, together with capreomycin, important components of the MDR-/XDR-TB drug regimens for 6 months or longer [86]. They are cost effective and widely used. The following strategies can be adopted to minimise the extent of hearing loss in such patients: reduction in therapy time, establishing an evidence-based audiological monitoring protocol, avoidance of excessive noise exposure, avoidance of drugs with synergistic ototoxic effects (e.g. loop diuretics, antimalarials), and the use of antioxidants [86] Heat shock proteins (HSPs) are induced in response to cellular stress and induction of HSP70 was previously shown to protect against the ototoxic effects of aminoglycoside antibiotics[87]. Although, early expression of heat shock proteins can protect hair cells

from aminoglycosides, proven clinical methods for the prevention of ototoxic injury are not yet available [88].Ototoxicity is particularly common in certain groups. For instance, Harris et al [86] showed that HIV-positive patients with multidrug-resistant tuberculosis (MDR-TB) (60/86; 70%) were more likely to develop hearing loss than HIV-negative patients (27/65; 42%, OR 3.25, 95% CI 1.65-6.37, p <0.001).The incidence of cochlear damage due to aminoglycosides varies from 7–90 [89]. According to the American Speech-Language-Hearing Association, the actual frequency of cochleotoxicity associated with aminoglycosides is unclear due to the inconsistent reporting of results[90]. Incidence rates appear variable and controversial due to differences in study design and methodologies. Studies have used different criteria to define cochleotoxicity as well as various means to monitor hearing.

1.5.2.5 Prevention of hearing loss

It is important to consider the frequency of different types of hearing loss in a population, as this drives the strategy for the primary, secondary and tertiary prevention of hearing impairment. For instance, infections such as rubella and measles are key causes of hearing loss in some settings, and imply the need for primary prevention through vaccination campaigns. Prevention of permanent hearing loss is important, and probably both cheaper and more effective than subsequent treatment especially in children. Children need to be treated early, particularly when suffering from chronic or recurrent ear infections which are important causes of later permanent hearing loss, particularly in developing countries like Malawi, where children under the age of 18 constitute 51% of the population.

As described above, conductive hearing loss is often more amenable to treatment, but this requires strengthening of relevant hearing services. On the other hand, treatment is difficult for sensori-neural hearing loss and the key interventions are preventive measures, rehabilitation and provision of hearing aids. This is described in more detail in the next section.

1.6 Availability of services for patients with ear and hearing disorders

In 2017, WHO adopted a resolution on ear and hearing care that urges member states to develop, implement and monitor screening programmes for early identification of ear diseases such as chronic suppurative otitis media and hearing loss in high risk populations, including infants and young children[91]. Ultimately, these initiatives may help towards the attainment of the Sustainable Development Goals 3 (Ensure healthy lives and promote well-being for all at all ages) and 4 (Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all). This new resolution should serve as a catalyst for a coordinated global movement, encouraged at the country level, with the involvement of health-care professionals, researchers, and advocates to help reduce the global hearing loss burden.

Although awareness of hearing loss and its sequelae is increasing, prevention and treatment are still not regarded as urgent needs in many countries, especially in LMICs where scarce resources force difficult choices[31]. An effective response would require intervention at the primary, secondary and tertiary levels, as shown in Table 2.

The WHO estimates that approximately half of hearing losses could be prevented with low-cost interventions that include immunisations for rubella, mumps, measles, and meningitis. Consequently, scale up of prevention programmes such as immunisation against mumps, measles, rubella, pneumococcus, haemophilus and meningitis; health education; improved maternal and child health services are useful for prevention of environmental causes of neonatal hearing impairment [92]. The Malawi policy regarding Expanded Program on Immunisation (EPI) is to immunise all children under 12 months old with the goal of reducing morbidity and mortality due to six preventable diseases namely measles, tuberculosis, whooping cough, diphtheria, poliomyelitis and tetanus[93]. In addition to these 6 diseases, the EPI has also included hepatitis B and *Haemophilus influenzae* type b.

For hearing losses that cannot be—or were not—prevented, treatment such as surgery and medicine can produce favourable outcomes in most cases. Services can be provided at primary level. For instance, in Malawi, we estimated that, there are approximately 1800 children per million population with conductive causes of hearing impairment that could be treated or prevented through the provision of basic primary ear and hearing care services [94]. Primary Ear and Hearing Care training courses have been conducted targeting community and primary health workers in order to scale up the availability of these services [48]. In addition, outreach programmes for identification of people with ear and hearing problems are routinely undertaken [95, 96]

Services at the secondary level of intervention include early detection of hearing loss with universal or at least targeted screening and, if possible, prompt intervention for the identified cases, provision of hearing aids in LMICs, which should assign priority to children with moderate or severe hearing loss, followed by adults. However, even though globally about 6 million hearing aids are dispensed annually, it is estimated that in LMICs, about 20% of people who have hearing loss require hearing aids, suggesting 72 million potential hearing aid users worldwide[97] . However, current production of hearing aids meets less than 10% of the global need. In LMICs, less than 3% of people who need a hearing aid are thought to have one [97]. In USA, the prevalence of hearing aid use among those with a hearing loss (pure-tone average > 25 decibels hearing level over 500, 1000, 2000, and 4000 Hertz, worse ear) was about 14%[98, 99].

At tertiary level, rehabilitation can be offered for people with irreversible hearing loss. This may include provision of hearing aids, cochlear implants, or assistive listening devices or other strategies according to severity of hearing loss (e.g. hearing rehabilitation; teach sign language to otherwise untreated children or children whose losses remain severe or worse after treatment with a hearing aid or cochlear implant; other special education for children who need it). Cochlear implants are provided to children and adults with severe and profound bilateral deafness including in countries

like Nigeria, South Africa, Malawi and Uganda [100-103]. However these have been shown to be cost effective in South Africa and Nigeria but not in Malawi, Rwanda, Kenya and Uganda [104].

1.7 Malawi country profile

Fig 3: MAP OF MALAWI

Source:[105]

The fieldwork of this thesis was conducted in Malawi, and so a brief description of the setting is included.

Malawi is a landlocked country in Southern/Central Africa, neighbouring Tanzania to the north/north-east, Zambia to the West and Mozambique to the east and southwest (Figure 3). It covers an area of about 118,500 square kilometres, one-third of which is made up by Lake Malawi, and has a population of just over 17.5 million people,

almost 84% of whom live in rural areas[106]. The population has increased from 13.02 million people in 2008. About 51% of the population of Malawi is under the age of 18 years [106]. Malawi is divided into three adminstrative regions (Northern, Central, and Southern) and 28 Districts, themselves subdivided into traditional authorities (TA), which are ruled by chiefs and at the more local level by group village headpersons (GVH) and village headpersons (VH). In Malawi, all chiefs have considerable status and power in their villages and areas.

Malawi remains one of the poorest countries in the world and relies heavily on an agricultural economy, which yields one third of its gross domestic product, and 90% of its export revenues[107]. In 2010, 50.7% of the Malawian population was living below the poverty line, 94.8% of whom in rural areas [108]. The national poverty rate increased slightly from 50.7% in 2010 to 51.5% in 2016, but extreme national poverty decreased from 24.5% in 2010/11 to 20.1 in 2016/17 [107]. The Human Development Index (HDI), a composite index “measuring long-term progress in three basic dimensions of human development: a long and healthy life, access to knowledge and a decent standard of living”, places Malawi in the low-development category with an HDI of 0.477, ranking 171 out of a total of 189 countries [109] The per capita GDP in 2003 was US$ 156 with an annual growth rate of 0.9% during the period 1990–2003. Although it has doubled to $338 in 2017, the GDP per capita for Malawi is much lower than the average values for low income and sub-Saharan African countries [110]. Educational attainment defined as median number of years of schooling was 3.1 years in 2015-16 among women, and for men, it was 3.9 years during the same period[108].

The country's health service delivery system is four-tiered, consisting of community, primary, secondary and tertiary care levels. At the community level, service is provided through health surveillance assistants (HSAs). The focus of HSAs is on provision of preventive interventions. Primary care is delivered through clinics and health centres. District and central hospitals provide secondary and tertiary care services respectively. The private not-for-profit sector plays a significant role in service provision.

Malawi has shown good progress on per capita public health expenditure. In 2014, the total expenditure on health per capita was $93 which is one of the highest in sub-Saharan Africa and is way above the US$ 34 recommended by the WHO Commission on Macroeconomics and Health to provide a basic package of services. The total expenditure on health amounts to about 11.4% of the GDP[111]. However, the share of the domestic budget allocated to health constitutes only 9.7% of total government expenditure. This is far below the Abuja target – a resolution by the African Heads of State to allocate 15% of the national budget to health [112].

In summary, health and development indicators for Malawi are those typical of other low-income countries in sub-Saharan Africa, as depicted in Table 2 below.

Table 2: Malawi: Health and development indicators

Characteristic	Value
Total population (millions) (2018)	17.5
Life expectancy at birth (male/female) (years)	61/67
Infant mortality rate (per 1000 live births) (2015/16)	42
Under-five mortality rate (per 1000 live births) (2015/16)	63
Total fertility rate (2015/16)	4.4
Maternal mortality ratio (per 100,000 live births)	439
Stunting in under-five children (%) (2015/16)	37
Adult (15–49 years) HIV prevalence rate (%) (2003)	8.8
Total Expenditure on health as a % of GDP (2014)	11.4
Official development assistance per capita (US$) (2003)	45.4
Physicians per 100,000 population (2004)	2.0
Nurses per 100,000 population (2004)	59

Sources: [106, 108, 111]

1.8 Ear and hearing care in Malawi

With only two resident ENT surgeons for a population of 17.5 million, Malawi has introduced several initiatives to improve access to ear and hearing services for its extremely underserved population.

Several improvements in capacity development have been achieved. An ENT unit together with an Audiology unit have been established and equipped at Queen Elizabeth Central Hospital in Blantyre, a private Audiology unit at African Bible College (ABC) in Lilongwe and planning for both an ENT unit and an Audiology unit at a second central hospital (Kamuzu Central Hospital) in Lilongwe has been completed and its funding for construction has been secured[113].

Thirty-two Medical Assistants have been upgraded and trained as ENT Clinical Officers and have been deployed throughout the country. A second ENT surgeon has been trained externally in Nairobi, Kenya. Three audiologists received basic training externally in Nairobi, Kenya. Three others received basic training at the African Bible College (ABC) in Malawi. Of these, four are undertaking further training externally to become Audiology Specialists. Two Nurses from Queen Elizabeth Central Hospital and one member of the Starkey Project staff are undergoing Hearing Specialist Training at Beit Cure Hospital in Lusaka, Zambia. 155 Nurses and Clinicians have been trained in Primary Ear Care. Several curricula have been developed in areas of Primary Health Care, upgrading Medical Assistants to ENT Clinical Officers, Village Health Workers, upgrading ENT Clinical Officers to Senior ENT Clinical Officers, ENT Specialist training for local doctors at Masters in Medicine level and BSc (Audiology)[113].

There has been an improvement in patient care and rehabilitation. Hearing aids have been introduced and routinely provided to patients with support from various partners such as Sound Seekers, Starkey Hearing Foundation and Hear the World Foundation. For instance, a total of 1,256 patients were fitted with hearing aids in 2015. Medicines

and equipment to ENT units are provided by the Malawi government through the Ministry of Health and partners such as CBM International.

However, there are also crucial barriers to the scale up of ENT services in Malawi. For instance, currently in the curriculum for HSAs, there is no ear and hearing care. As a consequence, ENT Services are inadequate to meet the need in Malawi, and innovative strategies must be developed to fill these gaps for the future.

2 Aims and objectives

The overall aim of the present thesis was to investigate the need for and feasibility of integrating ear and hearing care into primary health care in Malawi, specifically through task-sharing.

The specific objectives were:

Paper I: To synthesise the available data on the prevalence and causes of hearing impairment in Africa.

Paper II: To estimate the current status of ENT, audiology, and speech therapy services in sub-Saharan Africa, and to assess the extent and appropriateness of these services.

Paper III: To assess the outcome for children with ear and hearing disorders in Thyolo and Ntcheu districts, three years after identification and diagnosis, in terms of referral to hospital, treatment given and participation in life, like school enrolment, ability to make friends, and ability to communicate needs.

Paper IV: To assess the level of uptake and explore reasons for non-uptake of referrals to ear and hearing services among children in Malawi.

Paper V: To assess the feasibility and acceptability of training Community Health Workers to provide primary-level ear and hearing care, including,: identification of patients with ear and hearing disorders, referral of patients to services and treatment of simple ear conditions.

3 Methods

This thesis is based on following methods: a systematic review of literature, questionnaire survey, qualitative study and two population-based studies, one conducted in 2013 and another in 2016. This section contains a description in simple language of the rationale behind the choice of methods. For more detailed descriptions, the reader is referred to the reprints of the individual studies.

Paper 1:

The objective of this paper was to synthesise the available data on the prevalence and causes of hearing impairment in Africa. Weconducted a systematic review of the relevant data to answer this question. We searched seven electronic databases, EMBASE, PubMed, Medline, Global Health, Web of Knowledge, Academic Search Complete and Africa Wide Information to find relevant papers on the prevalence and causes of hearing impairment in Africa. For this review, we included all population-based surveys and school-based surveys conducted in Africa that estimated the prevalence of hearing loss, whether hearing loss was measured clinically or by self-report. A list of all potentially eligible articles was generated by the search. Together with a colleague, I screened all titles, then abstracts, then full texts to identify relevant articles. We had to agree on eligibility at each stage, and where we disagreed we settled this through discussion. When the final list of eligible papers was agreed, we read the papers in detail and made a table of the key relevant information, such as the prevalence and causes of hearing impairment, cut-offs for definition of hearing impairment, and methods used for measuring hearing impairment. Summary tables were produced to display this information across the eligible studies.

Paper II

The objective of this paper was to estimate the current status of ENT, audiology, and speech therapy services in sub-Saharan Africa, and to assess the extent and appropriateness of these services. To fulfil this objective, we distributed a questionnaire by email to an ad hoc group of ENT surgeons and audiologists in 30 sub-Saharan African countries. Questions were asked at the relevant country level about: the availability of ENT, audiology, and speech therapy services and equipment, the existence of training programmes for ENT surgeons, audiologists, and speech therapists, and the availability of services in rural areas. We also asked them to share their opinions about how to improve the situation. Data from the current survey were compared to those of a 2009 survey, conducted with comparable methods, to assess whether the status had changed over time.

Paper III:

The objective of this study was to assess the outcome for children with ear and hearing disorders in two districts in Malawi, three years after identification and diagnosis, in terms of referral to hospital, treatment given and participation in life, like school enrolment, ability to make friends, and ability to communicate needs. Initial identification of the children to identify those with hearing disorders was done in 2013 in two different districts: Thyolo (Southern region) and Ntcheu (Central region). This identification was undertaken through the Key Informant Method (KIM). Following training the Key Informants (KIs) returned to their village to identify and list children who were suspected of having a disability (including children with hearing impairment). The KIs then referred identified children to the assessment camps to undergo clinical investigation by a team of specialists (including ENT practitioners and audiology officers). In total, 752 children with hearing disorders were identified through this method. Three years after the initial survey, in 2016, a follow-up was conducted of all the children identified with hearing loss. This time we used KIs who were involved in the 2013 KIM study and community health workers (CHWs). They were given two weeks to gather data on the children. The caregivers of all children identified were interviewed by the CHWs using a structured questionnaire. Key

outcomes explored in the questionnaire were uptake of referral, difficulty in communicating needs effectively, difficulty in making friends and lack of school enrolment. We compared children who did and those who did not achieve the outcome (e.g. referral uptake) in terms of demographic characteristics, literacy of caregiver, income group, speech impairment and school enrolment. Odds Ratios (OR) and 95% Confidence Intervals for the associations were calculated. We also assessed loss to follow-up, defined as those who could not be traced three years after identification.

Paper IV:

The objective of this study was to assess the level of uptake and explore reasons for non-uptake of referrals to ear and hearing services among children in Malawi. A qualitative study was undertaken to explore this question. Semi-structured interviews were conducted with caregivers of children identified with hearing loss who did not take up their referral to QECH, as well as with stakeholders. Purposive sampling was used to select 30 children (<18 years) who did not take up their referral, chosen to ensure representation from different health centres, child age, sex, and severity of hearing loss. Interviews were conducted with the main caregiver, at the local health centres and lasted approximately one hour. The interviews used a range of open-ended questions and explored why the referral had not been taken, and explored a range of barriers, such as transport, and funding. These interview guides were pilot-tested and revised during the data collection period in light of the emerging themes. For stakeholders, the interviews explored their perspectives on the barriers experienced by families at the family, community, screening camp, and hospital levels and recommendations on how to address these challenges. The information was analysed to identify the key barriers reported by caregivers and stakeholders.

Paper V:

The objective of this study was to assess the feasibility and acceptability of training Community Health Workers (CHW) to provide primary-level ear and hearing care (PEHC), including: identification of patients with ear and hearing disorders, referral of patients to services and treatment of simple ear conditions. The study took place in Thyolo district, Malawi. A group of CHW was selected, and half of the participants were randomised to receive training in PEHC, while for the remainder training was delayed for 6 months. CHWs were selected among Malawian Health Surveillance Assistants (HSA), which is the formal cadre of CHWs in Malawi. These form a cadre of 10,500 frontline health workers employed by the Ministry of Health and comprise 30% of the health workforce in Malawi. Each HSA receives 12 weeks of training and has important roles in providing care, promoting community participation in healthcare activities and in promoting disease surveillance services at the community level. Prior to this study, they had not received any training in PEHC.

The HSAs were given training in PEHC, which lasted 3 days and was undertaken by an ENT surgeon and two ENT clinical officers. The training included learning about ear and hearing care using the WHO Ear and Hearing Care Training Manuals. The participants in the control group were assured of the training after 6 months. After training, each CHW was given one month to identify, list and refer patients with suspected ear and hearing disorders from their own village to their corresponding health centre. Identified patients with suspected ear disorder or hearing loss were asked to come to the scheduled screening camps, where they underwent thorough ear examinations.

The feasibility and acceptability of the training was assessed in a number of ways. First, CHWs were given a questionnaire before and after training to see if there was improvement in knowledge of ear and hearing care after the training. Second, the number of patients with ear or hearing disorders identified by CHWs and number recorded at health centres were assessed to see if there was an increase in identification after training. Third, the opinion of the CHWs on the training was sought. In the questionnaires, CHWs were asked about their opinions on the length of training and whether or not they felt comfortable in identifying people with ear and

hearing disorders. Focus group discussions (FGDs) were also undertaken with CHWs to gather more information on their views about the training. All this information was analysed to assess the overall feasibility and acceptability of the training.

Ethical considerations

Paper I: Used a systematic review of literature and so there were no ethical considerations.

Paper II: Involved a questionnaire survey. Participation was voluntary and at the discretion of the local ENT surgeons and audiologists, and so consent was implicit through return of questionnaires. Sensitive questions were not asked in the questionnaire, but rather it focussed on basic information such as the number of staff and equipment at different levels, which in any case, was often available from open records. Data received from the questionnaires was anonymised.

Paper III: Ethical approval was obtained from the College of Medicine Research Ethics Committee in Malawi and the London School of Hygiene & Tropical Medicine. All parents gave written consent for inclusion in the study. Children with hearing loss were given referrals to ENT services, as needed. Prior to the survey, we conducted a comprehensive mapping of the available referral services through discussions with local stakeholders and service providers. This was essential to ensure the availability of services needed to accommodate additional demand generated by the study.

Paper IV: Ethical approval was granted by the College of Medicine Research and Ethics Committee in Malawi and the London School of Hygiene & Tropical Medicine

Ethics Committee. All parents gave written or thumb-printed informed consent for inclusion in the study.

Paper V: Ethical approval was provided by the College of Medicine Research Ethics Committee in Malawi. The study was evaluated and found exempt from review by the Norwegian Regional Committee for Medical and Health Research Ethics (2016/1472 REC South East, Section D). The study was registered with the Pan African Clinical Trial Registry. Informed written consent was obtained from all CHWs who were included in the questionnaire and/or focus group discussions. Since this was a trial, half of the CHWs received training in PEHC and half did not. Training was given to the control group at the end of six months. CHWs were asked if they felt comfortable or not with the training and their ability to identify patients. If they were not, the lead trainers were available to attend to any post training issues or questions. Appropriate referrals were made for all people identified with CHWs who potentially had ear and hearing disorders, and patients who did not take up referral were followed up.

4 Summary of papers I-V

Paper 1: Mulwafu W, Kuper H, Ensink RJ. Prevalence and causes of hearing impairment in Africa. Trop Med Int Health. 2016 Feb;21(2):158-65.

Objective: To systematically assess the data on the prevalence and causes of hearing impairment in Africa.

Methods: Systematic review of literature on the prevalence and causes of hearing loss in Africa. We undertook a literature search of seven electronic databases (EMBASE, PubMed, Medline, Global Health, Web of Knowledge, Academic Search Complete and Africa Wide Information) and manually searched bibliographies of included articles. The search was restricted to population-based studies on hearing impairment in Africa. Data were extracted using a standard protocol.

Results: We identified 232 articles and included 28 articles in the final analysis. The most common cut-offs used for hearing impairment were 25 and 30 dB HL, but this ranged between 15 and 40 dB HL. For a cut-off of 25 dB, the median was 7.7% for the children- or school-based studies and 17% for population-based studies. For a cut-off of 30 dB HL, the median was 6.6% for the children or school-based studies and 31% for population-based studies. In schools for the deaf, the most common cause of hearing impairment was cryptogenic deafness (50%) followed by infectious causes (43%). In mainstream schools and general population, the most common cause of hearing impairment was middle ear disease (36%), followed by undetermined causes (35%) and cerumen impaction (24%).

Conclusion: There are very few population-based studies available to estimate the prevalence of hearing impairment in Africa. Those studies that are available use different cut-offs, making comparison difficult. However, the evidence suggests that the prevalence of hearing impairment is high and that much of it is avoidable or treatable.

Paper II: Mulwafu W, Ensink R, Kuper H, Fagan J. Survey of ENT services in sub-Saharan Africa: little progress between 2009 and 2015. Global Health Action. 2017 Jan 1;10(1):1289736.

Background: A 2009 survey of ENT, audiology, and speech therapy services and training opportunities in 18 Sub-Saharan African countries reported that the availability of services was extremely poor, the distribution of services was very inequitable, and training opportunities were limited.

Objective: We conducted a new survey to determine the current status of ear, nose, and throat (ENT), audiology, and speech therapy services in sub-Saharan Africa.

Method: This was a cross-sectional study. A questionnaire was distributed by email to an ad hoc group of ENT surgeons and audiologists in 30 sub-Saharan African countries. Data from the current survey were compared to those of a 2009 survey. The numbers of ENT surgeons, audiologists, and speech therapists/100,000 people were compared to the ratios in the United Kingdom.

Results: A total of 22 countries responded to the questionnaire. When data of the 15 countries that responded in both 2009 and 2015 are compared, the number of ENT surgeons had increased by 43%, audiologists had increased by 2.5%, and speech therapists by 30%. When the 23% population growth is taken into account, the numbers of ENT surgeons, audiologists, and speech therapists per 100,000 people had declined in four countries, and there remains a severe shortfall of ENT surgeons, audiologists, and speech therapists when compared to the UK Respondents cited lack of basic equipment as the most frequent limitation in providing ENT services. Other important factors causing limitations in daily practice were: lack of ENT training facilities and audiological rehabilitation, low awareness on the burden of ENT pathology, as well as poor human resources management.

Conclusions: There has been a lack of progress in ENT, audiology, and speech therapy services and training opportunities in sub-Saharan Africa between 2009 and 2015. There is a need to look at increased collaboration with developed countries and

non-governmental organisations, establishing new and improving existing training centres in Africa, and task-shifting of some ENT services to primary health workers.

Paper III: Wakisa Mulwafu, MyroslavaTataryn , Sarah, Polack , Asgaut Viste , Frederik Kragerud Goplen and Hannah Kuper **.** Children with hearing impairment in Malawi, a cohort study. *WHO Bulletin*. 2019**.** Accepted for publication 27.03.2019.

Objective

We aimed to assess the outcome of children with ear and hearing disorders, three years after diagnosis, in terms of uptake of referral to hospital, treatment given and satisfaction, and their participation in different aspects of life (school enrolment, ability to make friends, and ability to communicate needs).

Methods

A population-based longitudinal study was conducted of children with hearing disorders living in two regions of Malawi. The sample, identified at baseline (2013) through Key Informants in the community, were screened clinically and through questionnaires, and referred for clinical services as appropriate. Participants were retraced and rescreened at follow-up (2016). Outcomes included referral uptake school enrolment, ability to make friends and communicate needs and predictors were identified through multivariate logistic regression.

Results

At baseline, 752 children with HI were identified and 307 children (41%) retraced at follow-up. Referral uptake was low (56%), but higher among older children (i.e. age 15-18 years versus 0-4 years) (odds ratio [OR], 3.53;95% CI:1.22-1017) and lower for those with an illiterate caregiver(OR, 0.45; 95% CI:0.23-.087)). Difficulty in making friends for children with HI was related to speech impairment (OR,6.33; 95% CI:2.30-17.42)) and illiteracy of caregiver (OR,3.05; 95% CI:1.07-8.71)). Difficulty in communicating needs was linked to speech impairment (OR,4.38;95% CI: 2.08-9.24))and lower school enrolment (OR,0.23; 95% CI:0.09-0.62)).Lack of school enrolment was more common among older children, girls(OR=2.40;95% CI: 1.20-4.80)) and those with an illiterate caregiver (OR,2.05; 95% CI: 1.02-4.11)).

