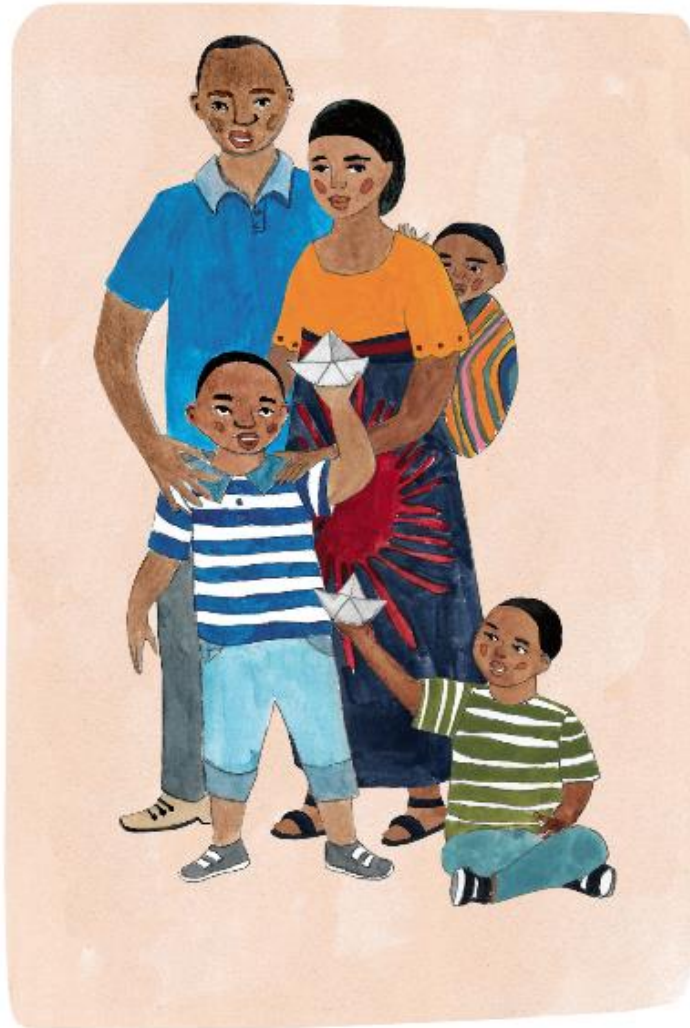


Executive summary

An intervention to improve uptake of referrals for children with ear disease or hearing loss in Thyolo District, Malawi: development and feasibility testing



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STUDY BACKGROUND

The World Health Organization (WHO) estimates that 34 million children have disabling hearing loss worldwide.[1] The majority of these children live in low and middle-income countries. In Sub-Saharan Africa, 1.9% of children are estimated to have hearing loss. In Malawi, the estimated prevalence in children is approximately 4.6 per 1000 population.[2] The impact of hearing loss can be profound, extending beyond the individual to the family and community. Childhood hearing loss can result in delayed speech and language and cognitive development. Evidence suggests that children with untreated HL have lower levels of literacy and poorer educational attainment compared to children with normal hearing.[3-6]

Early detection and provision of interventions such as hearing aids are important to limit the impact of hearing loss and maximise functioning. However, in many low and middle-income countries, there is a substantial shortage of human resources and equipment to provide these services, particularly in rural settings. In Malawi, there are two trained Ear Nose and Throat (ENT) surgeons and three audiologists for a population of >17 million people.[7, 8]

To address the lack of ear and hearing services, outreach camps are regularly held in the districts surrounding Blantyre by ENT specialists from Queen Elizabeth Central Hospital (QECH). Although many conditions can be treated in outreach, some need further assessments or treatment at the central hospital. However, evidence suggests that very few children referred to specialist services take up this referral; a recent study found that <5% of children attended with key barriers including lack of information about the referral, fear about the hospital, and transportation problems. Delayed or of lack of access these 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] There is therefore an urgent need to address this low uptake of referral. However, information is lacking on how best to improve uptake of referrals for ear and hearing services.

AIM

This study aimed to develop and test an intervention to improve uptake of referral for children with ear and hearing conditions in Thyolo district, Malawi.

METHODS

This study used the Behaviour Centred Design (BCD) approach to develop an intervention. This involves five steps – ABCDE: Assess, Build, Create, Design and Evaluate. The steps we took included those outlined in Figure 1 below.

