London School of Hygiene & Tropical Medicine

Uptake of health and rehabilitation referrals for children in Malawi

Findings from field research in Malawi and current literature

Summary Report

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Investigators:

- Tess Bright, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine
- Dr. Wakisa Mulwafu, ENT Surgeon and Senior Lecturer, Department of Surgery, College of Medicine, Malawi
- Richard Thindwa, Project Director, National Plan for Ear and Hearing Care in Malawi, ENT Department, Queen Elizabeth Central Hospital, Blantyre, Malawi
- Katrina Luthy-Kaplan, London School of Hygiene & Tropical Medicine
- Lambert Felix, London School of Hygiene & Tropical Medicine
- Dr Hannah Kuper, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine
- Dr Sarah Polack International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine

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Contact details

Tess Bright: Tess.Bright@lshtm.ac.uk

Sarah Polack: Sarah.Polack@lshtm.ac.uk

Uptake of health and Rehabilitation referrals for children in Malawi was conducted by the International Centre for Evidence in Disability (ICED) at the London School of Hygiene and Tropical Medicine (LSHTM) together with the University of Malawi.

A copy of the full report is available at: http://disabilitycentre.lshtm.ac.uk

Introduction

For many children with disabilities, being able to access health and rehabilitation interventions is important to maximise functioning and improve quality of life.[1, 2] The lack of available quality impairment-specific health and rehabilitation services is a significant challenge in many Low and Middle Income Countries (LMICs) such as Malawi.[3] However, even when services are available, evidence suggests that uptake of referrals to these services may remain low.[4, 5] Understanding the level of uptake and the reasons for non-uptake of health and rehabilitation services is important for planning and developing appropriate interventions to improve access.

Several studies have tested different interventions aimed at increasing access to health services for children in LMIC. There is a need to identify and review these studies in order to understand the evidence for the effectiveness for different types of interventions.

The aims of this project were to:

- Explore the uptake of and barriers to health and rehabilitation referrals among children in Malawi (PART A)
- Conduct a systematic review of interventions aimed at increasing uptake of health services for children in LMICs (PART B)

Part A: Uptake of referrals amongst children in Malawi

This study explored uptake of health and rehabilitation referrals among children who were identified through two previous projects using the Key Informant Method (KIM). The KIM approach involves training Key Informants (KIs) to identify children in the community who may have a disabling impairment. Identified children are invited to attend a screening camp where they are examined by relevant health professionals and referred to health and rehabilitation services as appropriate. The two KIM studies were:

- The 'Child Disability KIM' conducted in Thyolo and Ntcheu district which included children with vision, hearing, physical, intellectual impairments and epilepsy. Approximately 3000 children were referred to health and rehabilitation services as appropriate.
- The 'Hearing KIM' conducted in Thyolo district' which identified children with hearing impairments. In total 170 children were referred to ear and hearing services at Queen Elizabeth Central Hospital (QECH) in Blantyre.

We conducted a follow up of children from both of these KIM studies to address the following research questions:

- What proportion of children attended their referral?
- Among children who did not attend, what barriers were reported?
- Child Disability KIM only: Did uptake vary according to different socio-demographic characteristics of the child and caregiver (e.g. age, sex, socio-economic status)?

Methods

Quantitative Data collection: All 170 children from the Hearing KIM and a sample of approximately 10% of children from the Child Disability KIM were followed up. Using a structured questionnaire caregivers were asked whether they had attended their referral and, if not, what were the reasons for non-uptake. In addition, for the Child Disability KIM, data were collected on socio-demographic characteristics of the child and caregiver.

Qualitative data collection: In-depth interviews were conducted with i) a sub-sample of families of children who were referred during the KIM Hearing project but did not take up the referral (23 caregivers and 10 children) and ii) 15 key local stakeholders to explore barriers to uptake of ear and hearing services.

Key findings from the quantitative research

- Uptake of referral services was low: 56% of the children identified during the Child Disability KIM and only 3% from the Child Hearing KIM attended their referral

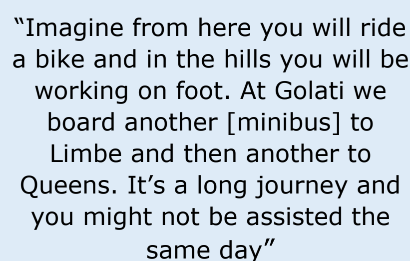
- The most common reasons given for non-uptake of referral were:
    - transport difficulties
    - lack of information or understanding regarding the referral
    - financial constraints

- In the Child Disability KIM study uptake was:
    - lower in Ntcheu (36%) than Thyolo (74%) district
    - lower among children from the poorest households
    - higher among children whose caregivers were divorced/separated
    - higher among children with epilepsy compared to those with other impairments

Key findings from the qualitative research

The in-depth interviews highlighted the following broad factors influencing the decision not to uptake referrals for ear and hearing services at QECH

Location of the hospital and **lack of transport**. The long distance over difficult terrain to the hospital and the lack of available transport presented significant challenges to accessing services in this largely rural, remote district of Malawi.