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Conclusion

We have explored potential factors that may enhance or limit their participation in different aspects of life for children with HI. Information on the impact of HI will help identify potential intervention strategies in order to mitigate the impact of HI in low resource countries beyond the provision of hearing aids and surgery for ear disorders.

Paper IV: Bright T, Mulwafu W, Thindwa R, Zuurmond M, Polack S. Reasons for low uptake of referrals to ear and hearing services for children in Malawi. PloS One. 2017 Dec 19;12(12):e0188703.

Background

Early detection and appropriate intervention for children with hearing impairment is important for maximizing functioning and quality of life. The lack of ear and hearing services in low income countries is a significant challenge, however, evidence suggests that even where such services are available, and children are referred to them, uptake is low. The aim of this study was to assess uptake of and barriers to referrals to ear and hearing services for children in Thyolo District, Malawi.

Methods

This was a mixed methods study. A survey was conducted with 170 caregivers of children who were referred for ear and hearing services during community-based screening camps to assess whether they had attended their referral and reasons for non-attendance. Semi-structured interviews were conducted with 23 caregivers of children who did not take up their referral to explore in-depth the reasons for non-uptake. In addition, 15 stakeholders were interviewed. Thematic analysis of the interview data was conducted and emerging trends were analysed.

Results

Referral uptake was very low with only 5 out of 150 (3%) children attending. Seven main interacting themes for non-uptake of referral were identified in the semi-structured interviews: location of the hospital, lack of transport, other indirect costs of seeking care, fear and uncertainty about the referral hospital, procedural problems within the camps, awareness and understanding of hearing loss, and lack of visibility and availability of services.

Conclusion

This study has highlighted a range of interacting challenges faced by families in accessing ear and hearing services in this setting. Understanding these context specific

barriers to non-uptake of ear and hearing services is important for designing appropriate interventions to increase uptake.

Paper V: Mulwafu W, Kuper H, Viste A, Goplen FK. Feasibility and acceptability of training community health workers in ear and hearing care in Malawi: a cluster randomised controlled trial. BMJ Open. 2017 Oct 1;7(10):e016457.

Objective To assess the feasibility and acceptability of training community health workers (CHWs) in ear and hearing care, and their ability to identify patients with ear and hearing disorders.

Design Cluster randomised controlled trial (RCT).

Setting Health centres in Thyolo district, Malawi.

Participants Ten health centres participated, 5 intervention (29 CHWs) and 5 control (28 CHWs).

Intervention Intervention CHWs received 3 days of training in primary ear and hearing care, while among control CHWs, training was delayed for 6 months. Both groups were given a pre-test that assessed knowledge about ear and hearing care, only the intervention group was given the post- test on the third day of training. The intervention group was given 1 month to identify patients with ear and hearing disorders in their communities, and these people were screened for hearing disorders by ear, nose and throat clinical specialists.

Outcome measures Primary outcome measure was improvement in knowledge of ear and hearing care among CHWs after the training. Secondary outcome measures were number of patients with ear or hearing disorders identified by CHWs and number recorded at health centres during routine activities, and the perceived feasibility and acceptability of the intervention.

Results The average overall correct answers increased from 55% to 68% (95% CI 65 to 71) in the intervention group ($p<0.001$). A total of 1739 patients with potential ear and hearing disorders were identified by CHWs and 860 patients attended the

screening camps, of whom 400 had hearing loss (73 patients determined through bilateral fail on otoacoustic emissions, 327 patients through audiometry). Where cause could be determined, the most common cause of ear and hearing disorders was chronic suppurative otitis media followed by impacted wax. The intervention was perceived as feasible and acceptable to implement.

Conclusions Training was effective in improving the knowledge of CHW in ear and hearing care in Malawi and allowing them to identify patients with ear and hearing disorders. This intervention could be scaled up to other CHWs in low-income and middle-income countries.

5 Discussion

5.1 Summary of findings

The main aim of the thesis was to investigate the need for and feasibility of integrating ear and hearing care into primary health care in Malawi, specifically through task-sharing.

The first step in fulfilling this aim was to perform a systematic review on the prevalence and causes of hearing impairment in Africa in order to consider the need for services. The questions we had in mind were: Is hearing loss common? Are most causes preventable, treatable or avoidable? We were able to estimate the prevalence of hearing impairment in Africa (**Paper I**). For a cut-off of 25 dB, the median was 7.7% for the children- or school-based studies and 17% for population-based studies. For a cut-off of 30 dB HL, the median was 6.6% for the children or school-based studies and 31% for population-based studies. This suggests that there is a much higher prevalence of hearing impairment in Africa than estimated by WHO at 5.3% of the world population in 2012[114]. In the community- and school-based studies, the most common causes of hearing impairment were middle ear disease (36%) followed by undetermined causes (35%) and cerumen impaction (24%). In the schools for the deaf, the most common causes of hearing impairment were cryptogenic deafness (50%) and infectious causes (43%). In the community- and school-based studies, we estimated that 64–97% of the causes of hearing impairment are avoidable and in the schools for the deaf we estimated that 63–85% of the causes of hearing impairment are avoidable.

The second stage of the thesis was to assess the availability of services to deal with this large, and ever growing, burden of ear and hearing disorders in Africa. Specifically, I wanted to ask: Are the available services sufficient? Our study indicated that there are between 0.1 and 4.6 ENT surgeons per million persons across the region. Apart from South Africa, there is less than one audiologist for every

million persons in sub-Saharan African countries. The number of ENT, audiology, and speech therapy training programmes remained the same over close to a decade. Any increases in training programmes and numbers of graduates was offset by the large population increase (23%) in the countries surveyed. In this study, only three countries were training ENT clinical officers. There is need to clearly define what these primary- and middle-level workers are able to do, to develop protocols for task-sharing of activities to these health workers and thereby increase access to ENT services for people outside the cities. (**Paper II**). This means that there are large gaps in resources available to address these ear and hearing disorders in Africa.

Next, we looked at the impact of ear and hearing disorders in children in Malawi, who form the majority of Malawi's population (51% are aged below 18 years) [106] (**Paper III**). The impact of ear and hearing disorders often goes unnoticed and has not been explored adequately in LMICs. This study showed that school enrolment among children with hearing loss was associated with ability to communicate and ability to make friends. Among children with hearing loss, those with speech impairment were more likely to report difficulties in making friends and communicating needs. Among children with hearing loss, older children, girls and those with an illiterate caregiver were less likely to be enrolled in school. Collectively, this shows that there is a large impact of ear and hearing disorders on children in Malawi, particularly for children with associated speech impairment or communication difficulties.

A follow-up study on the uptake of referrals to ear and hearing services by children showed that there was a low uptake overall, and few of the children had gone for services. The thesis has highlighted that while caregivers appeared to be motivated to seek care for their child, several often-interacting factors prevented them from doing so. These included location of/distance to the hospital, indirect costs, lack of transportation, procedural challenges in camps, awareness and understanding of ear and hearing issues, fear and uncertainty about the referral hospital, and lack of availability/visibility of hearing health services. Even when services are available, therefore, there are still barriers to accessing them.

Overall, the high prevalence of hearing disorders, low availability of services and barriers to accessing services shows that the system needs to be strengthened for the delivery of ear and hearing care, ideally at the primary level close to where people live. The last research question was therefore to assess the feasibility of training community health workers (CHWs) in ear and hearing care as way of task-sharing (**Paper V**). Training of CHWs in ear and hearing disorders proved feasible and acceptable, and CHWs were able to identify patients with ear and hearing disorders, and appropriately refer them to a tertiary hospital as appropriate. This strategy may therefore help to strengthen the health system for delivery of ear and hearing services in Africa.

The next section will consider these specific findings within the context of the broader literature.

5.2 High prevalence of avoidable hearing impairment in Africa, with large data gaps

Our analysis showed a high prevalence of hearing impairment in Africa and largely from avoidable causes and mainly from conductive causes. Therefore priority for ear and hearing services in Africa remains primary prevention and simple treatments, which need to be built within the health system.

Despite these broad findings, there were important gaps in the data that need to be filled. In our review of the prevalence and causes of hearing impairment in Africa (Paper I), we noted that there have been few population based studies done in Africa and that the hearing loss prevalence data in Africa varies greatly. Different contexts such as settings (school, clinic or population-based) and age ranges surveyed contributed to the prevalence variation. Different definitions and hearing test techniques employed also contribute to the variation. Also, in studies where pure tone audiometry was used as the screening method, there was also a wide variation in the cut-off criteria for disabling hearing loss i.e. 25 dB HL, 30 dB HL, 35 dB HL and 40 dB HL. Using a stricter screen intensity such as 25 dB HL will identify milder hearing losses, and will produce a higher prevalence whilst a pure tone cut off at 40 dB HL will result in a lower prevalence as only moderate and severe losses will be

included[115]. As stated above, we recommend using a standard WHO recommended cut-off point of 25dB HL for all studies reporting prevalence of hearing impairment, to aid comparability of findings.

The differences in age groups used in the surveys also contribute to the prevalence discrepancy in Africa, as the data from GBD 2015 show an upward trend in hearing loss prevalence with increasing age[116]. Prevalence of hearing impairment will therefore also vary in different age ranges surveyed, and this must be taken into account when interpreting the estimates from the survey. There is also a need for more population based studies for all ages, as these will provide close to true prevalence of hearing impairment especially in LMICs where the burden of hearing impairment is high. Clinic surveys are likely to overestimate the prevalence, while school surveys are likely to underestimate the prevalence of hearing impairment for the population as they only include the younger age group. For instance, the study at two primary health care clinics in underserved communities in the Tshwane area of South Africa revealed a hearing loss prevalence of 17.5% [115]. In a population based study reported in the Cape Town metropolitan area of South Africa, the prevalence was lower at 12.35% [117].

However, it was evident from our analysis that the overall message is that prevalence of hearing loss is high in Africa. Additional cross-sectional studies are needed to determine patterns and trends in hearing impairment, particularly in the regions with the highest prevalence [2]. There are different methods by which this information can be obtained, as outlined below.

5.3 Population based surveys

Smith and colleagues have advocated additional surveys to provide up-to-date information and greater geographical coverage [118, 119]. They have advocated using the WHO Ear and Hearing Disorders Survey Protocol (EHDSP). This protocol describes a standardized methodology to conduct a randomly selected population-based cluster sample from all subjects aged above 6 months in the population. All subjects are tested for hearing loss (the majority by audiometry) and then examined for

the presence of other ear diseases and to diagnose the cause of the hearing loss. The EHDSP was meant to provide credible data with true population-based prevalences which would not have the biases of school or clinic-based studies. However, there have been very few population-based studies in LMICs. One of the reasons why this is the case is because implementation of the protocol is expensive. The Rapid Assessment of Hearing Loss (RAHL) may offer an alternative to a full population survey, as it will be more rapid and cheaper as it focusses only on people aged 50+ and uses relatively simple screening and examination protocols. Because RAHL focuses on people aged 50+ means that the protocol for assessing hearing can be simplified to audiometry alone rather than including OAEs and ABR when children are included in the survey[120].

5.4 Generating data for children

The Key Informant Method (KIM) is an innovative method for generating population level data on the prevalence and causes of hearing impairments in children. The method provides an important alternative to population based surveys which can be time consuming and costly. KIM involves training volunteers (Key Informants, KIs) to identify children in their communities who may have disabling impairments. The children are invited to attend a screening camp where they are examined by relevant medical professionals and referred to appropriate services as available.. The KIM has been used to identify childhood disability (including hearing loss) in Bangladesh and Malawi (with myself as the local ENT lead), and epilepsy, childhood blindness and maternal mortality in other settings[94, 121]. It was found to be a valid and low-cost method to assess child disability when compared with a population based survey in Bangladesh. The other advantage of the KIM approach is that one engages with local communities and stakeholders and this has an important capacity building and raising awareness on ear and hearing disorders.

Establishment of child screening programmes may also assist in estimating the prevalence of childhood hearing loss. Effective programs of neonatal hearing

screening (NHS) are well established in most high income countries. With the introduction of objective methods of hearing evaluation in clinical practice, there is a real opportunity to detect hearing disorders in children from the first days of life including premature newborns. A successful new-born hearing screening programme requires extensive support services to manage infants requiring further testing and rehabilitation, which is not currently possible on a large scale in Malawi due to the small number of Audiology departments and trained staff[122]. Pre-school and school hearing screening programs provide another opportunity to identify children early in LMICs. The primary target population for pre-school and school-age hearing screening should be all children aged 4–7 years[123]. Additionally, students can be screened periodically in higher grades. These programmes have been established in countries such as South Africa, but not yet in Malawi.

5.5 The paradox of high burden of ear and hearing disorders vis-à-vis poor ear and hearing care services in Africa: Role of task-sharing

We have shown in **Paper II** that the availability of ENT, Audiology and Speech Therapy services in Africa is poor, and that little progress has been made over the last decade to address this problem. The high burden of hearing loss is a global dilemma and the lack of hearing healthcare providers in Africa is a challenge in itself and a major hindrance to providing ear and hearing care[124]. If both the burden of hearing impairment and the shortage of hearing healthcare providers are not addressed, the impact of ear and hearing disorders, including in children, will be amplified. We have explored the impact of ear and hearing disorders in children in **Paper III**.

These factors call for context specific interventions to scale up ear and hearing services in Africa, such as task sharing or task shifting. Task shifting has been described by WHO as a process of delegation or shifting of some tasks to less-specialized health workers with the advantages of allowing healthcare professionals to do more specialised tasks which could relieve congestion at the health units. “Task sharing”, a similar concept, refers to a partnership in which different levels of providers do similar work, rather than having less-credentialed providers take over all provision of a service[125]. A key assumption of both task shifting and task sharing is that, given adequate training and supervision, lower-level workers can provide services with adequate competency and quality. This thesis focuses on task sharing for provision of PEHC services and emphasizes the value of partnership in service provision.

We agree with O'Hare et al that task sharing must occur in the context of managed clinical network (MCN) , which is a hierarchically linked group of professionals and organizations, from primary, secondary and tertiary care, working together across professions and ranks to ensure equitable provision of high-quality healthcare [126]. Before this thesis, the MCN has been used in Malawi in the context of the ear, nose and throat (ENT) service. I myself, as the one ENT surgeon in the central hospital in the southern region, trained 15 clinical officers (CO) in ENT, each placed in a district hospital (Figure 4). This resulted in bringing ENT expertise much closer to the patient with the opportunity for the ENT CO in the district to discuss cases with the ENT surgeon and refer as appropriate[113]. This model of task sharing within hub-and-spoke networks may facilitate wider dissemination of scarce expertise and improve ear hearing healthcare in Malawi, and other LMICs.

Figure 4: District and Central Hospitals currently with qualified ENT Clinical Officers

We have shown in **Paper V** that training of CHWs in primary ear and hearing care is both acceptable and feasible. HSAs can work in their communities to identify people with ear and hearing conditions. HSAs are formal CHWs in Malawi, and are salaried, formal employees of the MOH. The HSAs provide health services at community level, and work in health posts, dispensaries, village clinics, and maternity clinics. Each HSA serves a catchment population of 1,000 people. Malawi currently has 7,932 HSAs supported by 1,282 senior HSAs. HSAs mainly provide promotive and preventive healthcare through door-to-door visitations, village and outreach clinics

and mobile clinics. This cadre can be added to the task sharing model and therefore radiating the hub and spoke further out to reach patients with ear and hearing disorders in their communities. In line with the Malawi Government guidelines on task shifting to CHWs, the following tasks in ear and hearing care are recommended for CHWs[127]. There are (1) information, education and communication on ear and hearing disorders; (2) identification of cases for referral, (3) follow-up of cases for treatment adherence; (4) support and counselling of families on ear and hearing disorders. All these tasks are based on the assumption that the CHWs have been trained in ear and hearing care and that equipment like otoscopes are made available to them. Including this training in their curriculum, rather than as post hoc courses, would be ideal.

This lack of ear and hearing care services in Africa presents an opportunity for outreach programs from high income countries to develop and support such services in Africa. Physicians, scientists, and others at universities; global health institutes, centres, and departments now in many universities worldwide are strongly encouraged to be involved in global hearing health care[31] . We have published rules of engagement for such outreach programs in Africa[128] . Outreach should be based on mutual respect, shared values, aspirations, internationally accepted best practice, and a desire to create durable and sustainable impact. The outcomes of the global outreach should be clear to both parties. Capacity building should be prioritised and making sure that skills are transferred to host surgeons. There should be provision of appropriate diagnostic and surgical equipment, development of resource-appropriate protocols/guidelines and building research capacity in the host country. The ultimate goal of this global collaboration should be to generate sustainable, long-term delivery of ear and hearing care services[129].

It is impossible for 2 ENT surgeons in a country with 17.5 million people to attend to even a fraction of patients with clinically significant perforated tympanic membranes. Endoscopic myringoplasty is however well suited to be done by clinical officers, as diagnosis and clinical decision-making are straightforward, the indications for surgery being recurrent otorrhoea and/or conductive hearing loss. An endoscope costs a fraction of an operating microscope, is easily transportable and hence can be used in ear surgery camps conducted in remote places, and the camera stack can be shared with other disciplines such as general and orthopaedic surgery and gynaecology. Some Malawian ENT clinical officers have therefore been formally trained to do endoscopic myringoplasties to restore hearing. They were trained during an "ENT week" with the assistance of visiting ENT surgeons from Bradford and Leicester in November 2016.

A cohort of 83 patients underwent endoscopic myringoplasty at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi between March 2017 to February 2018. The mean age of patients was 24 years (SD=13.9) and ages ranged between 8 and 65 years. There were 43 females (52%) and 40 males (48%). *Table 3* summarises who performed the surgery.

Table 3: Cadre which operated on patients undergoing endoscopic myringoplasty at QECH

Surgeon	Number of ears (%)
ENT Clinical Officer	60 (72%)
Medical Officer	5 (6%)
Assisted by Consultant	14 (17%)
Consultant only	4 (5%)
TOTAL	83

Tragal cartilage-perichondrium was used in all cases, and the surgery was done under general anaesthesia *(Figure 5).* The results of endoscopic myringoplasty, reflected in terms of closure of the perforation, are summarised in *Table 4*.

Figure 5: Photo of a tympanic membrane after endoscopic myringoplasty done by an ENT Clinical Officer

Table 4: Outcomes of endoscopic myringoplasty at 6 weeks and 3 months

	All surgeons		**Clinical officers**	
	6 weeks	**3 months**	**6 weeks**	**3 months**
Graft taken	47 (73%)	44 (96%)	38 (83%)	29 (97%)
Graft medialised	3 (5%)	0	2 (4%)	1 (3%)
Graft failure	14 (22%)	2 (4%)	6 (13%)	0
TOTAL	**64**	**46**	**46**	**30**

Even though some patients were lost to follow-up, the results at 6 weeks and 3 months, both overall and by the clinical officers, compare favourably with that reported in the literature. The *Royal College of Surgeons* suggested that a success rate of 65% should be expected[130], and a study in 2002 reported a success rate that ranged between 74% (small perforations) and 56% (large perforations) among British surgeons[131]. Success rates for closure of tympanic membrane perforations were reported in two separate studies as 80.8 % and 95%[132, 133]. The QECH results clearly demonstrate that with appropriate training, endoscopic myringoplasty can be successfully performed by mid-level health workers in LMICs.

5.6 Poor access to ear and hearing care and low uptake of referral services in Africa

It is clear that there is a large unmet need for ear and hearing services in Malawi and other LMICs. A key reason why access is low is lack of healthcare services. LMICs account for 90% of the global burden of disease but for only 12% of global spending on health[134]. Malawi's total health expenditure as a percentage of GDP is 11.4%. High-income countries spend about 100 times more on health per capita than low-income countries (US$3039 versus US$30)[135, 136]. It is thus not surprising that the density of health workers and hospital beds per population are much lower in LMICs than in high-income countries, decreasing the accessibility of services to many of the world's poor. This is clearly shown in paper II where ear and hearing care service availability was low. Furthermore, the poorer the country, the larger the amount of total health spending that is out of pocket[137]. On average, more than 60% of the meagre spending in low-income countries is from out-of-pocket payments, compared with about 20% in high-income countries.

Even when services are available, uptake of referrals and access to services is poor[138]. Access to health services is defined as timely use of health services according to need. Peters et al [136]described four main dimensions of access namely geographic accessibility, availability, financial accessibility and acceptability.

Using Peters' framework allows us to highlight the poor accessibility to ENT services in much of Africa. Geographic inaccessibility is a major problem. An inverse relationship between distance or travel time to health facilities and use of health services has been demonstrated as an important barrier to access. A common strategy of governments seeking to improve access to health services is to build more public clinics and hospitals. Although such strategies can be undermined by problems with staffing, equipping, and supplying facilities with drugs and medical supplies, they can also be complemented by a private market that may be even closer, as well as have the advantages of having more convenient opening hours and being more culturally acceptable or responsive to their demands.

Another constraint on the access of services provided by governments and non-governmental organisations is that even when treatment and rehabilitation services are available, there is evidence from LMIC settings that uptake of referrals to these services can be low[138] .

This was clear in the current study, where we found that uptake of referrals for children with ear and hearing issues was extremely low (3%) (Paper III). Our study (Paper IV) in Malawi also showed that uptake of referrals was low because of inter-related barriers, which included geographic accessibility, availability of services, affordability of transport and indirect costs, acceptability (knowledge and information about referral). This study also highlighted that despite the barriers, caregivers appeared to be motivated to seek care for their child. Mukara et al[139] also found

that the majority (76.6%) of respondents were knowledgeable about ear infections while 89.1% had positive care seeking practices.

Interventions are therefore needed to improve uptake of referrals to services. Bright et al conducted systematic reviews to assess the effectiveness of interventions aimed at increasing access to health services for children over 5 years and in less than 5 years in LMIC settings[140, 141]. Systematic reviews show that there are few interventions that have been identified as effective for children to improve uptake of referrals to services.

We therefore need to develop and test new interventions that work at improving uptake. From the findings in Paper IV, and Bright's systematic reviews, we designed an informational intervention to improve uptake of referral for children with ear and hearing conditions in Thyolo district, Malawi. The final intervention included a leaflet (Figure 6) with three main parts (1) An illustrated storyline of "The Banda Family" going through the process of being referred and attending the referral for ear and hearing services at QECH; (2) Information on how to get to the hospital including photographs of key landmarks that caregivers would see on the way to the ENT department; (3) Action planning stage that was tailored to each caregiver—including how they plan to go, how much money they need, and what they need to take with them. This booklet would be delivered by a trained "expert mother" (i.e., mother of a child with ear and/or hearing issue who has attended QECH for referral previously) at the point at which the referral was made (e.g. in outreach clinics, in camps). It also included a text-message reminder which was sent out two weeks after the referral. A qualitative study is underway to assess the feasibility of the intervention. Such interventions to increase uptake of services will need to complement efforts to improve availability of services at the primary, secondary and tertiary levels described above.

Figure 6: Leaflet with an illustrated story line of the Banda family


THE BANDA FAMILY
ONE DAY, THE PARENTS NOTICED THAT THEIR SON, CHIMWEMWE, HAD A PROBLEM WITH HIS EARS.
A COMMUNITY HEALTH WORKER CAME TO THEIR HOME AND TOLD THEM TO GO TO THE HEALTH CENTRE.
THEY TOOK THEIR SON TO THE HEALTH CENTRE, WHERE THEY WERE GIVEN A REFERRAL FOR QUEENS HOSPITAL.
THAT EVENING, THE PARENTS TALKED TO EACH OTHER ABOUT THE TRIP TO BLANTYRE.
THE NEXT DAY, THEY GOT ON A BUS TO LIMBE AND THEN WENT TO QUEENS HOSPITAL.
THEY MET A FRIENDLY NURSE WHO SAID EVERYTHING WOULD BE OK. SHE TOOK THEM TO THE EAR DOCTOR WHO HELPED CHIMWEMWE'S EARS.
AFTER THAT, CHIMWEMWE COULD HEAR BETTER. THE FAMILY WERE HAPPY AND CHIMWEMWE DID WELL AT SCHOOL.


HOW TO GET THERE
1
Bus stop for Queens - get off when you see the blue flyover. Then walk and ask for Queens.
2
QECH main gate - walk straight along main road. Image above is the Main reception, where you can ask for directions.
3
Junction 1 - when you walk up to the first junction, take the left road.
4
Junction 2 - then when you come to the second junction, take a right.
5
Eye clinic - the Qech eye clinic is approx 50 metres away from the ENT clinic. When at the eye clinic, you will be guided to the ENT.
6
John Hopkins Centre - this is what you will pass by, when you're on your way to the ENT clinic.
7
Entrance to ENT/Mercy James - turn left here when you see Mercy James Centre - it's a large building.
8
ENT Clinic - here is where you will meet the doctor who will treat your child. The Audiology Clinic is also next door.
PEOPLE YOU WILL MEET
THE NURSE
You can ask a nurse at the hospital to help you find the ENT department.
THE ENT CLINICIAN
They will be the person who will deal with your child's hearing problem.
THE HEARING SPECIALIST
They will check your child's ears and take you to the ENT doctor.
THINGS TO KNOW
TODAY YOUR CHILD WAS FOUND TO HAVE:
A problem with their ears that might be helped with surgery.
A problem with their hearing that might be helped with hearing aids.
YOU NEED TO GO TO QUEENS FOR FURTHER TREATMENT OR TESTS. YOU CAN GO BETWEEN MONDAY AND FRIDAY.
You will not be asked to give money at hospital but you will need to pay for transport. The counsellor will discuss with you how much money you need.
You may be asked to pay what you want for hearing aids (as much as you can afford).
WE WANT TO HELP YOU TO PLAN YOUR JOURNEY TO QUEENS SO THAT YOUR CHILD CAN ALSO GET THE HELP THEY NEED.
How are you going to get there?
How much money will I need?
Who will stay at home with the other kids when you go to Queens?
Who will go with you?
How are you going to get home?
How long to wait?
What you need to take?
When are you going to go?
DO YOU HAVE ANY QUESTIONS?
If you still have any questions here are some useful contacts:
QECH Audiology clinic: 0999471446 or 0881379664.
QECH ENT clinic: 0999683716
Mwanaisha Phiri: 0993567553.