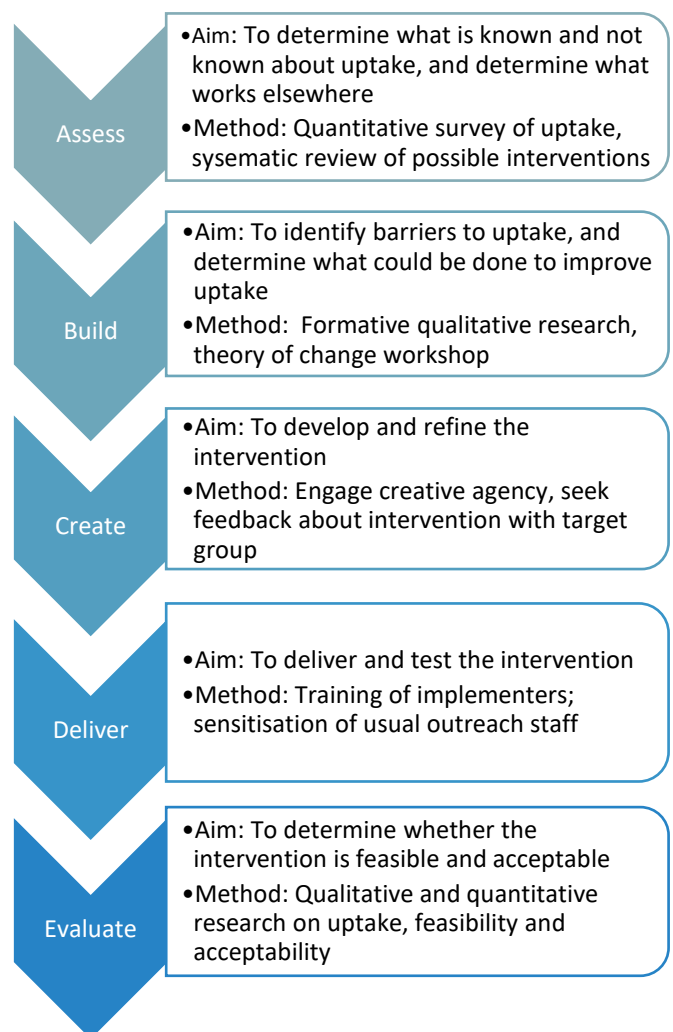


Figure 1: Steps taken to develop intervention

KEY FINDINGS

Developing the intervention (assess, build and create: ABC):

The key barriers to referral uptake identified in previous research using qualitative interviews were: lack of information about the referral, fear about the hospital, and transportation problems.

Through a participatory theory of change workshop the following intervention approach was proposed: educational interventions to address the lack of understanding about the referral process and fear of the hospital.

Providing transport to the hospital was also discussed but considered to be unsustainable by stakeholders.

Based on the theory of change, and the available literature and stakeholder consultation, the final agreed intervention is shown in the Box below:

Final intervention

Information booklet: containing an illustrated story about a child attending QECH with their caregiver, a map providing photographs of key landmarks and directions to the ENT department, and a plan of action for attending the referral tailored to each caregiver

Counselling: by a trained expert mother and community health worker using the booklet

Text message reminder: to be sent 2 days before scheduled appointment, and 2 weeks after initial outreach if the appointment was not attended.

An iterative process was used to develop the information booklet, whereby a creative agency was engaged to create an initial draft, which was adapted based on stakeholder and caregiver feedback.

Feasibility and acceptability testing (evaluate: E):

Of 30 children who attended outreach camps and were referred to QECH and received the intervention, 16 attended (53%).

Caregivers provided positive feedback about the intervention and reported that the intervention assisted with decision-making. Caregivers found the illustrated storyline included in the booklet to be motivating. They also valued the counselling, particularly with the expert mother who had been through a similar process before.

Counselling with an information booklet was acceptable, and helped caregivers understand and discuss logistical requirements for uptake and how to prepare. In total 63% of caregivers received text messages. Text messages were perceived to be helpful for those who received them. Although the majority of caregivers had phones (93%), network and power issues may have prevented some caregivers from receiving the text message, limiting feasibility of this component

The intervention helped overcome some of the key barriers identified in the formative research (lack of information and fear of the hospital). However, for those who did not attend, transportation was still the major barrier. Families who did not attend experienced competing financial priorities at the time of referral which meant the cost of transportation was prohibitive.

The estimated cost to deliver the intervention in camps was £3.70 per person

RECOMMENDATIONS

Addressing poor uptake of referral is crucial to maximise the benefit of outreach camps. Compared to previous research, which showed that 5% attended, more than half of caregivers and their children attended after receiving the intervention which suggests that it may help to improve uptake.

Based on the findings of this research, the following recommendations are made:

In future outreach camps, include patient education using the illustrated booklet, and counselling by an HSA and expert mother to assist in overcoming uncertainty about the referral and fear of the hospital

Consider approaches to facilitate transport to hospital or expanding delivery of ear and hearing services in rural areas to address the transport barrier

Given logistical challenges with text messages (e.g. power, network, and phone ownership), **alternative approaches such as text messages to HSAs should be explored in future studies.**

Conduct a larger-scale controlled trial of the intervention to understand the effectiveness of the intervention.

Routinely assess patient follow-up following outreach camps to **monitor referral uptake** and follow up with patients who do not attend through increased communication between primary, secondary, and tertiary ear and hearing services.

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