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- Funder:

CBM
Together we can do more
Background

- Prevalence of hearing impairment in children in Sub-Saharan Africa: 1.9% (WHO estimates)
Background

Specialist services

KCH
African Bible College

Queen Elizabeth Central Hospital
Primary ear care pilot project in Thyolo district

- Community health workers identified and trained
- People with ear and hearing issues in Thyolo identified and listed by community health workers
- Screening camps held in health centres in Thyolo
- Referral to Queen Elizabeth Central Hospital ENT Department

Source: Sound Seekers

Source: KIT Health

Source: Rice University News & Media

Mulwafu et al, 2017
Background

Primary ear care pilot project in Thyolo district

Community health workers identified and trained

People with ear and hearing issues in Thyolo identified and listed by community health workers

Screening camps held in health centres in Thyolo

170 children referred for medical rehabilitation (hearing aids, surgery)

Referral to Queen Elizabeth Central Hospital ENT Department

5% took up referral

Mulwafu et al, 2017
Why is the uptake so low?

How can uptake be improved?
Study aim

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

– MRC framework for development of complex interventions
– Behaviour Centered Design (LSHTM)
Research overview

Step 1: Formative research
Review of existing literature

Step 2: Develop intervention
Theory of Change workshop

Step 3: Create intervention

Step 4: Pilot testing
Step 1: Understanding the barriers to uptake

Research Question: What are the barriers to referral uptake for children with ear and hearing difficulties in Thyolo district, Malawi?

Methods:
- In-depth interviews with 23 caregivers of children referred to ear and hearing services
- 15 stakeholders
Step 1: Barriers to uptake - Key findings

Location of hospital

“Imagine from here you will ride a bike and in the hills you will be walking. At Golati we board another [minibus] to Limbe and then another to Queens. It’s a long journey and you might not be assisted the same day”
Step 1: Barriers to uptake - Key findings

Transport: cost and unavailability
Step 1: Barriers to uptake - Key findings

Fear and uncertainty about hospital

“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.”
Insufficient information about referral process

“I was not told that we needed to go. We were waiting information about the day to go”
Step 1: Barriers to uptake - Key findings

Multiple interacting barriers
Step 1: What works elsewhere?

• Systematic review of strategies to improve access to health services for children in LMIC

Encouraging evidence for:
• Text message reminders
• Delivery of services close to home

.....more research needed
Step 2: Developing an intervention

• Focus Group Discussion with caregivers
  – Feedback of findings
  – Discuss strategies to address the key barriers.

• Participatory theory of change workshop in Blantyre

• Interventions to address barriers discussed and prioritised
The intervention

Multi-component intervention package:

– Pictorial information booklet about referral and process of attending ear and hearing services at QEH

– Counsellors trained to deliver information booklet in camp settings, including one “expert” mother (peer support) and a community health worker

– Text message reminders for caregivers who had been referred to QEH
Step 3 – Creating the intervention

RE-UP: London based creative agency
The intervention - Booklet
The intervention - Booklet

Part 1 - Story

1. The parents noticed that their son, Chipwemwe, had a problem with his ears.

2. A community health worker came to their home and told them to go to the health centre.

3. They took their son to the health centre, where they were given a referral for Queen's Hospital.

4. That evening, the parents talked to each other about the trip to Blantyre.

5. The next day, they got on a bus to Limbe, and then went to Queen's Hospital.

6. They met a friendly nurse who said everything would be ok. She took them to the ear doctor who helped Chipwemwe's ears.

7. After that, Chipwemwe could hear better. The family were happy and Chipwemwe did well at school.
HOW TO GET THERE

1. Bus stop for Queenax - get off when you see the blue flyover. Then walk and ask for Queenax.
2. QEKH main gate - from here, walk straight along main road until you get to a junction.
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 60 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.

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.
The intervention - Booklet

Part 3 – Action Planning

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:

QBCH Audiology clinic: 0990471446 or 0861279004.
QBCH ENT clinic: 0996683716.
Mwanaleha Phone: 0992667655.
The Intervention – Text Message

• FGD and stakeholder consultation

• First message: two days before the scheduled appointment at 12:30pm

• Second message: if did not attend

Good afternoon, your child [name] was recently referred to Queen Elizabeth central hospital in Blantyre because of a problem with their ears or hearing. We want to remind you to attend your appointment on [day, date]. If you have any questions please call: [phone number]
Step 4: Pilot test of intervention in outreach camps in Thyolo district
Step 4: Pilot test - METHODS

Training community health worker and ‘expert’ mother to deliver counselling (1.5 days)

Pilot test in 3 outreach camps with children referred to QEH
   – 30 children from 28 families

Follow up after 4 weeks
   – In-depth interviews: carers of 11 children who did & 12 who did not attend QEH
   – In-depth interviews: 6 implementers
Out of 30 children referred, 16 (53%) attended QEH
Counselling: acceptability

• Enabled a two way conversation
  – Greater understanding

• Dispelling fear/misconceptions about hospital

“...wonderful because we were being encouraged. The doctor can explain to you, yes, but you might have questions, and we were able to have a discussion with them.”
Step 4: Pilot Test – KEY FINDINGS

Booklet: acceptability

• Motivation from storyline
  – Identification with family
  – Prompted questions, hope
  – Unrealistic expectations?

• Facilitating planning

• Sharing booklet with networks
  – Mobilising financial support

“I was refusing [uptake] since I didn’t have money for transport...And that’s when another woman [neighbour] said “can you bring your booklet and let me look at it”. And they read [it] and they told me that no matter what, I should do what I can to find money for transport and go with the child.”
Step 4: Pilot Test – KEY FINDINGS

Counselling & Booklet: Feasibility

• Time taken
  – Waiting time complaints
  – Limited time
  – ...Group counselling?

• Primary caregiver not attending camp

• Comprehension of booklet
  – ~50% primary education only
  – Counsellor guidance key
Step 4: Pilot Test – KEY FINDINGS

Text message: acceptability & feasibility

• Prompt for action

• Provoked anxiety

• Only two thirds received message – Electricity supply, faulty networks

• Involving community recommended

“What was good about the messages is that [caregivers] were greeted happily and we were not forcing them. ...And if you didn’t understand you could call the same number to ask”
Step 4: Pilot Test – KEY FINDINGS

Residual barriers to uptake

- Costs of seeking care (transport)
- Unfamiliarity with hospital

“There was no problem. Whatever happened here, everyone at home accepted it, and there was nothing to make us fail. We were just waiting. That’s when the sickness [of another family member] came. So when the time [for the child’s appointment] came close, we had spent the money [we had collected] for transport.”
Future adaptations

- Build in more community support/involvement
- Group ‘counselling’ for carers of children:
  - Time taken at camps
  - Group solutions to transport and funding
- Follow up involvement of community leaders and CHW
  - Reminders
  - Support
- Adapt/test in different settings
Summary

• Participatory intervention development

• Feasible and acceptable

• Overcame some barriers: confusion about referral, fear & uncertainty of hospital, [cost]

• Residual barriers: transport & cost

• Next step: adapt and test in trial
THANK YOU!