6 Key recommendations for policy practice and research

The main aim of the thesis was to investigate the need for (e.g. magnitude, causes, impact, and availability of services) and feasibility of integrating ear and hearing care into primary health care in Malawi, specifically through task-sharing.

The thesis has shown that there is high prevalence of ear and hearing disorders in Africa that are preventable or treatable. Early and holistic interventions that involve primary, secondary and tertiary services will reduce the impact of ear and hearing disorders in the lives of people affected. This thesis has also shown that there is lack of services available for people with these disorders. It follows that ear and hearing care services are not up to the required standards in Malawi to meet the need. Because of the paucity of data, lack of awareness and inadequate funding, ear and hearing disorders are not being systematically addressed in Malawi and are not commonly treated in primary and community settings, adding further to the burden of unmet need. A holistic approach that will address all pillars of the health system strengthening (service delivery, workforce, information systems, access to essential medicines, financing and leadership/governance) is required. The infrastructure and equipment for ear and hearing care services are still at rudimentary stage in Malawi and this needs to be scaled up. Training at all levels of EHC is required. Most of the ear and hearing disorders can be dealt with at the primary health care level. This thesis has shown that training of CHWs in ear and hearing care is feasible, and this programme can be scaled up. However, one way of making sure that this training is sustainable is by including the training program in the curriculum for CHWs in Malawi, which it is not the case at present time.

There are gaps in resources, such as human resources and equipment, needed to address the high burden of ear and hearing disorders in Africa. There is need to identify sources of funding from both governments and non-governmental organisations in order to bridge these gaps. This funding may provide return on investment, as people with hearing loss are able to be included in education and employment. There is need for ring-fenced funding allocation in the national budget to enable adequate provision of ear and hearing care services. At primary health care level, the funding allocation should include training and provision of basic ear equipment for CHWs. At secondary level, funding allocation should be for provision of equipment for trained ENT Clinical Officers. At tertiary level, funding allocation should be for training of ENT Surgeons, Audiologists and other middle level health care workers. Equipment will also be needed at each level.

Although prevention is ideal, not all ear and hearing disorders are preventable. Provision and timely access to ear and hearing care services are essential. Priority must be given to those that have been identified at primary and secondary care levels and been referred for tertiary ear care services as this thesis has shown that there is low uptake of referrals.

There are also data gaps that need to be filled to facilitate the scale up of ear and hearing services in Africa. Data is needed on prevalence and causes of hearing loss in different settings to design optimal interventions. Research efforts should focus on developing methods for affordable and standardised population based studies on the prevalence and causes of hearing disorders, such as the Rapid Assessment of Hearing Loss. Feasibility of training CHWs has been shown in Malawi, but not efficacy of the intervention. Efficacy trials are a test of whether an intervention does more good than harm when delivered under optimal conditions. Consequently another question that should be tested is - Does the intervention work in other African settings? Similarly, interventions to increase uptake of referrals for children with ear and hearing

disorders need to be developed and tested. Cost-based analysis will be critical priority setting in countries such as Malawi where resource limitations necessitate choices. Cost effectiveness studies are warranted in interventions such as task-sharing of ear and hearing disorders and interventions to increase uptake of referrals in children.

Future research projects should focus on whether or not task sharing will lead to reduced burden of ear and hearing disorders. For example, the task sharing of endoscopic ear surgery to middle level health workers might be a feasible intervention that should be explored further for cost effectiveness. Another area that needs further research is the interventions to increase uptake of referrals for childrenwith ear and hearing disorders.

7 Strengths and limitations of the thesis

The thesis has some important strengths. The primary researcher is one of only 2 ENT surgeons in Malawi who knew the setting very well and were able to use results to influence policy and practice. The researcher is closely connected to Global ENT movement and could use this knowledge to inform future research. Malawi is a new setting for research on ear and hearing disorders. There is now infrastructure available for doing ear and hearing care research.

The thesis used multiple sources of data and approaches to address question and triangulate results. Furthermore, the thesis utilised different types of designs such as systematic review, qualitative quantitative, cluster randomized control trial and including nesting parts of study in larger studies. Standard approaches were used throughout the study. We used WHO definitions for hearing loss and assessment as described above. In developing the intervention and assessing feasibility, we used CONSORT statement and in conduct of systematic reviews we used the PRISMA[142, 143]. For qualitative studies, we used the COREQ framework [144].

There were multiple stakeholders involved such as Ministry of Health in Malawi, College of Medicine in Malawi, Haukeland University Hospital and London School of Hygiene and Tropical Medicine. This has ensured necessary support and strengthened the collaboration of the stakeholders.

In countries like Malawi where there is chronic shortage of health workforce, additional country-specific cadres have been developed and deployed for many years to address priority needs. The study was possible because of the availability and abundance of formal middle level health workers and community level health

workers in Malawi. The work reported in this thesis has helped strengthen the integration of ear and hearing care into the formal health system

Limitations of individual studies are already discussed in specific papers. For the overall approach of the thesis, there were a number of limitations. Firstly, there were large data gaps which posed important challenges because there have been very few all ages population based surveys on ear and hearing care. We planned to do a all ages population based survey using the WHO ear and hearing care survey protocol in Malawi in order to establish the prevalence and causes of hearing impairment, but this proved to be too expensive. The systematic review for prevalence and causes of hearing impairment in Africa (**Paper I**) provided some information to address this question but having few studies on ear and hearing disorders in Africa made it difficult to get the precise estimates from the sytematic review. There are great data gaps in Africa and in Malawi. Improving a health system requires data. For Malawi specifically, no population based prevalence study has been done (now one undertaken, but not included in thesis). There is also lack of data on ENT services in Africa – and where it is available it is completed by "champions", so may overestimate service availability. There is limited data on impact of hearing impairment on children and adults in Africa, nor of the impact of interventions. Paper III has explored some independent associations in children with ear and hearing disorders.

High loss to follow-up is a challenge in LMICs. For instance, children who were identified to have hearing loss in 2013 could not be followed up annually. They were followed up after three years and hence high loss to follow up was reported in **Paper III,** compared to the rule of thumb that the loss to follow-up should not exceed 20% (Song 2010). We were not able to follow-up the children annually due to lack of funding. Funding constraints produced other limitations of this thesis. Basic equipment for ear and hearing disorders is a challenge for countries like Malawi, as

even the most basic equipment like otoscopes are expensive. This presented a challenge in training and equipping the CHWs, and so this may have limited the impact of the primary ear and hearing care intervention. Diagnostic accuracy could not be verified in CHWs who were trained in ear and hearing disorders as we did not have enough funds to carry out this activity. In **Paper V**, we trained only a small sample of CHWs, because of funding constraints. There was no long term follow up CHWs, This would have been useful in assessing the knowledge and skills of CHWs and to find out if they continued to identify and refer patients with ear and hearing disorders.

One has to exercise caution in generalising the findings from Malawi to other settings in Africa or other LMICs. Malawi is one of the poorest countries in the world with very limited ENT and audiology resources available. On the other hand, CHWs and middle level health workers may not be available in other countries as they are in Malawi. Research was conducted by one of only 2 ENT surgeons in Malawi therefore there is potential bias of results, which may have been overly favourably reported.

8 Conclusion

There is high prevalence of ear and hearing disorders in Africa, and these conditions have a significant impact on the people affected, their families and the society. The majority of the causes are avoidable, yet there are low level of services available for people with ear and hearing disorders and low uptake due to difficulties with accessing services. Task-sharing at primary level is feasible and acceptable and could fill gaps so that avoidable hearing loss can be prevented in Malawi, and in similar settings in other LMICs.

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Systematic Review

Prevalence and causes of hearing impairment in Africa

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Abstract

OBJECTIVE To systematically assess the data on the prevalence and causes of hearing impairment in Africa.

METHODS Systematic review on the prevalence and causes of hearing loss in Africa. We undertook a literature search of seven electronic databases (EMBASE, PubMed, Medline, Global Health, Web of Knowledge, Academic Search Complete and Africa Wide Information) and manually searched bibliographies of included articles. The search was restricted to population-based studies on hearing impairment in Africa. Data were extracted using a standard protocol.

RESULTS We identified 232 articles and included 28 articles in the final analysis. The most common cut-offs used for hearing impairment were 25 and 30 dB HL, but this ranged between 15 and 40 dB HL. For a cut-off of 25 dB, the median was 7.7% for the children- or school-based studies and 17% for population-based studies. For a cut-off of 30 dB HL, the median was 6.6% for the children or school-based studies and 31% for population-based studies. In schools for the deaf, the most common cause of hearing impairment was cryptogenic deafness (50%) followed by infectious causes (43%). In mainstream schools and general population, the most common cause of hearing impairment was middle ear disease (36%), followed by undetermined causes (35%) and cerumen impaction (24%).

CONCLUSION There are very few population-based studies available to estimate the prevalence of hearing impairment in Africa. Those studies that are available use different cut-offs, making comparison difficult. However, the evidence suggests that the prevalence of hearing impairment is high and that much of it is avoidable or treatable.

keywords prevalence, causes, Africa, hearing impairment

Introduction

Hearing loss or hearing impairment is the most prevalent sensory disability globally and a condition that is of growing concern. In 2005, WHO estimated that 278 million people in the world were living with disabling hearing impairment [1]. In 2012, WHO released new estimates on the magnitude of disabling hearing impairment based on 42 population-based studies [2]. Globally, they suggest that there are 360 million persons with disabling hearing loss (5.3% of the world's population). The prevalence of disabling hearing loss is greatest in South Asia, Asia Pacific and sub-Saharan Africa.

Hearing loss appears to be more common in sub-Saharan Africa than in richer parts of the world. The WHO estimates suggest that the prevalence of hearing impairment (defined as Hearing loss >35 dB) for adults aged >15 years old was 15.7% in sub-Saharan Africa *vs.* 4.9% in high-income countries. For children aged between 5 and 14 years, the prevalence was estimated at 1.9% in sub-Saharan Africa *vs.* 0.4% in high-income countries. However, the estimates for Africa are based on a very limited evidence base, as the review included only 11 studies (8 published and 3 unpublished), all of which relied on school-based hearing screenings. The lack of data has arisen because many countries struggle to conduct relevant population-based surveys using standardised protocols and classification methods [3].

Besides the lack of data on prevalence of hearing impairment in Africa, little is known about causes required to inform which prevention and treatment services are needed. Hearing impairment is a silent or invisible disability. It may therefore not be apparent to advocates and health officials. Thus, 'hard data' are needed on

prevalence, causes and impact of hearing impairment in the general population, and on services available to people with hearing impairment. Such data will help inform appropriate planning of policies and services and evidence-based advocacy for people with hearing impairment in low- and middle-income countries (LMIC).

This scale-up of services is needed urgently as the negative impact of hearing impairment has been well documented. In children, disabling hearing loss impedes speech and language development and sets the affected children on a trajectory of limited educational and vocational attainment [4, 5]. Children with hearing impairment may also be at increased risk of violence. In adulthood, disabling hearing impairment can lead to embarrassment, loneliness, social isolation and stigmatisation, prejudice, abuse, psychiatric disturbance, depression, difficulties in relationships with partners and children, restricted career choices, occupational stress and relatively low earnings [3].

The objective of the review was to synthesise the available data on the prevalence and causes of hearing impairment in Africa.

Methods

Data sources and search strategy

A systematic narrative review of published literature was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement [6]. Seven electronic databases, EMBASE, PubMed, Medline, Global Health, Web of Knowledge, Academic Search Complete and Africa Wide Information, were searched in October 2014.

Search terms for prevalence and causes of hearing impairment in Africa were identified through MeSH and from those used for systematic reviews on similar topics. No limits were placed on language, publication date or publication status.

Inclusion/exclusion criteria

Papers were included if they addressed prevalence and/or causes of hearing impairment in Africa. Population-based surveys and school-based surveys were included. Studies from schools for the deaf were included for the estimation of causes of impairment in those institutions, while clinic-based studies were excluded because they are not representative of the general population. Population-based studies which used self-reported hearing impairment as a way of measuring hearing impairment were included. Reviews were excluded, but we searched through the reference lists to identify relevant papers. Studies that focused on neonatal and infant screening for hearing impairment were excluded because most of them were clinic-based. Any study with an epidemiological design (survey, case–control, cohort, trials) was eligible for inclusion.

Definitions

Hearing impairment could be defined through: pure tone audiometry (PTA) [any cut-off eligible] and self-report. Avoidable causes of hearing impairment were defined as conditions that are preventable and treatable and can result in hearing impairment, such as middle ear disease causing conductive hearing loss, infectious diseases causing sensorineural hearing loss, ototoxicity and noise exposure. Some of these, for example otitis media with effusion, otosclerosis, are not themselves preventable but the resulting hearing loss can be prevented by surgical intervention. In this review, we assumed that all middle ear disease and half of the causes of sensorineural hearing loss are avoidable.

Study selection

Articles were screened by all reviewers, first by titles, then by abstract and finally by full text to determine eligibility in the final sample. Titles that were selected by two of the three reviewers were included for review of their abstracts. For those articles that were selected by only one reviewer, the other two reviewers were asked to look at the title and if there was consensus, the title was included for review of the abstract. A similar process was repeated for the abstracts and full text articles.

Data extraction

Data from the final sample were collated using an extraction table. Major outcome variables were extracted independently by two investigators (WM & RE) and any disagreement resolved by discussion. The main outcome variables extracted were prevalence and causes of hearing impairment, cut-offs for definition of hearing impairment, methods used for measuring hearing impairment and evidence of effect of age and sex on hearing impairment. Data on the study characteristics (e.g. year, country, age, gender) were also extracted.

Results

Search results

A total of 232 titles were retrieved. Of these, 182 titles were excluded for not primarily focusing on Africa or

prevalence and causes of hearing impairment. Fifty abstracts were retrieved. A further screening of the 50 abstracts resulted in the inclusion of 25 studies. Three additional reports were added making a total of 28 published and unpublished reports. The 25 studies were excluded because they were reviews [4]; conducted in a population subgroup like gold miners, people with albinism, tinnitus, ototoxicity, HIV or in children with sickle cell anaemia [9]; or focused on neonatal or infant hearing screening [7]. A further five studies were excluded because we could not retrieve full PDFs, even after contacting the authors.

School screening surveys

We identified 16 studies reporting the prevalence of hearing impairment from school screening surveys (Table 1) from 14 countries in sub-Saharan Africa (SSA) and two countries in the North African region. The studies were published between 1993 and 2013. The age range was 3.5–21 years and 48% of participants were female. The sample size ranged from 101 to 5528. Assessment of hearing impairment was by pure tone average (PTA) in seven studies, a combination of PTA and otoacoustic emissions (OAE) or tympanometry in eight studies and self-report in one study.

The prevalence of hearing impairment varied by cut-off. Only one study used a cut-off of 15 dB and prevalence was 13.9%; two studies used a cut-off of 20 dB and median prevalence was 20.1% (19.3–20.9); six studies used a cut-off of 25 dB and median prevalence was 7.7% (2.4–21.3); six studies used a cut-off of 30 dB and median prevalence was 6.6% (2.0–20); and one study used a cut-off of 40 dB and prevalence was 5%. Two studies reported differences between males and females. Bastos [7] reported that hearing impairment was more common in females in urban schools ($P < 0.05$). North-Mathiassen [8] reported that more males (16%) had hearing impairment than females (12%). Two studies reported age-related hearing impairment. Bastos reported that prevalence increased with age. Couper [9] reported that more children with hearing impairment (HI) in age group 6–9 years than younger ones.

Population-based surveys

We identified eight studies reporting on the prevalence of hearing impairment from population-based surveys (Table 2). These were from seven countries in sub-Saharan Africa (SSA) and one country in the North African region. The studies were reported between 2000 and 2014. All age groups were studied except Lasisi [10] who studied age groups over 65 years of age. 54% of participants were female. The sample size ranged from 1302 to 24 453. Assessment of hearing impairment was by PTA in one study only, a combination of PTA and OAE or tympanometry in four studies and self-report in three studies.

The prevalence of hearing impairment varied by cut-off. Two studies used a cut-off of 25 dB and average prevalence was 17%. Two studies used a cut-off of 30 dB and average prevalence was 31% (18–44%). One study used a cut-off of 35 dB and prevalence was 3.6%. Only one study assessed the evidence for age-related hearing impairment. Abdel Hamid [11] reported that there were two peaks of 0–4 years (22.4%) and >65 years (49.3%). None of the studies assessed male/female differences in prevalence of hearing impairment.

Evaluation of bias

The number of participants approached to participate in the studies was not reported in a number of studies making selection bias difficult to assess. However, all mainstream school-based studies are at risk of selection bias because children with severe to profound hearing impairment are unlikely to go to mainstream schools.

Causes of hearing impairment

The articles were examined to see whether useful data could be extracted regarding causes of hearing impairment. We tried to determine the proportion that was preventable. Causes of hearing impairment varied depending on the setting of the study, that is school, community and schools for the deaf. In the community- and school-based studies (Table 3), the most common causes of hearing impairment were middle ear disease (36%) followed by undetermined causes (35%) and cerumen impaction (24%). We estimated that 64–97% of the causes of hearing impairment are avoidable.

In the schools for the deaf (Table 4), the most common causes of hearing impairment were cryptogenic deafness (50%) and infectious causes (43%). We estimated that 63–85% of the causes of hearing impairment are avoidable.

Discussion

WHO reports on hearing impairment have included very few studies from Africa to produce the estimates of hearing impairment. Our review confirmed the lack of evidence available on hearing impairment in Africa. Although 28 studies met our selection criteria, only eight

Table 1 Prevalence of hearing impairment in school screening surveys

Author	Year of publication	Country (region)	Sample size (Response rate %)	Age group in years	% female	Method of measuring hearing	Cut-off level for hearing impairment	Prevalence (%) 95% CI	Evidence for Male/female differences	Evidence for age differences
Bastos [7]	1994	Tanzania	845	6–16 in rural areas, 6–13 in Urban areas	42% rural and 53% urban	PTA	25 dB	3%	HI more common in girls in urban schools ($P < 0.05$)	Prevalence increased with age
North-Mathiassen [8]	2007	South Africa	1101	6–12	53.2%	PTA	25 dB	7.9%	16% of males *vs.* 12% of females had HI	None
Couper [9]	2002	South Africa	2036	<10	Not reported	Self-reported	Self-reported	1%	No evidence	More children with HI in age group 6–9 than in younger age groups
Clark [10]	2008	Mozambique	2685	6–20	Not reported	OAE Tympanometry, PTA	40 dB	5	None	None
Minja [11]	1996	Tanzania	802	5–20 for rural, 5–19 for urban	49%	PTA	30 dB	14 Urban 7.7 Rural	None	None
Seely [12]	1995	Sierra Leone	2015	5–15	37	PTA	25 dB	9.1	None	None
Swart [13]	1995	Swaziland	2430	5–15	47%	PTA	30 or 35 dB	20%	None	None
Taha [14]	2010	Egypt	555	6–12	47%	PTA	20 dB	20.9	None	None
Olusanya [15]	2000	Nigeria	359	4.5–10.9	Not reported	PTA	15 dB HL	13.9	None	None
Adebola [16]	2013	Nigeria	101	3.5–6	45%	PTA	25DB	21.3	None	None
Omondi [17]	2007	Kenya	1411	6–14	Not reported	PTA	25 dB	2,4%	None	None
Yamamah [18]	2012	Egypt	453	7–10	49.7%	Tympanometry and PTA	20 dB	19.3%	None	None
Westerberg [19]	2004	Zimbabwe	5528	4–20	48.6%	PTA	30 dB	2.4% (CI 2.0–2.8)	None	None
Bastos [20]	1993	Angola	1030	5–17	55%	PTA	30 dB	2.0%	None	None
Van Rooy [21]	1995	South Africa	2036	<10	Not reported	PTA	25 dB HL	7.5%	None	None
Hatcher [22]	1995	Kenya	5368	5–21	50%	PTA	30 dB	5	None	None

Table 2 Prevalence of hearing impairment in population-based surveys

Author	Year of publication	Country (region)	Sample size	Age group	% female	Method of measuring hearing	Cut-off level for hearing impairment	Prevalence (%)	Evidence for male/female differences	Evidence for age differences
Abdel Hamid [24]	2007	Egypt	4000	All ages	Not reported	OAE, Tympanometry and PTA	25 dB	16	No evidence	Two peaks of 0–4 years (22.4%) and >65 years (49.3%)
Westerberg [25]	2008	Uganda	6041	All ages	53.8%	PTA	30 dB	18	No evidence	No evidence
T. Randrianarisoa, Unpublished report	2003	Madagascar	5572	All Ages	58.81%	PTA	30 dB	44.41	No evidence	No evidence
Nwawolo [26]	2000	Nigeria	8975	All Ages	Not reported	PTA	25 dB	17.9	No evidence	No evidence
Mac Taggart [27]	2014	Cameroon	3567	4–17 and >18 years	59.2%	OAE and PTA	35 dB	3.6	No evidence	No evidence
Fitaw [28]	2006	Ethiopia	24 453	>5 years	43.4%	Self-reported	Self-reported	8.3	No evidence	No evidence
Biritwum [29]	2001	Ghana	2556	<15 years	Not reported	Self-reported	Self-reported	0.08	No evidence	No evidence
Lasisi [23]	2010	Nigeria	1302	>65 years	Not reported	Self-reported	Self-reported	6.1	No evidence	No evidence

were population-based surveys and the rest were conducted in schools. These included four studies of self-reported hearing loss. The overall prevalence of hearing impairment varied depending on the cut-off used for measuring hearing impairment or whether they were school-based or population-based. The most common cut-offs used for hearing impairment were 25 dB HL and 30 dB HL, but in our selected articles ranged between 15 dB HL and 40 dB HL. Taking in regard the WHO criteria for a mild hearing loss (>25 dB) when a cut-off of 25 dB is considered, the median was 7.7% for the children or school-based studies and 17% for population-based studies. For a cut-off of 30 dB HL, the median was 6.6% for the children or school-based studies and 31% for population-based studies. This suggests that there is a much higher prevalence of hearing impairment in Africa than estimated by WHO. However, there may be inaccuracy in these figures because to be a truly representative of the prevalence the studies from which these figures were obtained would have to be statistically determined randomised cluster surveys of the area/region/country. Only five met this criterion, of which only two have been published [19, 24]. This is at least partly because lower thresholds were used for defining hearing impairment in some of the included studies (25–30 dB were common) than was specified in the WHO reports (35 dB).

The quality of the data presented was widely variable. Ideally data should be reliable, population- and community-based and inclusive of all groups; should cover all domains of interest; and should be collected both prospectively and continuously. However, in this review, there are only five studies by Abdel Hamid, Randrianarisoa, Westerberg, Nwawolo and Mac Taggart [19, 24, 26, 27; T. Randrianarisoa 2008, Unpublished report] that came close to meeting these criteria. Abdel Hamid and Westerberg used the WHO Ear Disease Survey protocol to survey all ages using a random cluster sample design. Using a cut-off of 25 dB, the Abdel Hamid study showed that the prevalence of hearing loss in Egypt (16%) is higher than many other countries; bilateral hearing loss was present in 76% of those with hearing loss and unilateral hearing loss was present in 24% (12% and 4% of the whole sample, respectively). Westerberg [25] in Uganda used a higher cut-off of >40 dB in the better ear in subjects aged 15 years or older and found a prevalence of hearing impairment of 11.7%; in subjects under 15 years of age, disabling hearing loss of 31 dB or greater in the better ear was found in 10.2%.