"I had no money to pay for travels to go to Queens so I just stayed at home"

Indirect costs (e.g. for transport, food and opportunity costs): Even in a context where most government health care is free at the point of care, financial insecurity was a significant reason for non-uptake of services. Many families were unable to pay the cost of travel to Blantyre by public transportation. Costs of food and loss of earnings due to taken the child to get to the hospital were also prohibitive

Fear and uncertainty regarding the referral hospital: Many caregivers were unfamiliar with the hospital, perceived it as a big place and were concerned they would easily lose their way. They were also worried about waiting times and availability of appropriate staff at QECH based on previous experiences seeking care.

Insufficient information about the referral: Caregivers were uncertain about the referral process including when and where they should attend and what for. The interviews suggests that insufficient time, perhaps due to the busy camps, was spent with families explaining about the child's diagnosis and the referral process.

"I was not told that we needed to go. We were waiting information about the day to go"

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

Lack of availability and visibility of ear and hearing services: Caregivers were worried, sometimes based on previous experience at a health centre, that even if they travelled the hospital they may not be seen by the doctor. Stakeholders suggested that the presence of audiology and ENT services at QECH was not common knowledge amongst staff from other departments. As a result, patients may not reach the services they need and this may deter patients from attending.

Part B: Systematic review on interventions to increase access to health services for children in low and middle income countries

In total the review identified 73 papers from 66 studies assessing the effectiveness of interventions to increase access to health services for children aged <18 years. The review identified six broad groups of interventions which are shown in table 1.

Table 1: Summary of types of intervention identified in the review. The full study report details the evidence on the effectiveness for each of these interventions.

	Examples of intervention	Number of studies	Reference
Supply side: non-financial			
Delivery of services at or closer to home	Delivery of immunisation, medication/treatment, and referrals by health care professionals, community health workers (CHW); school-based programmes; immunisation camps	8	6, 7
Service level improvements	Health worker training; scaling up services; integration of services	9	8-16
Supply side: financial			
Service level improvements	Contracting in or out of services; pay for performance	2	17, 18
Demand side: non-financial			
Health promotion/education programmes	Delivery of health promotion by varying personnel including health workers, CHW, peers, and participatory women's groups	27	19-42
Text messages	Text message reminders, and promotion of service	6	43-47
Demand side: financial			
Financial or other incentives	Cash transfers; vouchers, fee exemptions; food incentives	14	48-61

Evidence on the effectiveness of the interventions included in this review were mixed, even within the different intervention types. The two intervention types most consistently associated with a positive improvement in the uptake of health services for children were the use of text messages and the delivery of services closer to home. Overall, few studies in the review were judged as having a high quality highlighting a need for more rigorous research from a range of low and middle-income countries.

Conclusions

Uptake of referrals for health and rehabilitation services among children in these two districts in Malawi was low. Transport difficulties, lack of information regarding the referral and financial constraints were the most commonly reported reasons for non-uptake. Families referred to QECH for ear and hearing services experienced a range of multiple and interacting barriers. These included long distance to hospital, lack of transport, indirect costs, insufficient information about referral process given at the screening camps, fear/uncertainty of QECH and a lack of ear and hearing resources and staff.

The systematic review fills a gap in the literature by identifying the range and effectiveness of interventions that can be used to increase health care access for children in LMIC. It highlights some intervention areas that show encouraging trends which could address barriers to referral uptake identified in the studies in Malawi. Delivery of services at or close to home could be used to address distance, transportation issues and the lack of resources through task shifting to community health workers (e.g. Health Surveillance Assistants). Text message reminders have the potential to address communication challenges, fear and unfamiliarity of the hospital. Health worker training and educational interventions may be important to address the communication challenges about the referral process and the availability of ear and hear services.

Summary of recommendations

Potential strategies to overcome the barriers identified in this study, that need evaluating through robust research, include:

- Increase health and rehabilitation services at community and district hospital levels, for example, by:
    - Increasing outreach by staff at referral hospitals to remote communities
    - Developing capacity of community health workers such as Health Surveillance Assistants in Malawi (of which there are >10,000 in the country) to deliver basic ear and hearing care at community level and facilitate uptake of referrals
- Providing effective communication about the child's diagnosis and referral process. Further research is needed to develop and evaluate effective communication or counselling strategies
- Providing group transport from rural communities to referral hospitals
- Raising awareness of staff at tertiary hospitals about the different services available

Given that reasons for non-uptake were often multiple and interacting, a combination of these strategies may be important to improve access.

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