There was a wide variation in the methods used to measure hearing impairment as well as in the thresholds used. Most of the studies included used pure tone

Table 3 Main causes of hearing impairment in mainstream schools and general population

Author	Year of publication	Country (region)	Study type	Population age	Main causes of hearing impairment	% of the cases	Proportion avoidable
Abdel Hamid [24]	2007	Egypt	Community Based	All ages	Middle ear disease	44	77%
					Presbycusis	23	
					Other	33	
Westerberg [25]	2008	Uganda	Community Based	All ages (>6 months)	Undetermined	55	64%
					Middle ear disease	18	
					Cerumen Impaction	10	
					Other	17	
Westerberg [19]	2004	Zimbabwe	School based	4–20 years	Middle ear disease	42	87%
					Infectious causes	19	
					Undetermined	15	
					Cerumen Impaction	13	
					Others	11	
Olusanya [15]	2000	Nigeria	School based	4.5–10.9	Cerumen Impaction	53	97
					Middle ear disease	40	
					Others	7	

Table 4 Main causes of hearing impairment in deaf schools

Author	Year	Country	Sample size	Age range	% female	Main causes of hearing impairment	Percentage of all cases	Proportion avoidable
Obiako [30]	1987	Nigeria	267	1–7	47%	Unknown aetiology	30	85%
						Infectious causes	30.5	
						Convulsions	19.1	
						Ototoxicity	5.6	
						Neonatal Jaundice	5.6	
						Others	9.2	
McPherson [31]	1985	Gambia	257	2–10	Not reported	Infectious causes	56	78%
						Unknown Aetiology	31.9	
						Others	11.7	
Viljoen [32]	1988	Zimbabwe	885	5–20	41%	Cryptogenic deafness	42.8	70%
						Infectious causes	40	
						Others	17.2	
Sellars [33]	1983	South Africa	3064	Not reported	44%	Cryptogenic deafness	57	63%
						Acquired deafness	25	
						Other	18	

audiometry (PTA) both as a screening tool and as threshold evaluation tool. This may not have been the ideal method since PTA has several limitations in population-based studies. To start, it is expensive to procure the equipment. Then, equipment has to be well calibrated. It also requires ambient noise to be less than 40 dB, otherwise it becomes difficult to establish true thresholds especially at 500 Hz. In some studies, 500 Hz was omitted. Four studies used self-reported hearing loss. Self-report of hearing loss is insensitive to age effects and does not provide a reliable basis for estimating prevalence of age-related hearing loss, although may indicate perceived hearing disability [34]. The prevalence of hearing loss is often underestimated by self-report. In a study in Malaysia, prevalences of self-reported hearing loss using a single question and pure tone audiometry were 24.3% and 36.9%, respectively [35]. However, extensive data on self-reported data are sparse and no definitive conclusions can be made.

Only three studies [10, 24, 27] reported using the OAEs as a screening tool but they had false-positive rates of between 3% and 9%. OAEs have successfully been used as a screening tool in neonatal and infant screening. More studies are needed to validate the use of OAEs in

population-based studies. This may help in overcoming some of the difficulties in conducting population-based studies in Africa and compare this as the screening method against pure tone audiometry. Both OAEs and pure tone audiometry require expensive equipment and studies are needed evaluating a combination of basic otoscopy plus a voice test as a low cost screening method.

Unfortunately, many of the studies did not clearly present the cause of hearing impairment. Among those that did, the most common causes were unknown causes (cryptogenic) deafness, infectious causes and cerumen impaction. Cerumen impaction is frequently cited as an important cause of hearing impairment. For example, Bhoola [36] demonstrated that in the 'Middle Ear Screening Protocol' in 1997 in South Africa, 38–49% of the preschool children failed the test due to impacted wax. Olusanya [15] retrospectively reported (in 359 matched children) that children with impacted wax were more likely to have permanent hearing loss and more episodes of otitis media. The presence of wax in the ear canal is common, and it should be considered a cause of hearing impairment when hearing impairment is relieved after its removal. Cerumen impaction is a preventable cause of hearing impairment and can easily be managed at primary health care by trained primary healthcare workers. Therefore, every effort should be made to identify and manage it, especially in children.

Our review therefore found limited evidence on the prevalence and causes of hearing impairment in Africa. Where data were available, it was difficult to make meaningful comparisons because of variations in methods and cut-offs used. Moreover, causes of hearing impairment were often not defined, limiting the utility for improving service delivery. More and better data are urgently needed on the prevalence and causes of hearing impairment in Africa. The hurdles to research in hearing impairment are many. Apart from the general lack of adequate funding and lack of highly skilled researchers to do the work, research in hearing impairment is faced by issues of lack of unified definition of hearing impairment and its categories, and lack of a standardised, quick and easy screening tool. OAEs have become cheaper and can now be easily used by non-specialist ENT personnel. More research is needed to show the sensitivity and specificity of OAEs in routine screening of all forms of hearing impairment and for all ages.

Conclusion

This is the first systematic review to look at hearing impairment in Africa. It suggests a high prevalence of hearing impairment in children in Africa. The prevalence of hearing impairment is therefore currently likely to be underestimated and underreported for Africa based on global burden of disease reports. Further studies are required to quantify the exact prevalence and causes of hearing impairment in Africa.

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Survey of ENT services in sub-Saharan Africa: little progress between 2009 and 2015

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Survey of ENT services in sub-Saharan Africa: little progress between 2009 and 2015

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ABSTRACT

Background: A 2009 survey of ENT, audiology, and speech therapy services and training opportunities in 18 Sub-Saharan African countries reported that the availability of services was extremely poor, the distribution of services was very inequitable, and training opportunities were limited.

Objective: We conducted a new survey to determine the current status of ear, nose, and throat (ENT), audiology, and speech therapy services in sub-Saharan Africa.

Method: This study is a cross-sectional study. A questionnaire was distributed by email to an ad hoc group of ENT surgeons and audiologists in 30 sub-Saharan African countries. Data from the current survey were compared to those of a 2009 survey. The numbers of ENT surgeons, audiologists, and speech therapists/100,000 people were compared to the ratios in the United Kingdom.

Results: A total of 22 countries responded to the questionnaire. When data of the 15 countries that responded in both 2009 and 2015 are compared, the number of ENT surgeons had increased by 43%, audiologists had increased by 2.5%, and speech therapists by 30%. When the 23% population growth is taken into account, the numbers of ENT surgeons, audiologists, and speech therapists per 100,000 people had declined in four countries, and there remains a severe shortfall of ENT surgeons, audiologists, and speech therapists when compared to the UK Respondents cited lack of availability of basic equipment as the most frequent limitation in providing ENT services. Other important factors causing limitations in daily practice were: lack of ENT training facilities and audiological rehabilitation, low awareness of the burden of ENT pathology, as well as poor human resources management.

Conclusions: There has been a lack of progress in ENT, audiology, and speech therapy services and training opportunities in sub-Saharan Africa between 2009 and 2015. There is a need to look at increased collaboration with developed countries and non-governmental organisations, establishing new and improving existing training centres in Africa, and task-shifting of some ENT services to primary health workers.

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Background

Hearing impairment is more prevalent in sub-Saharan Africa than in other parts of the world [1]. It is likely to become increasingly common over the coming decades as the population continues to age given that hearing impairment is most prevalent in older age groups. Furthermore, the age-specific prevalence of hearing impairment may also increase for a variety of reasons. In the coming decade, HIV and tuberculosis will become more chronic conditions, thanks to the scaling up of antiretroviral therapy (ART) and other treatments, and so the burden of chronic suppurative otitis media (CSOM) and associated hearing loss will likely increase dramatically [2,3]. It is also predicted that 70% of cancers will occur in developing countries by the year 2030, including those relating to ear, nose, and throat (ENT) [4]. As a consequence, there is a great and growing demand for ENT services in sub-Saharan Africa.

A 2009 survey of ENT, audiology, and speech therapy services and training opportunities in 18 sub-Saharan African countries reported that the availability of services was extremely poor, the distribution of services was very inequitable, and training opportunities were limited [5]. As a consequence, people will not be able to access the services that they require and so will have hearing loss that may have been prevented and is now untreated, with consequent negative impacts on quality of life, mental health, and economic productivity. Furthermore, in Malawi, as elsewhere in Africa, the large burden of head and neck cancer is treated largely surgically, in the absence of radiotherapy services, so that a lack of

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ENT surgeons will increase mortality rates. Overall, the goal to achieve Universal Health Coverage will not be achieved without adequate ENT services [6]. Nor will the Sustainable Development Goal to 'Ensure healthy lives and promote well-being for all at all ages', since good hearing is fundamental to health and quality of life.

Since 2009, six new ENT training programmes have been established in sub-Saharan countries, 10 head and neck surgeons has completed the University of Cape Town Karl Storz Fellowship in Advanced Head and Neck Surgery, all of whom have returned to teaching hospitals in their own countries, and new audiology and speech therapy training programmes have been established in Ghana and Kenya. The authors therefore thought it timely to repeat the 2009 survey to determine the current status of ENT, audiology, and speech therapy services in sub-Saharan Africa, and to reassess the extent and appropriateness of these services. These data are important to plan and promote effective, targeted support, to initiate regional training initiatives for these services, and to raise awareness about the need to develop ENT, audiology, and speech therapy services in Africa.

Methods

Selection of study subjects

An ad hoc group of ENT surgeons and audiologists in 30 out of 48 sub-Saharan African countries in which there were known to be ENT services were traced through personal contacts of three of the authors (WKM, RJHE, JJF). The authors were unable to contact people in the two Portuguese-speaking countries (Mozambique and Angola). Although the questionnaire was translated into French the responses from West African countries were low.

Procedure

A questionnaire was distributed by email (see the Appendix), with emails obtained through personal contacts. Those who did not respond to the emails were telephoned and reminded about the questionnaire. Email reminders were sent a maximum of 12 times.

Material

Questions were asked about the availability of ENT, audiology, and speech therapy services and equipment (nil/poor/good/excellent), about training programmes for ENT surgeons, audiologists, and speech therapists, about the availability of services in rural areas, and about their opinions about how to improve the situation. The rating system used for availability of services was as follows:

- Nil: absent services scored;
- Poor: less than half of population has access to care;
- Good: most but not all have access to care;
- Excellent: almost all have access to care.

Data analysis

The numbers of ENT surgeons, audiologists, and speech therapists/100,000 people in sub-Saharan Africa were compared to the ratios in the United Kingdom (UK) [7]. Data were compared to the 2009 survey. Data analysis was done using SPSS version 21 using descriptive statistics. Categorical variables were represented by frequency and ratios.

Results

Twenty ENT surgeons and 2 audiologists from 22 sub-Saharan countries responded to the survey, giving a response rate of 73% (Figure 1). Fifteen countries responded in both 2009 and 2015 and progress in these countries could therefore be compared. Three countries (Botswana, Ivory Coast, and Namibia) that had been surveyed in the 2009 study did not respond and a further seven countries (Burundi, Cameroon, Guinea Conakry, Mali, Rwanda, Sudan, and Togo) responded in 2015 but not in 2009.

The total population of the 22 countries represented in the study was 720,500,000; this represents 75% of the population of sub-Saharan Africa. Among the 22 countries that were sampled, there were a reported total of 847 ENT surgeons, 580 audiologists,

Figure 1. Twenty-two countries that participated in the current study.

906 speech therapists, 264 ENT clinical officers, and 320 oncologists. When data are pooled across the sample, the regional ratio was 1.2 million people per ENT surgeon, 0.8 million people per audiologist, and 1.3 million people per speech therapist.

When data of the 15 countries that responded in both 2009 and 2015 are compared, the total number of ENT surgeons had increased from 442 to 634, representing a 43% increase (mean increase from 15 to 18 per country), the total number of audiologists had increased from 511 to 524, representing a 2.5% increase (mean increase from 1 to 3 per country), and the total number of speech therapists had increased from 1164 to 1514, representing a 30% increase (median increase from 2 to 3 per country). The number of audiologists and speech therapists had increased in 86% of the countries, although the actual numbers of audiologists and speech therapists are extremely low if South Africa, Kenya, and Sudan are excluded (Table 1).

However, there had been a large population growth (23%) in the countries surveyed between 2009 and 2015, from 486 million to 599 million people. When this population growth is taken into account when calculating the numbers of ENT surgeons, audiologists, and speech therapists per 100,000 people, it was found that in four countries (D.R.C, Lesotho, Madagascar, Senegal) there had been a decline in the number of ENT surgeons per 100,000 people between 2009 and 2015, while in Ghana, Kenya, and Zambia there had been an improvement in the numbers of ENTs, audiologists, and speech therapists per 100,000 people (Table 2). There remains a severe shortfall of ENT surgeons, audiologists, and speech therapists across all countries when compared to the UK (Table 2).

Table 1. Comparison of total numbers of ENT surgeons, audiologists, and speech therapists per country in 2009 and 2015 (* no data for 2009).

	ENT surgeons		Audiology		Speech therapy	
	2009	2015	2009	2015	2009	2015
Burundi	*	6	*	10	*	0
Cameroon	*	35	*	0	*	25
D.R.C	25	18	0	3	0	3
Ethiopia	11	22	0	1	0	1
Ghana	15	27	6	13	2	6
Guinea Conakry	*	6	*	6	*	1
Kenya	40	76	4	7	3	16
Lesotho	2	2	0	2	0	1
Madagascar	16	15	2	10	4	1
Malawi	1	2	0	3	0	0
Mali	*	15	*	0	*	2
Nigeria	70	140	5	13	3	4
Rwanda	*	8	*	4	*	1
S. Africa	200	246	490	444	1144	1470
Senegal	25	15	1	3	2	4
Sudan	*	105	*	5	*	2
Swaziland	2	3	1	5	1	3
Tanzania	11	18	0	1	2	3
Togo	*	8	*	0	*	25
Uganda	16	35	1	15	2	0
Zambia	2	7	1	1	0	1
Zimbabwe	6	8	0	3	1	1

Table 2. ENT surgeons, audiologists, and speech therapists/ 100,000 people in 2009 and 2015 compared to the UK

	ENT surgeons		Audiology		Speech therapy	
	2009	2015	2009	2015	2009	2015
Burundi	*	0.056	*	0.093	*	0.000
Cameroon	*	0.150	*	–	*	0.107
D.R.C	0.045	0.025	–	0.004	–	0.004
Ethiopia	0.014	0.022	–	0.001	–	0.001
Ghana	0.068	0.104	0.022	0.048	0.007	0.022
Guinea	*	0.049	*	0.049	*	0.008
Kenya	0.121	0.163	0.012	0.015	0.009	0.034
Lesotho	0.1	0.094	–	0.047	–	0.047
Madagascar	0.09	0.062	0.012	0.041	0.024	0.004
Malawi	0.01	0.012	–	0.017	–	0.000
Mali	*	0.092	*	–	*	0.011
Nigeria	0.054	0.076	0.004	0.007	0.002	0.002
Rwanda	*	0.064	*	0.032	*	0.008
S. Africa	0.417	0.46	1.021	0.827	2.383	2.748
Senegal	0.227	0.100	0.009	0.021	0.018	0.029
Sudan	*	0.265	*	0.013	*	0.007
Swaziland	0.2	0.233	0.1	0.039	0.1	0.233
Tanzania	0.031	0.034	–	0.002	0.006	0.006
Togo	*	0.111	*	–	*	0.417
Uganda	0.057	0.087	0.004	0.037	0.007	0.016
Zambia	0.017	0.045	0.004	0.006	–	0.006
Zimbabwe	0.043	0.053	–	0.020	0.007	0.007
UK	1.0	2.36	4.1		16.393	

Note: Shaded cells indicate declining numbers/100,000 people; no data for 2009 denoted by * [5]. DRC: Democratic Republic of the Congo; U.K: United Kingdom.

New training programmes had been introduced in six countries since the 2009 study (Table 3). In three countries (Rwanda, Zimbabwe, and Ethiopia) new ENT training programmes represent the only training programmes in the respective countries. One new audiology (Ghana) and one speech therapy (Kenya) programme had been introduced in the time between the two studies. However, there has been little overall change in the numbers of new ENT surgeons, audiologists, and speech therapists qualifying per annum. Five countries (Malawi, Kenya, Mali, Togo, and Cameroon) reported to have training programmes for ENT clinical officers (non-doctors who undergo an 18-month training programme in basic ENT diagnostic and therapeutic skills such as removing foreign bodies, and performing tonsillectomies and adenoidectomies).

Table 4 illustrates the poor state of ENT, audiology, and speech therapy services in state hospitals in the 22 African countries polled. Only three countries (Malawi, Burundi, and Ethiopia) provide ENT services for free in state hospitals. Sinus and rhinologic surgery had 66% 'poor' or 'nil' availability. Audiology and otologic surgery had 87% 'nil' or 'poor' availability. Head and neck oncologic surgery had 75% 'nil' or 'poor' availability. A big need in ENT practice appears to be equipment for otologic surgery and basic equipment. The availability of modern medical equipment remains problematic with 68% reporting 'nil' or 'poor' availability.

Table 3. Training programmes.

Countries	Number of medical schools		ENT training: Training programmes		ENT training: New ENTs p.a		Audiology training programmes		Speech training programmes	
	2009	2015	2009	2015	2009	2015	2009	2015	2009	2015
Burundi	*	3	*	1	*	1	*	–	*	–
Cameroon	*	4	*	1	*	5	*	–	*	–
D.R.C	4	6	1	1	1	2	–	–	–	–
Ethiopia	6	9	–	1	–	4	–	–	–	–
Ghana	3	4	2	2	1–2	2	–	Yes	–	–
Guinea Conakry	*	3	*	3	*	5	*	–	*	–
Kenya	2	6	1	1	4	1	Yes	Yes	–	Yes
Lesotho	–	1	–	–	–	–	–	–	–	–
Madagascar	2	6	1	1	0	1	–	–	–	–
Malawi	1	1	0	1	0	0	–	–	–	–
Mali	*	3	*	1	*	4	*	–	*	–
Nigeria	36	58	19	37	4	5	–	–	–	–
Rwanda	*	2	*	1	*	2	*	–	–	–
S. Africa	8	9	8	9	6	6	Yes	Yes	Yes	Yes
Senegal	2	5	1	1	5	4	–	–	–	–
Sudan	*	95	*	0	*	10	*	–	–	–
Swaziland	–	–	–	–	–	–	–	–	–	–
Tanzania	5	4	2	2	2	3	–	–	–	–
Togo	*	1	*	1	*	?	*	–	*	Yes
Uganda	3	3	1	2	1–3	4	–	–	–	–
Zambia	1	3	–	–	–	–	–	–	–	–
Zimbabwe	1	1	–	1	–	2	–	–	–	–

Note: Shaded cells indicate new training programmes established since the 2009 study.

Twenty of the 22 countries polled had schools for the deaf; the median number of deaf schools per country was 6 (range 1–120).

Availability of services outside major cities was shown to be a problem in 2009, and remains a concern in 2015. In 2015, all the respondents reported that availability of ENT services outside of the capital city was 'nil' (n = 8) or 'poor' (n = 8). In 2009, the availability of services outside the capital was mostly reported as 'nil' (n = 9) or 'poor' (n = 3), with some countries reporting it as being 'good' (n = 5) or 'excellent' (n = 1).

Respondents cited lack of availability of basic equipment as the most frequent limitation in providing ENT services, but they also cited poor ENT training facilities, audiological rehabilitation, and awareness of the burden of ENT pathology, as well as human resources management as among the top limitations encountered in daily practice.

Discussion

This study reports the current state of ENT, audiology, and speech therapy services and training opportunities in sub-Saharan Africa and compares it to a previous study undertaken in 2009. It is clear from the results that there has been little progress since 2009.

Although the absolute numbers of ENT surgeons, audiologists, and speech therapists have increased, the ratios to the populations in the individual countries have increased only marginally in some countries while in others they have declined due to rapid population growth. Comparing these ratios to the UK, sub-Saharan Africa has extremely low coverage of ENT, audiology, and speech therapy services. This trend has also been observed in eye health where the regional practitioner ratio of 2.9 per million people for sub-Saharan Africa was way below the Vision 2020 target of 4 per million people; that study called for substantial and more targeted investment in human resources for eye health if Vision 2020 aims for the prevention of avoidable blindness were to be achieved for sub-Saharan Africa [8].

The availability of equipment remains poor with most (66–87%) countries rating the availability of equipment between 'nil' or 'poor'. Poor infrastructure and equipment are a deterrent to working in such countries. There is clearly a need to invest in infrastructure and equipment and to create training centres for ENT specialists, audiologists, and speech therapists. Training within Africa will also make it more likely that graduates remain and work in Africa.

The number of ENT, audiology, and speech therapy training programmes has stagnated. Any increases in training programmes and numbers of graduates have been offset by the large (23%) population increase in the countries surveyed. It is possible to increase the number of training programmes and number of ENT surgeons, audiologists, and speech therapists qualifying in Africa, but this will require deliberate investments in such training, staffing, and infrastructure. It is unlikely that sub-Saharan Africa can meet this training obligation alone in the short to medium term. It requires assistance from high-income countries. This can be achieved partly by

Table 4. Numbers of countries with nil/poor/good/excellent services in state hospitals.

	Availability in state service			
	Nil	Poor	Good	Excellent
Sinus and rhinology surgery				
Endoscopic ethmoid sinus surgery	8	10	3	1
External ethmoidectomy	4	5	9	3
Inferior meatal antrostomy	4	10	4	3
Caldwell Luc/radical antrostomy	4	4	9	4
Cosmetic rhinoplasty	12	9	0	1
Audiology and otologic surgery				
Audiology	0	15	5	1
Auditory brainstem reflexes (ABR)	9	12	1	0
Otoacoustic emissions (OAE) screening	7	13	2	0
Hearing screening: newborn	18	3	1	0
Hearing screening: schools	11	11	0	0
Hearing screening: industry	9	13	0	0
Hearing aids	5	14	3	0
Myringotomies, ventilation tubes	0	14	6	2
Tympanoplasty	2	13	5	2
Mastoidectomy for cholesteatoma	0	14	5	3
Mastoidectomy for mastoiditis	1	13	5	0
Middle ear (ossicular) prostheses	14	7	1	0
Bone anchored hearing aids	19	3	0	0
Cochlear implants	18	4	0	0
Head and neck oncologic surgery				
Total laryngectomy	6	7	5	4
Speech prosthesis post-laryngectomy	16	4	1	1
Partial laryngectomy	12	6	3	1
CO_2 laser surgery	19	3	0	0
Parotidectomy	1	5	11	4
Radical neck dissection	6	9	3	4
Modified neck dissection	7	8	3	4
Selective neck dissection	7	9	2	4
Commando resection	11	7	3	1
Total maxillectomy	5	10	3	4
Craniofacial resection	10	10	1	1
Pedicled flaps e.g. pectoralis major	8	7	4	3
Free microvascular flaps	13	5	3	0
Mini and microplates	15	5	2	0
Fine needle aspiration	2	8	7	6
Frozen section	15	5	2	0
High-cost equipment and services				
Flexible nasopharyngoscopy (NR1)	2	12	3	5
Operating microscopes	1	14	4	3
Otology drill	2	14	4	2
CO_2 laser	17	3	1	0
Ultrasound of neck	2	4	11	5
Computerized tomography (CT) scanning	1	9	9	3
Magnetic resonance imaging (MRI) scanning	7	9	4	2
Positron emission tomography (PET) scanning	20	2	0	0
Radiation therapy	8	7	7	0

collaborative programmes with countries or organisations in high-income settings. There have been examples of such collaborative programmes that have helped train ENT cadres in Africa [9–12]. For instance, CBM International has helped build ENT units in Zambia, Malawi, and Zimbabwe. The University of Cape Town Karl Storz Head and Neck Fellowship has trained 10 Head and Neck Fellows in Africa. Operation Ear Drop Kenya in collaboration with the University of Nairobi have fully equipped a permanent temporal lab at the University of Nairobi and have conducted temporal bone courses every year since 1987. Improved regional collaboration through the College of Surgeons of East, Central and Southern Africa (COSECSA) needs to be fostered to permit training in smaller units. Increasing training programmes will improve ENT human resources only after a lead time of several years, and so establishing these programmes should not be delayed any further.

The training of primary- and middle-level health workers ('bottom-up procedure') can also have an impact on the management of ear and hearing disorders in sub-Saharan Africa, for instance through the management of otitis media. A study on the burden of disease caused by otitis media demonstrates clearly the enormous impact of acute otitis media (AOM)/CSOM on hearing in the African continent [13]. This article stresses that the African continent needs action on otitis media with effusion (OME)/CSOM and its effect on hearing. The high percentages of otitis media found in common daily African ENT practice of 45% of OME in children > 15 yrs and at about 11% of CSOM in adults emphasise this as well. Small changes in the treatment of CSOM were described by Guntinas-Lichius on optimising the pre-treatment process for CSOM in Ethiopia, such as regular cleaning, suctioning, dry mopping under microscopic control, and topical treatment with antibiotic ear drops [14]. Only three countries are training ENT clinical officers. There is need to clearly define what these primary- and middle-level workers are able to do, to develop protocols for task-shifting of activities to these health workers and thereby increase access to ENT services for people outside the cities.

In the current study, the respondents cited lack of availability of basic equipment as the most frequent limitation in providing ENT services. Other key limitations encountered in daily practice included poor ENT training facilities, audiological rehabilitation, and awareness of the burden of ENT pathology in the medical field as well as human resources management. Moving forward, further research is needed to explore which interventions will work to speed up the progress of ENT services in Africa, including developing innovative methods to fill these gaps.

The study has some limitations. We were not able to collect information from all the 48 countries in sub-Saharan Africa. Most countries in sub-Saharan Africa do not keep databases of their health workers and so most of the information was collected from proxy contacts in the respective countries. Another limitation of the study is that we collected the data for the total number of practitioners in the different countries, both active and inactive. Furthermore, the time period between the two surveys may be relatively short for a change to be detected, especially for training programmes of long duration such as those for training ENT surgeons. The major strength of this study, however, is that it provides a database for ENT services in sub-Saharan Africa, a region where data are scarce.

Conclusions

With little progress in the development of ENT services in Africa, there is need to look at ways of dealing with the increased burden of ENT conditions in the region in order to prevent unnecessary hearing loss and maximise the quality of life of those with untreatable ear conditions, as well as other diseases of the head and neck including cancers. Increased collaboration with high-income countries and non-governmental organisations is required to establish new and to improve existing training centres in Africa, and task-shifting is required of some ENT services to primary- and middle-level health workers.

Recommendations

- Human resource development by establishing new and improving existing training centres in sub-Saharan Africa.
- Targeted infrastructure development for ENT services in sub-Saharan Africa.
- Monitoring status of ENT conditions and services.
- Increased collaboration with high-income countries and non-governmental organisations in ENT capacity development.
- Task-shifting of some ENT services to primary- and middle-level health workers.

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None.

Author contributions

All authors contributed equally to this work.

Disclosure statement

No potential conflict of interest was reported by the authors.

Ethics and consent

Not required.

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None.

Paper context

A 2009 survey of ENT, audiology, and speech therapy services and training opportunities in 18 sub-Saharan African countries reported that the availability of services was extremely poor. We report that little progress has been made since 2009. There is an urgent need to increase collaboration with high-income countries and non-governmental organisations to establish new and to improve existing training centres in Africa and for task-shifting of some ENT services to primary- and middle-level health workers.

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Appendix.

SURVEY OF EXISTING ENT SERVICES IN AFRICA

Thank you for taking time to fill in this form.

Country

What is the latest population of your country?	
How many of the following do you have in your country	Number/ Comment
General ENT Surgeons	
Audiologists	
Speech Therapists	
ENT Clinical Officers	
Schools for the deaf	
Training programme	
How many medical schools do you have in your country?	
How many have ENT training programmes? What are they?	
How many ENT surgeons qualify per year?	
Do you have Audiology training programme? If yes, how many people qualify per year?	
Do you have Speech Therapy training programme? If yes, how many people qualify per year?	
Do you have ENT Clinical Officer training programme? How many people qualify per year?	

Guideline for rating services:
NIL = absent;
POOR = Fewer than half who need the service receive it when needed;
GOOD = Most but not all of those that need the service receive it when needed;
EXCELLENT = Virtually all of those that need the service receive it when needed.
Please take note that availability of service/equipment is not mere physical presence of it. For example if C.T Scanning is available but not working, it should be rated as POOR

Please rate the availability of the following services:	Nil	Poor	Good	Excellent
Hearing-related services in public hospital				
Audiology				
Auditory Brain Stem Reflexes				
Oto-acoustic emissions				
National newborn screening programme				
Newborn screening programme hospital based				
Hearing screening: schools				
Hearing screening: industries				
Hearing aids				
Myringotomies, Ventilation tubes				
Tympanoplasty				
Mastoidectomy for cholesteatoma				
Mastoidectomy for mastoiditis				
Middle ear (ossicular) prosthesis				
Bone anchored hearing aids				
Cochlear implants				
Modern ear equipment in public hospitals				
Operating microscopes				
Otology drill				
C.A.T scanning				
M.R.I scanning				
Please rate the availability of State ENT services outside major cities				

OPEN QUESTIONS

I: Are Ear services in public hospitals free or are they paid by the patient?
J: What are the biggest needs in general ENT practice in your country?
K: Which limitations occur most frequently in your practice?
L: Please estimate the percentage of Ear services concentrated in your capital city.

III

Children with hearing impairment in Malawi, a cohort study

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Objective To assess the outcomes of children diagnosed with hearing impairment 3 years earlier in terms of referral uptake, treatment received and satisfaction with this treatment, and social participation.

Methods We conducted a population-based longitudinal analysis of children with a hearing impairment in two rural districts of Malawi. Key informants within the community identified the cohort in 2013 (baseline). Informants clinically screened children at baseline, and by questionnaires at baseline and follow-up in 2016. We investigated associations between sociodemographic characteristics and outcomes by multivariate logistic regression.

Results We diagnosed 752 children in 2013 as having a hearing impairment and traced 307 (40.8%) children of these for follow-up in 2016. Referral uptake was low (102/184; 55.4%), more likely among older children (odds ratio, OR: 3.5; 95% confidence interval, CI: 1.2–10.2) and less likely for those with an illiterate caregiver (OR: 0.5; 95% CI: 0.2–0.9). Few of the children who attended hospital received any treatment (33/102; 32.4%) and 63.6% (21/33) of caregivers reported satisfaction with treatment. Difficulty making friends and communicating needs was reported for 10.0% (30/299) and 35.6% (107/301) of the children, respectively. Lack of school enrolment was observed for 29.5% (72/244) of children, and was more likely for older children (OR: 28.6; 95% CI: 10.3–79.6), girls (OR: 2.4; 95% CI: 1.2–4.8) and those with an illiterate caregiver (OR: 2.1; 95% CI: 1.0–4.1).

Conclusion More widespread and holistic services are required to improve the outcomes of children with a hearing impairment in Malawi.

Abstracts in عربي, 中文, Français, Русский and Español at the end of each article.

Introduction

Approximately 466 million people live with disabling hearing loss globally, including 34 million children, and most of these live in low- and middle-income countries.[1] Unaddressed hearing loss has a negative impact on language development, school performance, employment opportunities, psychosocial well-being and aspects of family life, with an estimated annual global cost to society of 750 billion United States dollars.[2] Hearing loss often goes unnoticed and unaddressed, and its impact has not been explored adequately in low- and middle-income countries.[3,4]

Early detection, treatment and rehabilitation are important to mitigate some of these negative effects and maximize functioning for affected individuals. In 2017, the World Health Organization (WHO) adopted a resolution on ear and hearing care that urges Member States to develop, implement and monitor screening programmes for early identification of ear diseases and hearing loss in high-risk populations, including infants and young children.[5] Ultimately, these initiatives contribute to the attainment of sustainable development goals 3 (that is, ensure healthy lives and promote well-being for all at all ages) and 4 (that is, ensure inclusive and equitable quality education and promote lifelong learning opportunities for all). However, in many low- and middle-income countries there is a shortage of good-quality ear and hearing services,[6] and even when services are available utilization remains low.[7,8] At national and regional levels, data are currently lacking on the need for ear and hearing services that would help to advocate for, plan and implement these programmes.

Data on the prevalence and causes of hearing loss in sub-Saharan Africa are sparse.[9] In Malawi, a low-income country in southern Africa, there are two ear, nose and throat surgeons and three audiologists to serve a population of approximately 17.6 million people.[10] A single community-based study has reported that the prevalence of childhood hearing impairment is high in Malawi, with 32/279 (11.5%) of children aged 4–6 years having bilateral hearing loss of greater than 25 decibels (dB) hearing level.[11] Information on the broader impacts of hearing loss, referral uptake and the outcomes of treatment is lacking. Timely and regular follow-up of children with hearing loss is important, but often difficult to achieve in low- and middle-income countries.[12,13] To provide a more comprehensive assessment of the impact of ear and hearing disorders, treatment outcomes should focus not only on formal diagnostic assessments and treatment received, but also on holistic assessments of children, such as well-being and education inclusion.

Here we aimed to assess the outcome of children with ear and hearing disorders 3 years after initial diagnosis, in terms of referral uptake, treatment received and satisfaction with this treatment. We also aimed to assess the social participation of the affected children, specifically, their ability to make friends and communicate needs, and their enrolment at school.

Methods

Study design and setting

Our hearing impairment investigation was part of a larger population-based study to estimate the prevalence of hearing, visual, physical and intellectual impairment and epilepsy in children in Malawi by the key informant method.[14] The key informant method is a two-stage process including identification of children with impairments by key informants, followed by assessment of these children by relevant medical profession-

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als at one of the 33 screening camps set up within the study area for the period April–November 2013.

We selected the two rural districts of Thyolo (Southern Region, 18 camps) and Ntcheu (Central Region, 15 camps) for our study to enable us to achieve the desired target population of 1 million people. These districts are located relatively close to Blantyre, the commercial capital of Malawi. Children were identified through this study could benefit from referral to the community-based rehabilitation facility in Ntcheu and the outreach and inpatient services provided in Thyolo by centralized centres in Blantyre (e.g. Queen Elizabeth Central Hospital), through links with the Christian Blind Mission and Malawi Council for the Handicapped.

We focused our longitudinal analysis on the population-based sample of children confirmed by audiologists at the screening camps as having a hearing impairment. Trained key informants interviewed parents or caregivers and completed questionnaires at baseline in 2013, and trained community health workers conducted the follow-up survey in 2016. Before the baseline survey, we conducted a comprehensive mapping of the available referral services through discussions with local stakeholders and service providers. This mapping was essential to ensure the availability of services needed to accommodate additional demand generated by the study.

Key informants

We selected a total of 500 literate key informants (250 per district) from existing pools of volunteers who work alongside health surveillance assistants, a formal cadre of community health workers in Malawi, to cover all the communities within the two districts. All key informants were trusted members within the community, but without formal expertise related to ear health and hearing.

We trained the volunteers in groups of approximately 25 key informants per session (holding 10 training workshops per district) at a 4–5-hour workshop that included disability sensitization, identification of key impairments (including hearing), methods for case finding and procedures for the screening camps. We delivered training using specially designed flipcharts and hand-out information sheets produced in the local language (Chichewa) that contained information and illustrations regarding the impairments to be identified (including hearing), and instructions on how to conduct case finding and complete the registration forms. We based these materials on those developed and validated by the International Centre for Evidence in Disability that were previously used in studies conducted in Bangladesh and Pakistan.[15]

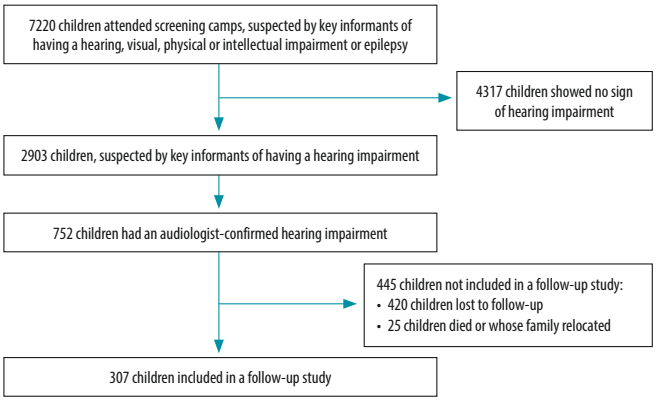
In 2013, trained key informants identified children suspected of having a disability (including hearing impairment) by spreading the word through their daily activities and existing social and professional networks, and visiting the homes of such children. The key informants then referred such children to the screening camps for clinical investigation by a team of specialists, including ear, nose and throat practitioners and audiologists.

Screening camps

Using funding from the Christian Blind Mission, the College of Surgeons of East Central and Southern Africa Oxford Orthopaedic Link programme, Cure International UK, Fight for Sight and the Liliane Foundation, we set up screening camps at which children suspected of having an impairment could be assessed. Screening camps were usually open for a single 8–12-hour day, unless demand was sufficiently high for a second day. A single team of medical professionals, comprising up to three from each of the different specialities (orthopaedic clinical officers, ear, nose and throat clinical officers, audiologists, ophthalmic clinical officers, nurses, social workers and rehabilitation technicians), attended each camp in turn. This attendance was on a voluntary basis and additional to normal medical duties. To assist the team, we delivered a 1-day training course on the organization of the screening camps and clinical examination protocols. Field supervisors (a Malawi key informant method project coordinator and a researcher from the London School of Hygiene & Tropical Medicine) attended the screening camps to monitor the quality of data collection and ensure consistency.[14]

On presentation at a screening camp, caregivers were asked a series of six questions to determine the type of medical assessment required. Audiologists used the WHO ear and hearing disorders survey protocol[16] in the assessment of children suspected of having a hearing impairment. Audiologists conducted otoacoustic emission tests for children aged 6 months–4 years, and hearing impairment was defined as failed otoacoustic emission screening in both ears. For children aged 5–18 years, we attempted to use pure tone audiometry with a KUDUwave 5000 audiometer (eMoyoDotnet (Pty) Ltd, Randburg, South Africa). Pure tone audiometry requires the active cooperation of the child being tested, however, and some children aged 5–18 years could not be tested in this way; we therefore performed otoacoustic emission screening on some children of age 5–18 years. We diagnosed a hearing impairment for a hearing level of greater than 25 dB in the better hearing ear averaged across

Fig. 1. **Numbers of children identified as having a hearing impairment by key informants in 2013 and traced to follow-up in 2016, Malawi**



the frequencies of 0.5, 1, 2 and 4 kHz. The categories of hearing impairment were defined as: mild, 26–40 dB hearing level; moderate, 41–60 dB hearing level; severe, 61–80 dB hearing level; and profound, over 81 dB hearing level.[17]

The audiologist referred all children with hearing loss or ear disease to ear, nose and throat services, while explaining to the parent or caregiver what the findings were, why a referral was appropriate, how the referral could be pursued and what would happen at the appointment.

Baseline survey

Key informants completed an initial questionnaire by interviewing the parent or caregiver. The covariates were guided by evidence from published literature,[18–20] and included sociodemographic variables such as age, sex, location, income group, school enrolment, whether the child had a speech impairment and the literacy of the parent or caregiver. Speech impairment was defined as a caregiver's response of "no" to "does the child have speech or vocalization?" (children aged < 2 years) or "can the child say names of familiar objects or speak whole sentences?" (children aged ≥ 2 years). Any child whose speech was different from or poorer than other children of the same age as reported by the caregiver was also categorized as having a speech impairment.

Follow-up survey

In 2016, we conducted a follow-up of all the children originally identified as having a hearing impairment in 2013. We requested the assistance of key informants in tracing relevant children in their respective villages, using baseline data including the child's name, age, sex, village of residence, contact number if any, and names of next of kin and relevant key informants. Our research assistants and the key informants worked together with community health workers in each of the relevant villages.

We delivered a 1-day training course to community health workers in tracing the children and administering a questionnaire to parents or caregivers during a home visit. The questionnaire included referral status (whether a referral was made and uptake of referral), treatment received and satisfaction with this treatment, ear and hearing status at follow-up (self-reported; caregivers were asked the question "Does he/she have difficulties in hearing sounds, such as people's voices or music?"), speech and language difficulties, and participation outcomes. Participation outcomes were linked to the framework of the International Classification of Functioning, Disability and Health for Children and Youth,[20] and measured using ability to make friends (d750, forming relationships) and communicate needs (d310, communicating with-receiving spoken messages; d315, communicating with-receiving nonverbal messages), and whether they were enrolled at school (d820, school education). In this case, school included primary- (for children aged 6 years and older), secondary- and university-level education.

We maintained contact with community health workers by mobile telephone text, assisting where children could not be traced. We also assessed loss to follow-up, defined as those who could not be traced 3 years after initial identification.

Data management and analysis

We entered all baseline data into an Access database (Microsoft, Redmond, United States of America). We double-entered 722/7220 (10.0%) of the forms and compared these to verify the quality of the data entry. We entered follow-up data into an Excel spreadsheet (Microsoft). We undertook data cleaning and analyses using Stata version 15 (StataCorp LCC, College Station, USA). We investigated the associations between children achieving an outcome (referral uptake, well-being and inclusion, and school enrolment) in terms of sociodemographic characteristics, such as

Table 1. **Sociodemographic characteristics of children identified with hearing impairment at baseline in 2013 and traced for follow-up in 2016, Malawi**

Characteristic as recorded at baseline	No. at baseline	No. in follow-up (%)	OR (95% CI)
Total	**752**	**307 (40.8)**	**NA**
Age at baseline, years			
0–4	169	63 (37.3)	Reference
5–9	264	98 (37.1)	1.0 (0.7–1.5)
10–14	210	91 (43.3)	1.3 (0.9–2.0)
15–18	109	55 (50.5)	1.7 (1.1–2.8)
Sex			
Female	342	137 (40.1)	Reference
Male	410	170 (41.5)	1.1 (0.8–1.4)
District			
Thyolo	444	176 (39.6)	Reference
Ntcheu	308	131 (42.5)	1.1 (0.8–1.5)
Degree of hearing loss			
Mild	151	66 (43.7)	Reference
Moderate	138	63 (45.7)	1.1 (0.7–1.7)
Severe to profound	21	13 (61.9)	2.1 (0.8–5.4)
Bilateral otoacoustic emission failure	442	165 (37.3)	
Causes of hearing loss			
Ear infection			
Yes	510	205 (40.2)	0.9 (0.7–1.3)
No	242	102 (42.1)	Reference
Impacted wax			
Yes	250	97 (38.8)	0.9 (0.7–1.2)
No	502	210 (41.8)	Reference
Sensorineural			
Yes	188	78 (41.5)	1.0 (0.7–1.5)
No	564	229 (40.6)	Reference
Speech impairment			
Yes	179	73 (40.8)	1.0 (0.7–1.4)
No	573	234 (40.8)	Reference

CI: confidence interval; NA: not applicable; OR: odds ratio.

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literacy of caregiver, income group and whether the child had a speech impairment. We calculated odds ratios (OR) and 95% confidence intervals (CI) for the associations using a multivariate logistic regression model with stepwise backward selection. To reduce the chance of missing variables that could be relevant, a liberal *P*-value of 0.20 or less was chosen for inclusion in the model; factors that did not contribute to the model ($P > 0.20$) were eliminated to calculate an adjusted OR (aOR).

Ethics

We obtained ethical approval from the College of Medicine Research Ethics Committee, Malawi and the London School of Hygiene & Tropical Medicine, United Kingdom of Great Britain and Northern Ireland. All parents gave written consent for inclusion in the study. If caregivers were illiterate, then the information sheet was read to them and they gave consent by thumb print. Caregivers were informed that participation in the study was voluntary, that refusal to participate would not affect any medical care they would receive and that they could discontinue participation at any time.

Results

Of an estimated 15 000 children suspected by key informants as having either a hearing, visual, physical or intellectual impairment or epilepsy, 7220 (48%) attended one of the 33 screening camps. The key informants identified 2903 children as having a suspected hearing impairment, which was confirmed by audiologists in 752 children. Three years after baseline, we traced 307 (40.8%) of these children (Fig. 1). There was no significant difference between the groups included at baseline and at follow-up, except that children aged 15–18 years were slightly more likely to be included in the follow-up (OR: 1.7; 95% CI: 1.1–2.8), demonstrating that those followed up were relatively representative of the baseline group (Table 1). At baseline, 159 out of 310 (51.3%) of the children with hearing loss who underwent pure tone audiometry had moderate to profound hearing loss, and the remainder had mild hearing loss (Table 1).

Of the 307 children included at follow-up, 184 (59.9%) were reported by the caregiver as having been referred to the district hospital at the original screening camp. Approximately half (102, 55.4%) of those referred to the district hospital reported that they had attended the district hospital for their referral. After eliminating non-significant variables (sex, whether enrolled in school, whether a speech impairment, income and degree of hearing loss), referral uptake was lower among children living in Ntcheu district (aOR: 0.4; 95% CI: 0.2–0.8) and among those with caregivers who were illiterate (aOR: 0.5; 95% CI: 0.2–0.9). Uptake was higher in the older age groups of 15–18 years (aOR: 3.5; 95% CI: 1.2–10.2; Table 2). Regarding intervention or treatment given, only nine patients received hearing aids, 15 underwent surgery and nine received special needs education. The caregivers of 63.6% (21/33) of the children who received any treatment reported that they were satisfied.

Of the 307 children included at follow-up, whether the child had diffi-

Table 2. **Sociodemographic characteristics of children with hearing impairment whose caregiver reported referral uptake, Malawi, 2013 and 2016**

Characteristic as recorded at baseline	No. referred to district hospital (*n* = 184)	No. (%) who attended hospital (*n* = 102)	cOR (95% CI)	aOR (95% CI)[a]
Age, years				
0–4	38	17 (44.7)	Reference	Reference
5–9	55	29 (52.7)	1.4 (0.6–3.2)	1.1 (0.5–2.8)
10–14	56	31 (55.4)	1.5 (0.7–3.5)	1.7 (0.7–4.2)
15–18	35	25 (71.4)	3.1 (1.2–8.3)	3.5 (1.2–10.2)
Sex				
Female	80	39 (48.8)	0.6 (0.3–1.1)	NA
Male	104	63 (60.6)	Reference	NA
District				
Ntcheu	93	42 (45.2)	0.4 (0.2–0.8)	0.4 (0.2–0.8)
Thyolo	91	60 (65.9)	Reference	Reference
School enrolment				
Yes	112	61 (54.5)	0.8 (0.3–1.9)	NA
No	22	13 (59.1)	Reference	NA
Not of school age[b]	50	28 (56.0)	NA	NA
Speech impairment				
Yes	46	30 (65.2)	1.7 (0.9–3.5)	NA
No	138	72 (52.2)	Reference	NA
Illiterate caregiver				
Yes	61	25 (41.0)	0.4 (0.2–0.8)	0.5 (0.2–0.9)
No	111	70 (63.1)	Reference	Reference
Not recorded	12	7 (58.3)	NA	NA
Income group, MWK				
≤ 12 000	165	89 (53.9)	0.4 (0.1–1.4)	NA
> 12 000	15	11 (73.3)	Reference	NA
Not recorded	4	2 (50.0)	NA	NA
Degree of hearing loss[c]				
Mild	41	24 (58.5)	Reference	NA
Moderate	45	26 (57.8)	1.0 (0.4–2.3)	NA
Severe to profound	6	4 (66.7)	1.4 (0.2–8.8)	NA
Bilateral otoacoustic emission failure	92	48 (52.2)	NA	NA

aOR: adjusted odds ratio; CI: confidence interval; cOR: crude odds ratio; MWK: Malawian Kwacha; NA: not applicable.

[a] After eliminating non-significant variables (sex, whether enrolled in school, whether a speech impairment, income and degree of hearing loss).

[b] School age is defined as 6 years or older.

[c] Categories of hearing loss are defined as: mild, 26–40 dB hearing level; moderate, 41–60 dB hearing level; severe to profound, 61 dB hearing level and greater.

Note: Children were referred in 2013 and followed-up in 2016.

culty making friends or communicating needs was not recorded for eight and six children, respectively. Children experiencing difficulties making friends was reported by 10.0% (30/299) of the caregivers. After eliminating non-significant variables (age, sex, district, income and degree of hearing loss), children enrolled at school were less likely to report difficulty making friends (aOR: 0.2; 95% CI: 0.1–0.6), while children were more likely to experience difficulty making friends if they had a speech impairment (aOR: 6.3; 95% CI: 2.3–17.4) or an illiterate caregiver (aOR: 3.1; 95% CI: 1.1–8.7; Table 3). Children having difficulty communicating needs was reported by 35.6% (107/301) of the caregivers. After eliminating non-significant variables (age, sex, illiterate caregiver, income and degree of hearing loss), having difficulty

Table 3. **Sociodemographic characteristics of children with hearing impairment whose caregiver reported their difficulty making friends or communicating needs, Malawi, 2016**

Characteristic as recorded at baseline	Difficulty making friends ($n = 30$)				Difficulty communicating needs ($n = 107$)			
	No. followed-up ($n = 299$)[a]	No. (%)	cOR (95% CI)	aOR (95% CI)[b]	No. followed-up ($n = 301$)[c]	No. (%)	cOR (95%CI)	aOR (95% CI)[d]
Age, years								
0–4	63	6 (9.5)	Reference	NA	63	24 (38.1)	Reference	NA
5–9	95	7 (7.4)	0.8 (0.2–2.4)	NA	96	37 (38.5)	1.0 (0.5–2.0)	NA
10–14	88	9 (10.2)	1.1 (0.4–3.2)	NA	90	28 (31.1)	0.7 (0.4–1.5)	NA
15–18	53	8 (15.1)	1.7 (0.5–5.3)	NA	52	18 (34.6)	0.9 (0.4–1.9)	NA
Sex								
Female	132	11 (8.3)	0.7 (0.3–1.6)	NA	134	44 (32.8)	0.8 (0.5–1.3)	0.4 (0.2–0.7)
Male	167	19 (11.4)	Reference	NA	167	63 (37.7)	Reference	Reference
District								
Ntcheu	126	12 (9.5)	0.9 (0.4–2.0)	NA	128	30 (23.4)	0.4 (0.2–0.6)	0.4 (0.2–0.7)
Thyolo	173	18 (10.4)	Reference	NA	173	77 (44.5)	Reference	Reference
School enrolment								
Yes	180	13 (7.2)	0.2 (0.1–0.4)	0.2 (0.1–0.6)	181	59 (32.6)	0.2 (0.1–0.5)	0.2 (0.1–0.6)
No	30	10 (33.3)	Reference	Reference	30	21 (70.0)	Reference	Reference
Not of school age[e]	89	7 (7.9)	NA	NA	90	27 (30.0)	NA	NA
Speech impairment								
Yes	70	19 (27.1)	7.4 (3.2–17.2)	6.3 (2.3–17.4)	73	43 (58.9)	3.7 (2.1–6.5)	4.4 (2.1–9.2)
No	229	11 (4.8)	Reference	Reference	228	64 (28.1)	Reference	Reference
Illiterate caregiver								
Yes	107	13 (12.1)	1.3 (0.6–2.9)	3.1 (1.1–8.7)	107	37 (34.6)	0.9 (0.6–1.5)	NA
No	169	16 (9.5)	Reference	Reference	171	63 (36.8)	Reference	NA
Not recorded	23	1 (4.3)	NA	NA	23	7 (30.4)	NA	NA
Income group, MWK								
≤ 12 000	262	24 (9.2)	Reference	NA	265	89 (33.6)	Reference	NA
> 12 000	24	5 (20.8)	2.6 (0.9–7.7)	NA	23	13 (56.5)	1.5 (0.6–3.6)	NA
Not recorded	13	1 (7.7)	NA	NA	13	5 (38.5)	NA	NA
Degree of hearing loss[f]								
Mild	65	7 (10.8)	Reference	NA	64	18 (28.1)	Reference	NA
Moderate	59	5 (8.5)	0.8 (0.2–2.6)	NA	61	15 (24.6)	0.8 (0.4–1.6)	NA
Severe to profound	11	3 (27.3)	3.1 (0.6–15.0)	NA	11	7 (63.6)	3.0 (0.9–10.5)	NA
Bilateral otoacoustic emission failure	164	15 (9.1)	NA	NA	165	67 (40.6)	NA	NA

aOR: adjusted odds ratio; CI: confidence interval; cOR: crude odds ratio; MWK: Malawian Kwacha; NA: not applicable.
[a] Data not recorded for eight children.
[b] After eliminating non-significant variables (age, sex, district, income and degree of hearing loss).
[c] Data not recorded for six children.
[d] After eliminating non-significant variables (age, sex, illiterate caregiver, income and degree of hearing loss).
[e] School age is defined as 6 years or older.
[f] Categories of hearing loss are defined as: mild, 26–40 dB hearing level; moderate, 41–60 dB hearing level; severe to profound, 61 dB hearing level and greater.

making friends was negatively associated with school enrolment (aOR: 0.2; 95% CI: 0.1–0.6) and living in Ntcheu (aOR: 0.4; 95% CI: 0.2–0.7), but more common among children with a speech impairment (aOR: 4.4; 95% CI: 2.1–9.2).

Table 4 shows that 29.5% (72/244) of the school-aged children were not enrolled at school. After adjusting for non-significant variables (district, whether a speech impairment, income and degree of hearing loss), factors associated with lack of school enrolment were being in the two older age groups (10–14 years, aOR: 4.8; 95% CI: 1.9–12.1; 15–18 years, aOR: 28.6; 95% CI: 10.3–79.6), being female (aOR: 2.4; 95% CI: 1.2–4.8) or having an illiterate caregiver (aOR, 2.1; 95% CI: 1.0–4.1).

Discussion

Less than half of the children identified with a hearing impairment at baseline were traced 3 years later, showing that mechanisms are needed to improve follow-up in the community. However, those lost to follow-up had similar baseline characteristics to those that were included at follow-up, reducing the potential for selection bias. Possible strategies to improve follow-up could include improving parental involvement and working together with established community structures, such as traditional leaders.[21]

Another challenge highlighted was the relatively low referral uptake, particularly for girls and younger children. Our results showed that referral uptake was higher among children living in Thyolo than in Ntcheu. Both districts are rural and poor, but Thyolo is closer to Blantyre, meaning children from Thyolo may have better access to health professionals and services than children from Ntcheu.

Another study in Malawi also showed that uptake of referrals was low among children with a hearing impairment, and reported that barriers include geographical accessibility, availability of services, affordability of transport and indirect costs, and acceptability (dependent upon knowledge and information about referral).[8] To increase the availability of services in Malawi, the ear, nose and throat lead at the College of Medicine and colleagues developed and initiated relevant services and the training of clinical officers who are now serving in different districts of the country, including Ntcheu and Thyolo.[22] Other potential interventions that could improve uptake of referrals include increased awareness of ear and hearing disorders, and the provision of transport and outreach services.[23] Our findings suggest that illiteracy of the caregiver is an important predictor of lack of referral uptake and low participation outcomes in children with hearing impairment. For interventions in children with hearing loss to be effective, they should therefore be appropriate, timely and family-centred, and undertaken through an interdisciplinary approach (e.g. involving both traditional leaders and community health workers).[24]

As expected, many children with hearing loss had speech impairments and difficulties communicating their needs. Communication defines us and underlies our ability to function in the world. The ability to communicate effectively is essential for living independently, pursuing personal goals and interests, performing social roles and functions, maintaining personal and familial relationships, making decisions, and exercising control over quality of life and care.[25] Our results show that children with communication difficulties were less likely to be enrolled at school and more likely to experience difficulties making friends. One way of improving

Table 4. **Sociodemographic characteristics of school-aged children with hearing impairment who were not enrolled at school, Malawi, 2016**

Characteristic as recorded at baseline	No. of school-aged children	No. (%) not enrolled at school	cOR (95% CI)	aOR (95% CI)[a]
Total	244	72 (29.5)	NA	NA
Age, years				
5–9	98	8 (8.2)	Reference	Reference
10–14	91	26 (28.6)	4.5 (1.9–10.9)	4.8 (1.9–12.1)
15–18	55	38 (69.1)	25.2 (7. 6–83.5)	28.6 (10.3–79.6)
Sex				
Female	107	39 (36.4)	1.8 (1.0–3.2)	2.4 (1.2–4.8)
Male	137	33 (24.1)	Reference	Reference
District				
Ntcheu	107	39 (36.4)	1.8 (1.0–3.2)	NA
Thyolo	137	33 (24.1)	Reference	NA
Speech impairment				
Yes	54	20 (37.0)	1.6 (0.8–2.2)	NA
No	190	52 (27.4)	Reference	NA
Illiterate caregiver				
Yes	85	30 (35.3)	1.6 (0.9–2.8)	2.1 (1.0–4.1)
No	139	36 (25.9)	Reference	Reference
Not recorded	20	6 (30.0)	NA	NA
Income group, MWK				
≤ 12 000	212	62 (29.2)	Reference	NA
> 12 000	22	8 (36.4)	1.4 (0.6–3.5)	NA
Not recorded	10	2 (20.0)	NA	NA
Degree of hearing loss[b]				
Mild	65	28 (43.1)	Reference	NA
Moderate	63	23 (36.5)	1.3 (0.6–2.7)	NA
Severe to profound	13	4 (30.8)	1.7 (0.6–6.2)	NA
Bilateral otoacoustic emission failure	103	17 (16.5)	NA	NA

aOR: adjusted odds ratio; CI: confidence interval; cOR: crude odds ratio; MWK: Malawian Kwacha; NA: not applicable.

[a] After eliminating non-significant variables (district, whether a speech impairment, income and degree of hearing loss).

[b] Categories of hearing loss are defined as: mild, 26–40 decibels (dB) hearing level; moderate, 41–60 dB hearing level; severe to profound, 61 dB hearing level and greater.

speech or vocalization in children with hearing loss is the provision of speech therapy services, of which there is a shortage in sub-Saharan Africa; training programmes are needed to fill this gap.[6]

Our findings that one third of the school-aged participants were not enrolled at school are consistent with previous published studies showing that children with disabilities are less likely to attend and progress through school.[18] However, children with hearing loss also have a right to education and should be encouraged to enrol in schools as part of the inclusive education strategy. Teachers in schools should be made aware of the needs of children with hearing loss, and the impact this disability has on a child's ability to make friends and communicate needs. However, information is lacking as to what works best to improve educational outcomes among children with disabilities.[26] These challenges are set against wider concerns about access to schooling in Africa. In Malawi, about 1.5 million out of 3.7 million (about 40%) of the children do not go beyond primary school education.[20] This general pattern may explain our findings that older children with a hearing impairment were particularly unlikely to be enrolled at school.

Our study has limitations. We did not investigate school enrolment or participation outcomes in a comparison group of children without hearing loss. Furthermore, outcomes such as educational inclusion and difficulties making friends were recorded subjectively, and information from school records and exam results were not included. We did not develop mechanisms to make a link between the children seen at the screening camp and those seen by the ear, nose and throat specialist at the hospital, or obtain ethical approval for making this connection. This link would have been difficult to make without including additional mechanisms, as children often have multiple names and cannot be traced by name alone. Finally, the follow-up questionnaire was administered by a community health worker, raising the possibility of a positive-response bias for service satisfaction even though the health worker was not connected to the ear, nose and throat services.

Our study also has strengths, including the 3-year follow-up, the large cohort identified by our key informants and that children were recruited from the community rather than the clinic, improving the generalizability of the results. We used the International Classification of Functioning, Disability and Health for Children and Youth framework to assess outcomes, therefore looking holistically beyond functional status alone. With poor outcomes, in terms of referral uptake, social inclusion and well-being, for children with a hearing impairment in Malawi, more widespread and holistic services are required. ■

Competing interests: None declared.

ملخص

الأطفال الذين يعانون من ضعف السمع في ملاوي، دراسة أترابية

الغرض تقييم للنتائج الخاصة بالأطفال الذين تم تشخيص إصابتهم بضعف السمع منذ 3 سنوات، فيما يتعلق بالحصول على فرصة للإحالة، وتلقى العلاج، والرضا عن هذا العلاج، والمشاركة الاجتماعية.

الطريقة قمنا بإجراء تحليلاً طولانياً على أساس السكان من الأطفال الذين يعانون من ضعف السمع في اثنين من المناطق الريفية في ملاوي. يمثل المبلغون الرئيسيون في المجتمع مجموعة الأتراب في عام 2013 (خط الأساس). قام المبلغون بفحص الأطفال سريرياً عند خط الأساس، ومن خلال الاستبيانات عند الأساس والمتابعة في عام 2016. وقمنا بفحص الارتباطات بين الخصائص الاجتماعية الديموغرافية ونتائج التحوف اللوجستي متعدد المتغيرات.

النتائج لقد قمنا بتشخيص 752 طفلًا في عام 2013 على أنهم يعانون من ضعف في السمع، وقمنا بتتبع 307 طفلاً (40.8%) منهم للمتابعة في عام 2016. كانت نسبة الحصول على فرصة الإحالة منخفضة (184/102؛ 55.4%)، وكانت أكثر احتمالية بين الأطفال الأكبر سناً (نسبة الاحتمالات: 3.5؛ فاصل الثقة 95%: 1.2 إلى 10.2)، واحتمالية أقل لهؤلاء الأطفال ممن يخضعون لرعاية شخص أمي (نسبة الاحتمالات: 0.5؛ بفاصل ثقة 95%: 0.2 إلى 0.9). عدد قليل من الأطفال الذين تلقوا الرعاية في المستشفى، وحصلوا على أي علاج (102/33؛ بنسبة 32.4%) وأعربت نسبة 63.6% (33/21) من مقدمي الرعاية عن رضاهم عن العلاج. تم الإبلاغ عن صعوبة في تكوين الصداقات، واحتياجات التواصل لنسبة 10.0% (299/30)، و35.6% (301/107) من الأطفال، على الترتيب. تمت ملاحظة نقص في الالتحاق بالتعليم لنسبة 29.5% (244/72) من الأطفال، وكانت أكثر احتمالية بالنسبة للأطفال الأكبر سناً (نسبة الاحتمالات: 28.6؛ بفاصل ثقة 95%: 10.3 إلى 79.6)، والبنات (نسبة الاحتمالات: 2.4؛ بفاصل ثقة 95%: 1.2 إلى 4.8)، وهؤلاء الأطفال ممن يخضعون لرعاية شخص أمي (نسبة الاحتمالات: 2.1؛ بفاصل ثقة 95%: 1.0 إلى 4.1).

الاستنتاج هناك حاجة إلى خدمات أكثر انتشاراً وشمولية لتحسين نتائج الأطفال المصابين بضعف السمع في ملاوي.

摘要

一项针对马拉维患有听力障碍儿童的群组研究

目的 从转诊率、接受治疗情况、对治疗的满意程度及社会参与度等方面对 3 年前确诊为听力障碍儿童的治疗结果进行评估。

方法 我们对马拉维两大农村地区中患有听力障碍的儿童进行了一项基于人口的纵向分析。我们确定了 2013 年社区内关键受访者群组（基准值）。受访者在 2016 年通过基准值调查问卷和随访的形式对儿童进行了临床筛查。我们采用多变项逻辑回归法对社会人口特征与结果之间的关系进行了研究。

结果 我们在 2013 年诊断出 752 名儿童患有听力障碍，并在 2016 年对其中的 307 名儿童 (40.8%) 进行了随访。转诊率较低 (102/184；55.4%)，且多见于年龄较大的儿童（比值比，OR: 3.5；95% 置信区间，CI：1.2-10.2），而其看护人未受过教育的儿童转诊率更低（比值比，OR：0.5；95% 置信区间，CI：0.2-0.9）。只有极少数在医院就诊的儿童接受了治疗 (33/102；32.4%)，其中 63.6% (21/33) 的看护人对治疗表示满意。报告表明，10.0% (30/299) 的儿童交友困难，35.6% (107/301) 的儿童有沟通障碍。据悉，儿童失学率达到 29.5% (72/244)，其中年龄较大的儿童（比值比，OR：28.6；95% 置信区间，CI：10.3-79.6）、女孩（比值比，OR：2.4；95% 置信区间，CI：1.2-4.8）以及其看护人未接受过教育的儿童（比值比，OR：2.1；95% 置信区间，CI：1.0-4.1）的失学率更高。

结论 马拉维仍需要一系列更广泛的服务来改善患有听力障碍儿童的治疗结果。

Résumé

Enfants présentant une déficience auditive au Malawi, une étude de cohorte

Objectif Évaluer la situation des enfants chez lesquels une déficience auditive a été diagnostiquée 3 années plus tôt, en matière de consultation d'un spécialiste, de traitement reçu et de satisfaction quant à ce traitement, ainsi que de participation sociale.

Méthodes Nous avons réalisé une analyse longitudinale dans la population des enfants présentant une déficience auditive dans deux districts ruraux du Malawi. Des informateurs clés de la communauté ont défini la cohorte en 2013 (point de référence). Ils ont pratiqué un examen clinique chez les enfants à cette date, et ont eu recours à des questionnaires à cette époque et lors du suivi en 2016. Nous avons étudié les associations entre certaines caractéristiques sociodémographiques et la situation des enfants à l'aide d'une régression logistique multivariée.

Résultats Nous avons diagnostiqué une déficience auditive chez 752 enfants en 2013 et avons fait le suivi de 307 (40,8%) d'entre eux en 2016. Le taux de consultation d'un spécialiste était faible (102/184; 55,4%), plus fréquent chez les enfants les plus âgés (rapport des cotes, RC: 3,5; intervalle de confiance de 95%, IC: 1,2–10,2) et moins fréquent chez ceux à charge d'une personne analphabète (RC: 0,5; IC 95%: 0,2–0,9). Parmi les enfants qui se sont rendus à l'hôpital, peu ont reçu un traitement (33/102; 32,4%) et 63,6% (21/33) des accompagnateurs se sont dits satisfaits du traitement. Des difficultés à se faire des amis et à communiquer ses besoins ont été rapportées respectivement par 10,0% (30/299) et 35,6% (107/301) des enfants. L'absence de scolarisation a été observée pour 29,5% (72/244) des enfants, plus fréquemment chez les plus âgés (RC: 28,6; IC 95%: 10,3-79,6), les filles (RC: 2,4; IC 95%: 1,2-4,8) et les enfants à charge d'une personne analphabète (RC: 2,1; IC 95%: 1,0-4,1).

Conclusion Il est nécessaire de proposer des services plus complets et généralisés pour améliorer la situation des enfants présentant une déficience auditive au Malawi.

Резюме

Дети с нарушениями слуха в Малави: когортное исследование

Цель Оценка результатов вмешательства у детей, у которых за три года до этого были диагностированы нарушения слуха, применительно к использованию направлений к врачам-специалистам, полученному лечению и удовлетворенности его результатами, а также социальному участию.

Методы Авторы провели популяционное лонгитюдное исследование детей с нарушениями слуха в двух сельских районах Малави. Основные информанты в сообществе определили когорту в 2013 году (базовые данные). Информанты провели клинический скрининг детей в момент сбора базовых данных, а также анкетирование в момент сбора базовых данных и повторно в 2016 году. Авторы исследовали взаимосвязь между социодемографическими характеристиками и результатами вмешательства с использованием множественной логистической регрессии.

Результаты Диагноз нарушений слуха был поставлен 752 детям в 2013 году, из них 307 детей (40,8%) участвовали в последующем контроле в 2016 году. Использование направлений к специалистам было низким (102 из 184; 55,4%). Вероятность обращения к врачу была выше для детей старшего возраста (отношение шансов, ОШ: 3,5; 95%-й ДИ: 1,2–10,2) и ниже в том случае, если осуществляющее уход лицо было неграмотным (ОШ: 0,5; 95%-й ДИ: 0,2–0,9). Немногие из детей, посетивших больницу, прошли курс лечения (33 из 102; 32,4%), а 63,6% (21 из 33) лиц, осуществлявших уход за детьми, сообщили о том, что они довольны лечением. Сложность в приобретении друзей и проблемы в общении отмечались у 10,0% (30 из 299) и 35,6% (107 из 301) детей соответственно. Недостаточная посещаемость школы отмечалась у 29,5% (72 из 244 детей) и была выше у детей старшего возраста (ОШ: 28,6; 95%-й ДИ: 10,3–79,6), девочек (ОШ: 2,4; 95%-й ДИ: 1,2–4,8) и в случаях, когда осуществляющее уход лицо было неграмотным (ОШ: 2,1; 95%-й ДИ: 1,0–4,1).

Вывод Для улучшения результатов лечения детей с нарушениями слуха в Малави необходима система повсеместного и комплексного медицинского обслуживания.

Resumen

Niños con discapacidad auditiva en Malawi, un estudio de cohorte

Objetivo Evaluar los resultados de los niños diagnosticados con hipoacusia hace tres años con respecto a la asimilación de la remisión, el tratamiento recibido y la satisfacción con este tratamiento, y la participación social.

Métodos Se realizó un análisis longitudinal basado en la población de niños con discapacidad auditiva en dos distritos rurales de Malawi. Los informantes clave dentro de la comunidad identificaron a la cohorte en 2013 (inicio del estudio). Los informantes examinaron clínicamente a los niños y aplicaron cuestionarios desde el inicio, y luego el seguimiento se

realizó en 2016. Se investigaron las asociaciones entre las características sociodemográficas y los resultados mediante la regresión logística multivariada.

Resultados En 2013, diagnosticamos a 752 niños con discapacidad auditiva y en 2016 seguimos el rastro de 307 (40,8 %) de ellos para su seguimiento. La asimilación de la remisión fue baja (102/184; 55,4 %), más probable entre los niños mayores (razón de momios, OR: 3,5; intervalo de confianza del 95 %, IC: 1,2-10,2) y menos probable entre los que tenían un cuidador analfabeto (OR: 0,5; IC del 95 %: 0,2-0,9). Pocos de los niños que asistieron al hospital recibieron tratamiento (33/102; 32,4 %) y 63,6 % (21/33) de los cuidadores informaron satisfacción con el tratamiento. La dificultad para hacer amigos y comunicar las necesidades fue reportada para el 10.0 % (30/299) y 35.6 % (107/301) de los niños, respectivamente. La falta de escolarización se observó en el 29,5 % (72/244) de los niños, y fue más probable en los niños mayores (OR: 28,6; IC del 95 %: 10,3-79,6), las niñas (OR: 2,4; IC del 95 %: 1,2-4,8) y los que tenían un cuidador analfabeto (OR: 2,1; IC del 95 %: 1,0-4,1).

Conclusión Se necesitan servicios más amplios y holísticos para mejorar los resultados de los niños con discapacidad auditiva en Malawi.

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IV

PLOS ONE

RESEARCH ARTICLE

Reasons for low uptake of referrals to ear and hearing services for children in Malawi

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Abstract

Background

Early detection and appropriate intervention for children with hearing impairment is important for maximizing functioning and quality of life. The lack of ear and hearing services in low income countries is a significant challenge, however, evidence suggests that even where such services are available, and children are referred to them, uptake is low. The aim of this study was to assess uptake of and barriers to referrals to ear and hearing services for children in Thyolo District, Malawi.

Methods

This was a mixed methods study. A survey was conducted with 170 caregivers of children who were referred for ear and hearing services during community-based screening camps to assess whether they had attended their referral and reasons for non-attendance. Semi-structured interviews were conducted with 23 caregivers of children who did not take up their referral to explore in-depth the reasons for non-uptake. In addition, 15 stakeholders were interviewed. Thematic analysis of the interview data was conducted and emerging trends were analysed.

Results

Referral uptake was very low with only 5 out of 150 (3%) children attending. Seven main interacting themes for non-uptake of referral were identified in the semi-structured interviews: location of the hospital, lack of transport, other indirect costs of seeking care, fear and uncertainty about the referral hospital, procedural problems within the camps, awareness and understanding of hearing loss, and lack of visibility and availability of services.

Conclusion

This study has highlighted a range of interacting challenges faced by families in accessing ear and hearing services in this setting. Understanding these context specific barriers to non-uptake of ear and hearing services is important for designing appropriate interventions to increase uptake.

Introduction

Globally, an estimated 32 million children have disabling hearing impairment (HI) and the vast majority live in low and middle-income countries (LMIC).[1, 2] HI can have a substantial negative impact on language development, school performance, employment opportunities later in life, and psychosocial well-being.[3–6] There is also evidence to suggest that caregivers of children with a profound hearing impairment are at greater risk of stress, have higher out-of-pocket expenses and lose more work days than other caregivers.[3]

Early detection coupled with appropriate treatment (e.g. surgery) or rehabilitation interventions (e.g. hearing aids) are important in order to maximise functioning and quality of life for children with hearing impairments.[2, 3, 7] However, in many LMIC, there is a severe shortage of quality ear and hearing services.[8] In Malawi, there are only two Ear Nose and Throat (ENT) surgeons and three audiologists to serve a population of approximately 17.2 million.[9] Even when treatment and rehabilitation services are available, there is evidence from LMIC settings that uptake of referrals to these services can be low among children with different impairments.[10–14] However empirical evidence on the uptake of and barriers to referrals for ear and hearing services among children is lacking.

It is important to understand the barriers faced in accessing these services in order to develop tailored approaches to overcome barriers, and ultimately result in an increase in children receiving needed ear and hearing services. In this mixed-methods study, we aimed to assess the level of uptake and explore reasons for non-uptake of referrals to ear and hearing services among children in Malawi.

Methods

This study took place in Thyolo district, in the Southern Region of Malawi between November 2015 and August 2016.

Key Informant Method parent study

In November 2015 a study using the Key Informant Method (KIM) was undertaken to identify people with hearing impairment in Thyolo district Malawi. The KIM approach involves training Key Informants (KIs) to identify children in their communities who may have a disabling impairment and referring them to a screening camp where they are examined by relevant clinicians and referred for services accordingly.[15]

In the study in Malawi, 29 community health workers (known as Health Surveillance Assistants, HSAs) from five randomly selected health centres in Thyolo district were trained by an ENT surgeon to be KIs. The HSAs were trained in Primary Ear and Hearing Care (PEHC) using the World Health Organization (WHO) Basic and Intermediate training modules on PEHC.[16] The training had theoretical and practical components. The practical component included: history taking, ear and otoscopic examination, and voice testing. Following the training, HSAs were asked to identify adults (>18 years) and children (<18 years) with ear conditions and/or hearing loss in their communities and invite them to attend a screening camp at a selected health centre. HSAs used multiple methods for identification, using the skills learnt in the training. This included door-to-door visits, and school screenings.

Screening camps were conducted by an ENT Surgeon, ENT Clinical Officers and Audiology Officers from Queen Elizabeth Central Hospital (QECH). Children underwent a hearing test hearing (using otacousitic emissions tests for <4 years and Pure Tone Audiometry for 4 + years) and examination of the ear using otoscopy. Participants were referred to ear and hearing services at the QECH, as appropriate. For example, children with chronic suppurative otitis media were treated with ciprofloxacin ear drops and referred to QECH for surgery and

children with suspected sensorineural hearing loss were referred for further audiological assessment and possible fitting of hearing aids. The QECH, in Blantyre, is the largest hospital in Malawi, and one of the few central hospitals with ENT and audiology departments. Services at QECH are free at the point of care. In total, HSAs identified 1739 people (adults and children) with suspected ear disorders or hearing loss. Of these 860 attended camps, 484 of whom were children, who are the focus of this paper. Of these children, 170 were referred to QECH for ear and hearing services.

Quantitative survey

A follow-up survey to the KIM study was conducted in June 2016 to assess the uptake of referrals. All households of the 170 children referred to QECH were invited to participate. The primary caregivers were interviewed using a structured pre-coded questionnaire, in private, at a central location in the village (e.g. a health post or school) (S3 File). Interviewees were asked whether they had attended the referral(s) and if not, the reasons why. Reason for non-uptake was asked as a single open question with pre-coded response options developed based on previous research, discussions with stakeholders and pilot testing.

Qualitative study

Informed by the quantitative study, a qualitative study was undertaken to understand the barriers to referral uptake in more depth. Semi-structured interviews were conducted with caregivers of children identified in the KIM study who did not take up their referral to QECH as well as stakeholders.

Study sample. Purposive sampling was used to select a sub-sample of 30 children (<18 years) who did not take up their referral. The sample was selected to ensure representation from different health centres, child age, sex, and severity of hearing loss. Interviews were conducted with the main caregiver.

Data collection. Interviews with caregivers were conducted at the local health centres and lasted approximately one hour. Topic guides were developed that included a range of open-ended questions. These were piloted and revised during the data collection period in light of the emerging themes. Caregiver interviews covered: history and impact of the child's ear and hearing issues, experiences at screening camps, and barriers faced in attending the referral (S1 File). For stakeholders the interviews explored their perspective on the barriers experienced by families at the family, community, screening camp, and hospital levels and recommendations how to address these (S2 File). Interviews were audio-recorded and detailed field notes taken. The recordings were transcribed and translated.

Research team and reflexivity. Two experienced researchers conducted the interviews: a male Malawian researcher (RT) together with a female UK-based researcher (TB). For stakeholders who were proficient in the English language, the interviews were conducted by TB in English, and the remaining were conducted in Chichewa by RT.

Analysis and findings. Transcripts were coded by two researchers, and data was managed by nVivo (Version 11). A thematic analysis was used; data was coded into key themes and subthemes through an iterative process, and a constant comparison of emerging issues identified between the two researchers.[17]

Ethics

Informed written or thumb-printed consent was obtained from all study participants. Ethical approval was granted by the College of Medicine Research and Ethics committee in Malawi and the London School of Hygiene & Tropical Medicine ethics committee.

Results

Quantitative survey

Out of the 170 families of children who were referred for ear and hearing services, 150 were traced (88% response rate). All caregivers interviewed were female. The majority of the children referred were female (74%). The children ranged in age from 0–18 years with a mean age of 9.4 years (95%CI 8.7–10.2).

Only five out of the 150 children (3%) had attended their referral at QECH. The remaining 145 were interviewed about reasons for non-uptake of referral. The most commonly reported reasons for not attending referral services were transportation difficulties (41%), lack of information or knowledge about the referral process (60%) and financial barriers (33%) (Table 1). The main reported financial barriers included lack of money for transport (28%), and food (21%). In addition, 40% of caregivers reported that they expected someone, such as a community health worker, to visit the family to follow-up with them.

Qualitative follow-up

In total 23 caregivers were interviewed. For seven selected child/caregiver pairs, the HSAs were unable to locate the families. We did not select additional families for interview, because theoretical saturation was reached (i.e. no new information was emerging from the interviews). Table 2 shows the characteristics of the children included in the sample. Of the children of school going age, the majority (83%) attended school. However, 93% of these children were in a lower than age appropriate grade.

In addition, we interviewed 15 key stakeholders within Thyolo and Blantyre districts involved in ear and hearing care and the screening camps. At least one key stakeholder from

Table 1. Reported reasons for not attending referral services (n = 145).

	Number reporting	%
Transport difficulties (practical/geographic challenges not including cost)		
No Transport available	35	24%
Distance too far	36	25%
Unable to carry child	2	1%
Not safe	1	1%
Total*	**59**	**41%**
Lack of information/understanding		
Not enough information about referral	73	50%
Location referral wasn't specified	22	15%
Unclear if service would cost money	4	3%
Total*	**87**	**60%**
Financial		
Not enough money for transport	41	28%
Not enough money for the service	6	4%
Not enough money for food needed	31	21%
Total*	**48**	**33%**
Told health worker would visit family but did not happen	58	40%
Forgot appointment	3	2%
Afraid	13	9%

*More than one response permitted explaining why category sub-totals are less than sum of individual responses

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Table 2. Characteristics of children in qualitative study (n = 23).

	N	%
Age group		
0–4 years	4	17
5–10 years	9	39
11 years+	10	43
Sex		
Male	10	43
Female	13	57
Diagnosis		
Normal hearing with ear disorders	5	22
Mild hearing loss	3	13
Moderate hearing loss	5	22
Severe hearing loss	3	13
Profound/probable profound hearing loss	4	17
Fail OAE (one or both ears)	3	13
Referral		
Surgery	9	39
Hearing aids	7	30
Unknown	7	30
School attendance		
Yes	15	83*
No	3	17*
N/A (<6 years)	5	-
Repeated grade^		
Yes	14	93
No	1	7

* % of those eligible for school (n = 18)

^ % of those attending school (n = 15)

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each health centre was interviewed as well as staff at the district hospital in Thyolo and QECH. A table of the key stakeholders is provided below (Table 3).

Seven key themes described non-uptake of referral by stakeholders and caregivers.

1. Location of hospital. The distance to QECH was perceived by most caregivers to be vast and a significant obstacle to taking up the referral. For example, one caregiver explained that their village was 100km from Blantyre and, because of the challenging terrain, the journey would be at least 2.5 hours. It also required walking or cycling up steep hills to reach public

Table 3. Key stakeholders interviewed.

Stakeholder role	Number
Health Surveillance Assistant supervisor	1
Health Surveillance Assistant	4
Medical Assistant	5
Ear Nose & Throat clinical officer	2
Audiologist	1
Malawi Council for the Handicapped (MACOHA) staff member	1
Chief clinical officer	1
Total	15

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transportation. Thus the journey was perceived to be challenging particularly for their children. Another caregiver described the challenges of making this journey particularly in the context of concerns that they would not be seen on the same day at the clinic:

It's a long journey, imagine from here to Goliati you will ride a bike and in the hills you will be walking on foot. At Goliati we board another [minibus] to Limbe and then another to Queens. Its long journey and you might not be assisted the same day when you go. [Caregiver 14]

2. Lack of transport. Several caregivers and stakeholders reported that transportation services, both public buses and ambulances, were not easily available to travel to Blantyre. Some explained that ambulance services at the health centre and district hospital level, in theory, can transport patients to the next level referral facility (i.e. from the health centre to district and district to QECH). However, this service was reported to be unreliable or only used for priority services such as maternity care. One caregiver explains their unsuccessful attempts to use the ambulance service:

We tried that time to get an ambulance but failed because every time we came to ask about the ambulance, we were told that it had already left. [Caregiver 14]

Further, stakeholders reported that the ambulance service to QECH was one-way only and once patients were in Blantyre they faced the additional challenge of finding a way back to their villages.

The other challenge is when they are discharged, because coming here is easy because they have an ambulance. When everything has been done here and they have been helped or they have been assisted, they still need an ambulance to take them back, so we don't have a ready ambulance to pick them up. [Stakeholder 9]

3. Indirect costs. Although most health care in Malawi is free at the point of delivery, over a third of caregivers raised concerns about indirect costs of seeking care associated with travel and time spent at QECH. Some reported that, because of the long distance, from their village to QECH it would cost around 1500 Kwacha, a price which is prohibitive for rural farming families.

A few caregivers mentioned that if they requested an ambulance, they were told to buy fuel for the journey, which they could not afford. In addition, there were also difficulties with paying for food required for both the journeys and time spent at the hospital.

Some things might be needed, [to travel to and wait at QECH] such as flour, firewood and relish and some other things like porridge flour, sugar and others. [Caregiver 1]

Some caregivers explained that their income depends on seasonal activities; at certain times of year they are not engaged in income generating activities making it difficult for them to meet the additional costs involved in care seeking. Many also felt concerned that seeking care would be a lengthy process resulting in several days where they could not be engaged in work on their farms. Further, some of the caregivers reported that there would be nobody to care for their other children if they travelled to QECH for several days. These interacting challenges were summarised by one caregiver:

From here [Chisoka] to Queens there is a need for proper transportation as you know this place is far. And when you arrive there you know these days [outside harvesting season], people don't harvest enough and it is possible that we might not be treated same day, maybe we may spend some days. So [money for] food would and transport would be a problem. [Caregiver 9]

4. Fear and uncertainty of the hospital. Several factors relating to the referral hospital were mentioned by caregivers and stakeholders as potential barriers to the referral uptake. Many caregivers and stakeholders expressed fear and unfamiliarity of QECH as a reason for not attending. Most caregivers had never previously been to QECH, which was perceived as a "big hospital". Several caregivers asserted a fear that they "would not know where to go" once they arrived at the hospital. Further, fear of long waiting time at the hospital was raised as a concern by some caregivers.

Some people think that Queens is a very big hospital, you can spend the whole day without being helped. [Caregiver 7]

It is just fear, some have never been to Queens so referring them to Queens. . . and you give them directions. They may have money but for them to go, maybe it is fear. [Stakeholder 6]

5. Procedural challenges in the camps. The interviews revealed a number of issues with communication at the screening camps that negatively influenced uptake of referral. As part of the camp protocol, caregivers were verbally advised to attend QECH and this was noted in their health passport. HSAs were instructed to then follow up with patients to check attendance to QECH and ensure they adhere to treatment or instructions. However, it was evident that many caregivers were confused about the referral process. Many caregivers reported that either they were not aware that they had been given a referral at all or that they were waiting to receive more information about when to attend QECH. Where possible, we examined health passports for the referral and found referral notes were lacking on several occasions. Caregivers explain the lack of information:

I was not told that we needed to go. We were just waiting for information on the day to go to Queens. [Caregiver 1]

Several caregivers expressed a motivation to take up the referral. However, lack of information about the referral in the camps together with other barriers prevented them from taking it up. One caregiver explains this:

I: *But if you were told to go to Queens would you have managed to go*?

P: *Yes, I would have gone. . . perhaps transport would have been difficult. I would first have looked for transport and once found then I would go* [Caregiver 5]

This caregiver also mentions difficulty with transport, highlighting the multitude of barriers faced in this context. Screening camps were reported to be very busy and the majority of caregivers described long waiting times to be seen by the clinicians. Most caregivers reported that the results of the tests were not explained by the doctor in the camps. As a result, caregivers expressed an uncertainty about what would happen at QECH. Some caregivers mentioned that they were just told that the problem was "big". In addition, caregivers were not given information on how to manage their children while waiting to go for referral. Stakeholders

also highlighted the lack of information given to caregivers as a substantial shortcoming of the camps, as explained by one stakeholder:

Of course giving them advice, advising them on what to do with the conditions, because they needed counselling for them to understand the problem, if the problem could be treated, or how can they be assisted with their problem. We didn't have that time, and we just said no, just go to Queens and you will be treated or come to Thyolo you will be treated in such a way. [Stakeholder 8]

6. Awareness and understanding of hearing loss. The majority of stakeholders felt that limited knowledge of ear and hearing health for most people living in the rural areas of Malawi was a substantial barrier to uptake of referrals, and some also indicated that children with disabilities may be neglected by the their families.

The most important issue which is like a barrier for them to access the services it is; themselves, because sometimes they don't even know, even understand what is going on, so at the end of the day they don't give them [the child] a second chance. They just declare that this is the way things are. Maybe you've heard somewhere that these kinds of children, or the disabled, people would just dump their house and just sit there. [Stakeholder 11]

Interviews with caregivers suggested that specific knowledge regarding the causes and available treatments for their child's ear and hearing loss was limited, despite attendance at the KIM screening camps. Some caregivers also described seeking alternative or home-based treatments for their child. For instance, distilling cooking oil or traditional medicines in to the ear canal. However, many acknowledged that no improvements were seen post-treatment. Despite this, many of the caregivers did display an awareness of their child's hearing loss. Most were able to recall when their child's hearing loss or ear condition started, even if it was delayed and several described the impact on their child. For example:

We can say that the problem started at birth but then for us to realise her difficulty in hearing was when she was 4 years old. That's when we realised that the child does not hear properly because when spoken at if she was not looking at you then she was acting in way like she hasn't heard you while if she is looking at you, she was able to hear. [Caregiver 5]

In contrast to the stakeholder perceptions, caregivers did appear to be motivated to seek care for their child. They attended KIM camps and the majority of caregivers (n = 18) interviewed had also previously sought treatment at health centres for their child's ear or hearing problem.

7. Lack of availability and visibility of ear and hearing services. As well as the specific challenges to uptake of referral to QECH, the interviews raised more broadly the lack of resources at health facilities as a serious problem limiting access to ear and hearing services. Several stakeholders highlighted the lack of visibility of the ear and hearing services at QECH and Thyolo district hospital as a barrier to patients receiving appropriate care. They felt that because other staff at the hospitals were not always aware of the ear and hearing services, patients do not always actually reach the ENT department. Instead patients may be sent from department to department without ever finding the appropriate provider.

What is working well is; at least there is somebody who deals with these issues like the ENT clinician, where it doesn't work well is; these other people who are not ENT clinicians, they don't

know what to do and they may send back some of the children when they are not supposed to be sent back. [Stakeholder 11]

Some stakeholders felt that these experiences would make people reluctant to seek care again. This was supported by caregivers who said that if they attended QECH, there was a risk of not receiving assistance at the hospital on the same day. This perceived risk discourages them from spending the money to get there:

We might go there and may not find the doctor. We only have money for one day [so] we may be stranded. [Caregiver 14]

Limited availability of the ENT personnel, in general, at health facilities was raised as an issue by both caregivers and stakeholders. For example, some caregivers reported previously attending the district hospital, which often involved a day of travel, but finding that the ENT clinical officer was not available and therefore no care was received. Stakeholders attributed this to lack of ENT personnel.

They think of transport issues, and how they will reach there if they will be admitted or how they will meet the ENT person since its only one person. Sometimes he is not there, he goes to the meetings, and there is no one to help them on the issues of hearing problems. [Stakeholder 1]

Several caregivers also asserted that health facilities were not able to provide treatment for ear problems because they did not have drugs and once they had experienced this, they did not feel it was worthwhile to seek ear and hearing services again. The lack of adequate medication, equipment and human resources to enable diagnosis and appropriate treatment for children with ear and hearing problems was raised by several stakeholders. For example, health centre staff described the challenges of managing ear conditions due to limited resources and expertise:

We don't look into the ear, we just see if the child is discharging, we look at how the pus looks like and give them a cotton to wipe with but we don't look inside because we don't have the equipment to use. [Stakeholder 4]

Discussion

Uptake of referrals for children with ear and hearing issues was extremely low (3%) in this study setting. In the survey, transport difficulties, lack of information regarding the referral and financial constraints were most commonly reported as reasons for non-uptake. The semi-structured interviews enabled us to explore these barriers in more detail and highlighted that, while caregivers appeared to be motivated to seek care for their child, several often-interacting factors prevented them from doing so. These included location of/distance to the hospital, indirect costs, lack of transportation, procedural challenges in camps, awareness and understanding of ear and hearing issues, fear and uncertainty about the referral hospital, and lack of availability/visibility of hearing health services.

Delayed or of lack of access to appropriate health and rehabilitation services can have substantial long-term consequences for children and their families, including poorer health and quality of life, increased risk of mortality, lower rates of school participation and a greater risk of poverty.[18] To avoid these consequences, efforts to tackle the identified barriers are

essential. The findings of this study suggest a multi-dimensional approach may be required to increase uptake of referral for ear and hearing services.

Several barriers raised in this study (distance to hospital, lack of transport, and indirect costs) concur with previous literature on challenges in accessing health care services in poor, rural settings.[18, 19] For example, in the 2015–2016 Malawi Demographic Health Survey, distance to health facilities was the most commonly reported problem by women in accessing care for serious health conditions (56%).[20] Despite free health services at the point of care in Malawi, many families in this study were unable to afford the in-direct costs of seeking care such as transportation and food. This aligns with a previous study in Malawi, which found that that economic hardship and distance to health facilities decreased acceptance of free cataract surgery for children highlighting the often prohibitive indirect costs of seeking care.[21]

Additional specific challenges were raised in this study such as procedural challenges in the screening camps resulting in a lack of information about the referral process. This concurs with findings from a similar study in Bangladesh following KIM screening camps for children with disabilities, where confusion and misunderstanding about the referral process contributed to non-uptake of referral.[13] The interaction between health workers and services users is well recognized to be an important factor in uptake of services, although this has not been well explored for children in low-income settings.[22, 23] In the current study caregivers were verbally informed about the referral, but the interviews revealed that they were still uncertain about the referral process. Screening camps were reported to be very busy, which may have limited the time specialists spent explaining the referral as well as making it more challenging for caregivers to absorb the information. The lack of information also likely contributed to caregiver's fear and uncertainty about attending QECH. Fear of surgery has been highlighted in previous studies in LMIC as influencing lack of uptake of referrals for example for clubfoot and cataract procedures.[24–26]

These barriers highlight a critical need for more effective communication with caregivers and children in future KIM studies and other community outreach activities that involve onward referral to health services. A core component of these activities should be dedicated personnel who appropriately communicate information on diagnoses and recommended action and create a safe space for caregivers and children to discuss their concerns and questions. In this setting, this could be delivered, for example, through the HSAs, other dedicated trained counselors or peer educators (e.g. people from same community who have previously used ear and hearing services). There is evidence that health education interventions (such as structured group education, or use of pictorial cards) delivered by health care workers or community health workers can have positive effects on uptake of health interventions for children including treatment commencement for malaria in Nigeria, and child vaccination uptake in Pakistan.[27] Further research is needed to assess the effect of educational or counseling interventions on uptake of ear and hearing referrals in the Malawian context.

The limited availability of human resources for ear and hearing care was highlighted in this study. This a significant challenge throughout the African region–with many countries having less than 1 ENT per million population.[28] In this context, delivery of services at the community, to tackle geographic and financial barriers, could be achieved through training of community health workers in basic ear care alongside outreach activities conducted by ENT specialists. The effect of delivering of services close to home has been evaluated in several African countries with promising results.[27] [29] The WHO Programme for Prevention of Deafness and Blindness advocates for a "task shifting" approach to managing ear and hearing conditions in the community and provides training materials in primary ear care.[30] In this Malawian setting, one strategy could be to train HSAs to identify and manage basic ear and hearing conditions in the community. Training health-centre staff in the management of

simple ear issues, such as the removal of impacted wax, also warrants investigation. However, evidence is required on the feasibility and effectiveness of the WHO training materials and the task shifting approach, in light of competing time demands for health workers. Key lessons about integrating basic ear care into primary health services may be drawn from the field of blindness, as primary eye care has been introduced in many countries in sub-Saharan Africa, including Malawi and Rwanda.[31]

Although "task shifting" to non-specialist staff can relieve the burden on secondary and tertiary services, certain interventions such as surgery cannot always be readily provided in a community setting. Thus the journey to QECH may not always be avoidable. This research highlighted that ambulance services are available from the health centre to QECH, however certain health conditions (e.g. maternal health) are prioritized. This is not surprising in a resource constrained setting such as Malawi. However, with the growing burden of non-communicable diseases in LMIC, ambulance services provision for non-emergency health conditions should be considered.[32] We also found that ambulance services are not always available for the return journey to Thyolo, resulting in families becoming stranded at QECH. Careful planning of return services to Thyolo from QECH warrants further attention.

Other interventions that deserve attention include the use of text messages to remind patients about appointments and provide health education which has been found to be effective for increasing uptake of health services.[27] Further, awareness of ear and hearing service availability at QECH must be raised amongst general medical staff at the hospital to avoid caregivers being turned away, and assist navigation to ENT department. This could be approached through sensitization meetings and display of information across all departments.

Strengths and limitations

This study had several strengths. We used a mixed-methods approach to quantify uptake and key barriers to referral uptake, and then explore these barriers in more depth. We interviewed caregivers and stakeholders in order to explore different perspectives. In doing this we were able to triangulate the barriers reported by the different groups of participants.

There were some limitations, which need to be taken in to account. Qualitative interviews were conducted at health centres for pragmatic reasons and caregivers may have responded differently compared to if they were in their home. For example, they may have felt reluctant to fully express concerns related to the camps that were held at the health centres. Efforts were made to limit this risk by ensuring the interview room was always private, health centre staff were not present and experienced researchers familiar with qualitative interview techniques conducted the interviewers. We purposively sampled the children according to degree of hearing impairment and/or ear disease as well as age. This was done to reflect the types of children who were referred to QECH. It is possible that children with more severe impairments experience different barriers that could not be explored in depth within this study due to limited numbers included in the study.

Conclusions

Very few children identified in the community as needing ear and hearing services attended their referral appointment. Families referred to QECH for ear and hearing services experienced a range of interacting barriers which contributed to non-uptake. Understanding these context specific barriers to non-uptake of ear and hearing services is important for planning services and designing interventions to increase uptake.

Supporting information

S1 File. Topic guides for caregivers.
(DOCX)

S2 File. Topic guides for stakeholders.
(DOCX)

S3 File. Data collection form for quantitative survey.
(DOCX)

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Feasibility and acceptability of training community health workers in ear and hearing care in Malawi: a cluster randomised controlled trial

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ABSTRACT

Objective To assess the feasibility and acceptability of training community health workers (CHWs) in ear and hearing care, and their ability to identify patients with ear and hearing disorders.

Design Cluster randomised controlled trial (RCT).

Setting Health centres in Thyolo district, Malawi.

Participants Ten health centres participated, 5 intervention (29 CHWs) and 5 control (28 CHWs).

Intervention Intervention CHWs received 3 days of training in primary ear and hearing care, while among control CHWs, training was delayed for 6 months. Both groups were given a pretest that assessed knowledge about ear and hearing care, only the intervention group was given the posttest on the third day of training. The intervention group was given 1 month to identify patients with ear and hearing disorders in their communities, and these people were screened for hearing disorders by ear, nose and throat clinical specialists.

Outcome measures Primary outcome measure was improvement in knowledge of ear and hearing care among CHWs after the training. Secondary outcome measures were number of patients with ear or hearing disorders identified by CHWs and number recorded at health centres during routine activities, and the perceived feasibility and acceptability of the intervention.

Results The average overall correct answers increased from 55% to 68% (95% CI 65 to 71) in the intervention group ($p<0.001$). A total of 1739 patients with potential ear and hearing disorders were identified by CHWs and 860 patients attended the screening camps, of whom 400 had hearing loss (73 patients determined through bilateral fail on otoacoustic emissions, 327 patients through audiometry). Where cause could be determined, the most common cause of ear and hearing disorders was chronic suppurative otitis media followed by impacted wax. The intervention was perceived as feasible and acceptable to implement.

Conclusions Training was effective in improving the knowledge of CHW in ear and hearing care in Malawi and allowing them to identify patients with ear and hearing disorders. This intervention could be scaled up to other CHWs in low-income and middle-income countries.

Trial registration number Pan African Clinical Trial Registry (201705002285194); Results.

Strengths and limitations of this study

- ► Structured framework was used to assess the feasibility and acceptability of the intervention to train community health workers (CHWs) in primary ear and hearing care.
- ► The training and screening camps were led by an ear, nose and throat surgeon, and drew on tools prepared by the WHO.
- ► Through focus group discussions with CHWs, we explored the reasons why people did not attend at the screening camp. In-depth interviews with people who did not attend screening camps could have provided additional information.
- ► Roles and responsibilities of CHWs is different in different countries. Therefore, generalisation of these findings to other settings must be done with caution.
- ► Although the cost of the training is reported, the full cost of the intervention, taking into account costs of referrals and final treatment, was not assessed.

INTRODUCTION

Hearing loss is the most common sensory disability and its prevalence is increasing globally with population ageing.[1] According to the WHO, an estimated 360 million people, or 5.3% of the world's population, are living with disabling hearing impairment.[2] Data for sub-Saharan Africa are sparse, but the prevalence of hearing impairment may be even higher in this region.[3] The leading causes of hearing impairment in sub-Saharan Africa are believed to be middle ear disease and impacted wax, and are therefore easily amenable to treatment and prevention.[4]

Ear and hearing problems can cause life-long difficulties. They may have profound effect on the ability of individuals to communicate with others, on their education and on their ability to obtain and keep employment.[5] Furthermore, hearing loss also impacts negatively on social relationships and may lead to stigmatisation.[6] Consequently, ear and hearing problems

are likely to produce substantial economic burdens on individuals, communities and countries.[7]

The high prevalence of ear diseases and hearing loss in sub-Saharan Africa is at least partly due to the severe shortage of health workers including audiologists and of resources for hearing aid provision, support and aural rehabilitation programmes.[8] Educating community health workers (CHWs) about ear disease and hearing loss can help to fill these gaps in settings with a scarcity of specialist health workers. CHWs are members of the communities where they work, selected by the communities, answerable to the communities for their activities and have shorter training than specialist health workers.[9]

The role of CHWs may be particularly important in controlling ear and hearing problems. Effective interventions against ear and hearing problems include ear wax removal, treatment of chronic suppurative otitis media and provision of hearing aids. These interventions can be implemented at the primary level by trained CHWs and have the potential for a major impact on the burden of ear disease and hearing loss when used on a large scale.[10 11] However, most low-income and middle-income countries do not have CHWs trained in primary ear and hearing care (PEHC).[12]

Malawi is a setting where CHWs can potentially make an important contribution to controlling ear and hearing problems. There are only 2 ear, nose and throat (ENT) surgeons for a population of >17 million, and only 25 ENT clinical officers.[13] Data are limited, but a study among children showed a high prevalence of hearing loss, with an estimated 1800 children per million population with hearing impairment from avoidable causes that could be treated through provision of basic primary-level ear and hearing care, in particular wax and middle ear disease.[14]

The aim of this study was to assess the feasibility and acceptability of training CHWs to provide primary-level ear and hearing care, including: identification of patients with ear and hearing disorders, referral of patients to services and treatment of simple ear conditions.

METHODS

Ethical approval

Ethical approval was provided by the College of Medicine Research Ethics Committee in Malawi. The study was evaluated and found exempt from review by the Norwegian Regional Committee for Medical and Health Research Ethics (2016/1472 REC South East, Section D).

Study design

An intervention study was undertaken to assess the feasibility and acceptability of training CHWs in PEHC. A group of CHW were selected, and half the participants were randomised to receive training in PEHC, while for the remainder training was delayed for 6 months.

Study outcomes

Primary outcome measure was improvement in knowledge of ear and hearing care among CHWs after the training. CHWs were given 60 multiple choice questions from the first six modules of the WHO Primary Ear and Hearing Care Trainer's Manual.[15] Secondary outcome measures were number of patients with ear or hearing disorders identified by CHWs and number recorded at health centres, and the perceived feasibility and acceptability of the intervention. The records at the health centres were examined at baseline (before training) and after training, the records were examined at 3 months and 6 months.

SETTING

Thyolo district was selected as the study area. Thyolo is a tea-growing district with a population of approximately 460 000, mainly Lomwe people. It is situated about 30 km away from Blantyre, where the only dedicated ENT Unit in Malawi is located. The district hospital is one of eight district hospitals which has an ENT clinical officer, who has been working in Thyolo for 2 years. Within this district there are 33 health centres. Each health centre is supported by about 10 CHWs and serves a catchment area of approximately 14 000 people.

SUBJECTS

CHWs were selected among Malawian Health Surveillance Assistants, which is the formal cadre of CHWs in Malawi. These form a cadre of 10 500 frontline health workers employed by the Ministry of Health and comprise 30% of the health workforce in Malawi.[16] Each health surveillance assistant in Malawi is assigned to a catchment area of approximately 1000 inhabitants and its associated health facility, covering a radius of 8 km except in district-defined hard-to-reach catchment areas. They track pregnancies, births and deaths using their village health registers, conduct health talks and vaccinations. Each receives 12 weeks of training and has important roles in providing care, promoting community participation in healthcare activities and in promoting disease surveillance services at the community level. Prior to this study, they had not received any training in PEHC.

A list of all the 33 health centres together with all the names of the CHWs in Thyolo district was compiled with the help of the District Health Environmental Office in Thyolo district. Using a random number generator, we selected 10 health centres for inclusion in the trial (figure 1); we then randomly allocated 5 health centres to the intervention group and 5 health centres to the control group. Using the random number generator, we selected 6 CHWs (out of approximately 10 CHWs) per health centre. Consequently, a total of 30 intervention CHWs and 30 control CHWs were selected.

Figure 1: Flow of participants through the study

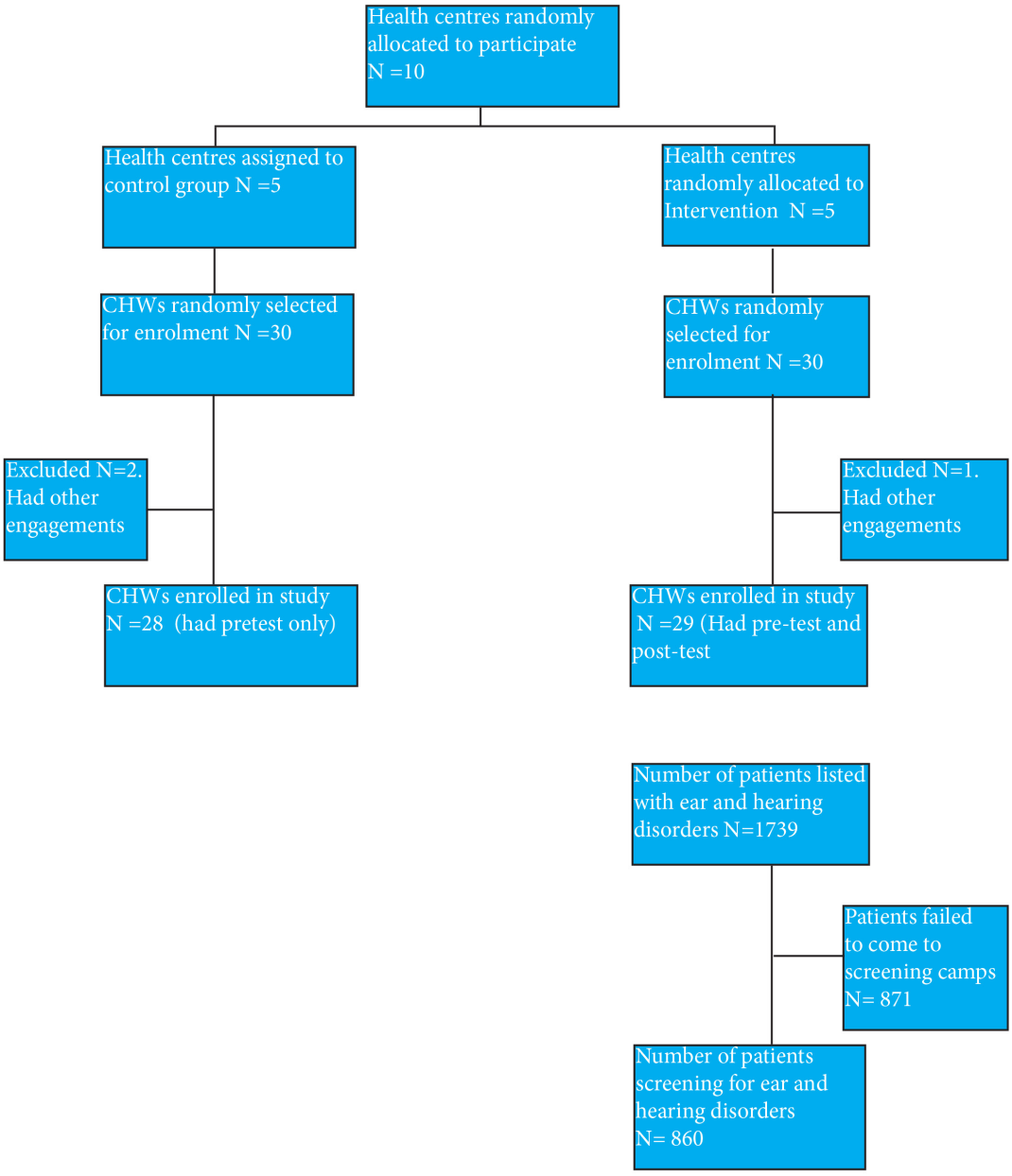

Figure 1 Flow of participants through the study.

Consent and pretest

The selected CHWs were called up for a briefing at a central location, with intervention and control groups meeting separately. They were briefed on the study and written consent was taken from them to be part of the study after they had received details of what participation involved. Data collected from the CHWs included age, sex and years of formal education. They were administered a

pretest questionnaire containing the questions from the first six modules of the intermediate-level WHO Primary Ear and Hearing Care Trainer's Manual (10 questions per module).[15] The participants in the control group were assured of the training after 6 months.

Training for intervention group

The training lasted 3 days and was undertaken by an ENT surgeon and two ENT clinical officers. The two ENT clinical officers each had 18 months of training in ENT and had participated in a PEHC course. A training curriculum and manual was developed in English by local experts (one audiologist, three audiological officers, three ENT clinical officers and one ENT surgeon). The training manual was based on both the Basic and Intermediate Manual of WHO Primary Ear and Hearing Care Training Resources.[15]

The first part of the training focused on knowledge about ear and hearing disorders. Training emphasised the structure and function of the ear, causes of hearing impairment and their management and levels of hearing impairment. Next, the training focused on skills training, including: (1) history taking in patient with ear and hearing disorders, (2) ear examination, (3) steps in doing otoscopy, (4) steps in doing voice tests and (5) assessment of hearing in children. Training methods included lectures, posters of ear and hearing disorders, flip charts, demonstrations, practical of voice tests, discussion and group work. Training was done both in English and Chichewa (national language of Malawi). At the end of the training, each CHW was given a training manual that contained the key points of training and which could be referred to when needed. They were also given Arclight otoscopes (WJW Ltd, Liverpool, UK), to allow ear examination.

The participants were given a posttest questionnaire on the third day of training, using the same questionnaire as in pretest. The participants were also asked how their opinions about the length of training and whether or not they felt comfortable in identifying people with ear and hearing disorders.

MOBILISATION OF PATIENTS BY COMMUNITY HEALTH WORKERS

After training, each CHW in the intervention group was given 1 month to identify, list and refer patients with suspected ear and hearing disorders from their own village to their corresponding health centre. First, the CHW met with the village headman, village development committee members and village health committee members to explain in detail about the programme. Next, the CHW met with the community members to explain about the programme and to schedule dates for screening of the community members. CHWs were asked to use multiple methods in their identification (door to door, school screenings, health education and church/mosque announcements). CHWs took history, did otoscopy and voice tests as a way of identifying community members with ear and hearing disorders. CHWs created a list of patients they suspected of having ear and hearing disorders in their community.

Identified patients with suspected ear disorder or hearing loss were asked to come to the scheduled screening camps, which took place at the five health centres of Bvumbwe, Chimaliro, Chisoka, Changata and Gombe.

SCREENING CAMPS

The listed patients were asked to come to the health centre in their catchment area together with their CHW. A team of six people (1 ENT surgeon, 1 ENT clinical officer, 2 Queen Elizabeth Central Hospital (QECH) audiological officers and 2 research assistants) from the ENT Department at QECH in Blantyre travelled to all the five health centres in Thyolo to conduct the screening camps.

All patients underwent otoscopy, pure tone audiometry, transient evoked otoacoustic emissions (TEOAEs) and tympanometry performed by one of two audiological officers.

- Otoscopy was performed on all patients using the Heine Mini 2000 (HEINE Optotechnik, Herrsching, Germany).
- Audiometry was performed in all patients aged >4 years who were able to cooperate in a quiet room using the KUDUwave 5000 audiometer (eMoyoDotnet (Pty) Ltd, Randburg, South Africa). Thresholds were obtained at frequencies of. 5, 1, 2 and 4 kHz according to WHO recommendations. Pure tone average (PTA) was calculated based on these four frequencies. Hearing impairment was defined as PTA >25 dB in the better ear.
- TEOAEs were measured in subjects aged <4 years and those who were not able to cooperate for audiometry. TEOAEs were tested using the Sentiero handheld device (PATH Medical Solutions, Guymark, UK) and assessed in each ear at frequencies between 1000 and 4000 kHz. Results were graded as 'pass' (indicating normal hearing) or 'fail' (indicating impaired hearing).
- Tympanometry was done in all patients using Tympanometer S/N P 99 0556, Grason-Stadler, USA.

Data was recorded on the WHO/Prevention of Blindness and Deafness (PBD) Ear and Hearing Disorders Survey Form.

Patients with ear wax had this removed on site by ENT clinicians. Those with discharging ears had ear toilet and were given ciprofloxacin ear drops. Those with bigger wet perforations had candiderm (beclomethasone dipropionate, clotrimazole and gentamicin sulfate) inserted in the middle ear. All patients with chronic otitis media (active or inactive) were referred to QECH.

Recorded data of patients with ear and hearing disorders at the health centres were collected at baseline (1 month

data before the study), at 3 months and 6 months after intervention.

Qualitative data collection

We used the consolidated criteria for reporting qualitative studies' checklist to report our methods and results.[17] Focus group discussions (FGDs) were undertaken by a female research assistant in three of the five health centres (Chimaliro, Bvumbwe and Chisoka). In each health centre, we chose a quiet room where the discussion were conducted. The CHWs involved in the FGDs were purposively selected. There were a total of 17 CHWs (9 women and 8 men) who participated in the three FGDs, each including 5–6 participants. The female research assistant was not involved in quantitative data collection or analysis to reduce the possibility of bias. We conducted the FGDs using semistructured interview guide. The guided discussions asked CHWs about their impressions on training, and challenges faced when identifying people with ear and hearing disorders. Each FGDs took approximately 45 min. The discussions were in Chichewa. FGDs were audio recorded.

DATA ANALYSIS

Data were analysed using Stata V.13. Tests for normality were done using SPSS V.21. All the scores were tested for normal distribution using the Shapiro-Wilk test. We conducted an independent t-test to determine the difference in the mean knowledge scores between the intervention and control groups and paired t-test in the intervention group before and after the training. For all procedures, alpha was set at 0.05. A paired t-test and X^2 statistic were used to compare number of patients seen at baseline in the health centres to those seen at 3 months and 6 months in both intervention and control groups.

Transcripts from each FGDs were generated and translated into English, and those transcripts were examined for recurring themes and patterns through open coding and qualitative content analysis. NVivo 11 was used for coding the data.

RESULTS

A total of 57 CHWs were included, 28 in the control arm and 29 in the intervention arm. Intervention and control CHWs were similar in terms of proportion of men (59% vs 54%), mean age (37 years, range 28–51 vs 38 years, range 29–55), and proportion who had ≥10 years of formal education (56% vs 54%).

Test scores are shown in table 1. In the pre-test questionnaire, the intervention group scored slightly lower (55%, 95% CI 52% to 58%) compared with the control group (58%, 95% CI 56% to 60%; p<0.05). After training, the mean score for the posttest in the intervention group increased to 68% (95% CI 65% to 71%), showing a statistically significant improvement from baseline (p<0.001). There was also improvements in knowledge for the individual modules, except for the module on the inner ear, and assessment and counselling.

The majority of the CHWs (67%) said that the length of the training was right, whereas 33% thought that it was too short. In dealing with patients with ear and hearing disorders, 52% reported that they felt comfortable and 48% felt very comfortable after the training. None of the CHWs reported feeling uncomfortable. Overall, the average cost of training one CHW was $189, including trainer's costs ($33), trainee's stipend ($64), training supplies ($61) and travel costs ($31).

After training, the CHWs identified and referred a total of 1739 patients with suspected ear disorder or hearing loss. Of these, only 860 patients (49%) attended the screening camp. Of those attending, 67.2% were women and the mean age was 23 years (range 2 months–90 years).

TEOAEs were obtained for subjects <4 years and those who were not able to cooperate for audiometry. Out of 860 patients attending the screening camp, 249

Table 1 Proportion of CHWs who answered correctly in the six different modules

	Proportion of questions answered correctly			
Module	Control group pretest (n=28)	Intervention group pretest (n=29)	Intervention group posttest (n=29)	Significance (paired t-test pretest vs posttest)
Structure and function of the ear	58%	61%	82%	<0.0001
Hearing impairment and deafness: causes and prevention	52%	53%	78%	<0.0001
The outer ear: examine, treat and refer	59%	53%	74%	<0.0001
The ear canal: examine, diagnose and clean	54%	47%	57%	0.03
The middle ear: examine, diagnose and treat	55%	48%	52%	0.28
Assessing hearing and counselling	72%	69%	66%	0.17
All modules	58%	55%	68%	<0.0001

CHW, community health worker.

Table 2 Categories of hearing impairment reported as pure-tone average of 0.5, 1, 2 and 4 kHz in the better hearing ear among participants attending the screening camp

	Children (<18 years)		Adults (>18 years)	
Hearing impairment category (dB)	Number of subjects	%	Number of subjects	%
Normal (≤25)	149	60.3	116	33.6
Slight (26–40)	73	29.6	119	34.5
Moderate (41–60)	19	7.7	74	21.5
Severe (61–80)	4	1.6	23	6.7
Profound (>80)	2	0.8	13	3.8
Total	247	100	345	100

patients had TEOAEs, 592 audiometry and for 19 it was not possible to undertake either audiometry or TEOAE. Out of the 592 patients who underwent audiometry, 327 (55%) had hearing impairment defined as PTA >25 dB in the better hearing ear (table 2). Of the 265 subjects without hearing impairment according to this definition, 115 had unilateral hearing loss, whereas 152 subjects had normal hearing (PTA ≤25 dB) in both ears. Of those who underwent TEOAE, 73 patients (30%) had bilateral fail. Consequently, of the 841 who were screened, 400 (48%) were found to have a hearing impairment. The rest had either unilateral hearing loss (n=115, 14%), normal hearing but with ear disorders (n=148, 18%) or normal hearing without an ear disorder (n=184, 22%).

The causes of ear and hearing disorders were determined by an ENT surgeon and ENT clinical officer (table 3). It was not possible to determine the cause for one in three ears with an ear and hearing disorder for adults. For those conditions that we were able to determine the cause, the majority were caused by chronic suppurative otitis media and impacted wax. Impacted wax was removed on site and no further action was required.

Table 4 Further actions needed for patients with ear and hearing disorders who attended the screening camp

	Children (<18 years)		Adults (>18 years)	
Action needed	Number	%	Number	%
Medication	110	20.8	90	22.3
Hearing aid evaluation	86	16.2	146	36.2
Language and speech rehabilitation	3	0.6	0	0.0
Special needs education	14	2.6	1	0.2
Vocational training	4	0.8	0	0.0
Surgery referral	49	9.2	42	10.4
	264	49.8	124	30.8
*Total	530	100	403	100

*Out of total actions (not patients).

Table 4 presents further action required for patients with ear and hearing disorders. The majority of the patients were given medication on the spot, but were asked to be followed up by the ENT clinical officer at the district hospital. Those requiring hearing aid evaluation and surgery referral (mainly for tympanomastoid surgery) were referred to a tertiary hospital of QECH.

Table 5 shows the patients with ear and hearing disorders recorded at the 10 health centres, comparing intervention and control groups at baseline, third and sixth

Table 3 Causes of ear and hearing disorders among participants who attended the screening camp

	<18 years		>18 years	
Ear conditions	Total number of ears	%	Total number of ears	%
Wax	89	9.2	122	16.2
Foreign body	8	0.8	1	0.1
Otitis externa	3	0.3	1	0.1
Acute otitis media	23	2.4	11	1.5
Chronic suppurative otitis media	165	17.0	110	14.6
Otitis media with effusion	36	3.7	45	6.0
Dry perforation	5	0.5	14	1.9
Infectious diseases	22	2.3	8	1.1
Genetic diseases	8	0.8	3	0.4
Non-infectious diseases	4	0.4	22	2.9
Undetermined causes	124	12.8	250	33.2
Not tested	36	3.7	2	0.3
Normal ear and hearing	445	46.0	163	21.7
Total	968	100.0	752	100.0

Table 5 Patients with ear and hearing disorders recorded at the 10 health centres

	Baseline (1 month preintervention)	Third month after intervention	Sixth month after intervention
Intervention group			
Chimaliro	28	8	26
Chisoka	7	13	8
Changata	14	7	5
Gombe	11	6	2
Bvumbwe	—	—	—
Total (%)	60 (88)	34 (85)	41 (77)
Mean	15	1.5	10.3
p Value		0.31	0.16
Control group			
Satemwa	2	3	2
Nansonia	1	0	0
Zoa	5	1	5
Ntambanyama	0	2	5
Nsabwe	—	—	—
Total (%)	8 (12)	6 (15)	12 (23)
Mean	2	1.5	3
p Value		0.73	0.51

Data were not collected for the two health centres.

months. Although the numbers recorded are small, there were more patients seen at baseline, third month and sixth month in the intervention group as compared with the control group. There was no difference in referral rates at baseline and 3 months or 6 months (paired t-test and X^2: p>0.05).

FINDINGS FROM FGDS

Three main themes emerged from the FGDs: training of CHWs and other health workers, identification of patients and problems faced in the mobilisation of patients.

Training of CHWs and other health workers

Overall, the training was felt to be successful, however there was an expressed need to expand the training for CHWs to include medical assistants and other health workers in health facilities in their areas. As one trainee put it:

> It is only a few of us who have received this training, therefore I feel that those other remaining HSA's and other health workers should also get the training, so that the other remaining communities should be assisted

There were issues concerning the complexity of the diagrams used in the training manual, as the participants found these difficult to understand.

> Do you see that, these words written about the anatomy of the ear, but when I now come to the real ear and ask what's this? For me to find the part, according to the way the picture looks like, I cannot manage to identify that, because the picture and the real ear are two different things, eeh but, the manual has been helpful.

There was also a request for more practice, rather than theory, particularly with respect to diagnosis of conditions.

> 'I feel that if only we had trainings where we could also have practicals, it would have been helpful'

Identification of participants

A number of problems were encountered by the CHWs in the identification of participants with ear disorders or hearing loss and these included failure of the otoscopes, which were solar powered and so reliant on sunshine for charging:

> "Like at the beginning, when using the otoscope, maybe you may have prepared to go out for work, you happen to find that it is cloudy, there are showers, whereby you couldn't have charged the device"

On the other hand, other participants were happy with the equipment.

> "This work shows that this doesn't require expensive instruments or instruments that are hard to purchase, that's what I observed, those are my views"

Others reported on particular methods that helped in the identification of patients, such as the involvement of the traditional chief of the village to legitimise the work.

Problems faced with mobilisation of patients for screening camps

A number of problems were encountered by the CHWs, and these included poor weather conditions, belief in different deities so that people would rather go and receive prayers than meet health personnel, lack of support from the village heads and competing ongoing events that were a distraction (eg, the free distribution of fertiliser coupons).

> 'Whenever we could go to the field just as my friend has said it, it used to be very hard because whenever we could go to the field and happen to get to the venue, it would be found that people could have gone for registration (for fertilizer coupons) just the way it happens during this time to register for coupons in the village, and were supposed to stay in the village and wait for them'

DISCUSSION

The primary ear and hearing training increased the knowledge and confidence of CHWs in ear and hearing care, an area of healthcare in which they had not previously been trained. The trained CHW demonstrated their ability to identify patients with ear and hearing disorders, both through outreach and as part of routine practice. They identified 1739 people with potential ear or hearing disorders of whom 860 attended a screening, and almost half (400) had significant hearing loss and a further 115 had unilateral hearing loss. There was little change, however, in the patients with ear and hearing disorders recorded at the health centres after the intervention. The trainees perceived that the intervention was feasible and acceptable. Although the number of CHWs who were trained per health centre was small, these positive findings are encouraging as it can be scaled up. Furthermore, the training was relatively cheap ($189 per CHW trained) and well received by the participants.

Successful integration of ear and hearing care into primary healthcare requires resources, to raise awareness, train CHWs and provide equipment and medications at the health centre. Important lessons can also be learnt from the study and the existing literature in considering whether and how to scale up the primary ear and hearing training.

Were CHW the appropriate target for training?

This study showed that trained CHWs proved to be a valuable resource in mobilising patients with ear and hearing disorders. This is in contrast to what Kalua *et al* showed that other community key informants (eg, village volunteers) were much better at identifying blind children than CHWs.[18] In that study, CHWs reported lack of time as a major constraint in identifying blind children, and it is well known that CHWs are often overloaded with many competing tasks. Although, we did not compare with other cadres of community like village volunteers, we found that the number of patients with potential hearing loss identified by CHWs were still large.

Was the content of the training appropriate?

There was an improvement in the knowledge of ear and hearing disorders among CHWs overall showing that the training was appropriate. However, there was no improvement in knowledge about the middle ear or assessing hearing and counselling. Further improvement of these modules is needed to ensure that the material is at the right level for CHWs. About 22% of the patients examined at the screening camps did not have an ear and hearing disorder. We consider this to be a relatively low false-positive rate showing that the CHWs were reasonably competent at identifying people with hearing loss. There is still room for improvement, however, and a further emphasis on future training should focus on normal ear anatomy and more practical sessions on normal ears. The CHWs were trained in otoscopy, but their practical skills were not assessed. The primary aim was to enable them to identify common pathologies like wax and discharge. However, in a possible higher level course in the future, it would be a good idea to test both manual and diagnostic skills.

Was the length of training sufficient?

Most of the CHWs were happy with the length of the training while few would like it to have been extended. The cost of training of our training was an average of $189 per health worker. Kyabayinze *et al* in Uganda showed that the average cost per health worker of the 1-day training was $101 (range $92–112) with the main cost drivers being trainee travel and per diems.[19] One of the ways of reducing the cost of training is to reduce the length of the training, which would require further testing. In mental health and blindness, they have successfully conducted 1-day training sessions.[20] However, reducing the length of training was against the expressed wishes of the CHWs.

Were the CHW able to identify people with ear and hearing disorders?

CHWs were able to identify people with ear and hearing disorders both within the community and in the clinics. However, the accuracy of diagnosis made by CHWs compared with that of ENT specialist was not measured, which is a limitation.

Although the CHWs were able to identify about 1739 patients, only 860 patients appeared for screening. The major reason given for non-attendance was that most clients went to receive free fertiliser coupons. Other barriers in ear and hearing care need to be explored in more detail and could include difficulties in accessing care, limited engagement of communities and inadequate support from health systems.[21] Müller *et al* reported

that of the 84 trained village health workers in primary eye care, only 13 (15%) brought patients to the health centres and the main reason suggested for the difference was lack of motivation among village health workers.[20]

Resources may be required to pay for transport reimbursements for patients to travel from their villages to the health centre as there is clearly a large unmet need for services among people in the communities.

Were the CHWs appropriately equipped?

Equipping CHWs with a tool like an Arclight otoscopes may have improved the diagnostic accuracy especially for impacted wax and chronic suppurative otitis media.

There is need to do more research on the provision of diagnostic and therapeutic PEHC services by CHWs and general health workers at frontline health facilities. With the advent of a lot of software applications for audiometry,[22] there is need to look at the feasibility of equipping the CHWs with the tool. Furthermore, research is needed as to which therapeutic approaches are appropriate at the primary level. For instance, primary healthcare workers are often taught to do dry mopping for wet perforations. Among our patients with wet perforations, a number of them had dead house flies in the ears which may have been difficult to remove with dry mopping alone. Evidence is also needed as to whether or not ear syringing may be useful for these sort of conditions.

In summary, in line with the Malawi Government guidelines on task shifting to CHWs,[23] the following tasks in ear and hearing care are recommended for CHWs. There are (1) information, education and communication on ear and hearing disorders; (2) identification of cases for referral, (3) follow-up of cases for treatment adherence; (4) support and counselling of families on ear and hearing disorders. All these tasks are based on the assumption that the CHWs have been trained in ear and hearing care and that equipment like otoscopes are made available to them.

There are important strengths to the study. It used a structured framework to assess the feasibility and acceptability of the intervention to train CHW in PEHC. The training and screening camps were led by an ENT surgeon, and drew on tools prepared by the WHO. There are also limitations to consider. It was not possible to explore in detail why people did not attend at the screening camp. We only conducted FGDs with CHWs. In-depth interviews with people who did not attend the screening camps could have provided more information. Furthermore, the impact of training CHW in PEHC on their routine clinical activities was not fully evaluated, nor the impact on the number of diagnoses and referrals made of ear and hearing disorders at the primary care level on reducing the burden at the secondary and tertiary levels. We are aware that roles and responsibilities of CHWs is different in different countries. Therefore generalisation of these findings to other settings must be done with caution.

Conclusions

The training was effective in improving the knowledge of CHW in ear and hearing care in Malawi and allowing them to identify people in the community requiring ENT services. Based on the success of this study, training of CHWs and their identification of patients with ear and hearing disorders could be scaled up in Malawi and tested in other low-income and middle-income countries.

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