

RESEARCH ARTICLE

Reasons for non-uptake of referral: children with disabilities identified through the Key Informant Method in Bangladesh

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Abstract

Purpose: To identify reasons for the non-uptake of referral for children with disability identified through the Key Informant Method in Bangladesh. **Method:** Core data was collected and analysed using qualitative methodologies. Fifty-one semi-structured interviews were completed with parent(s) of children who had attended a screening camp at the invitation of a Key Informant, but had not taken up their subsequent referral for health or rehabilitative services. Thematic analysis of the interview data resulted in emerging trends that were critically analysed according to the research objective. **Results:** Seven thematic reasons for non-uptake of referral were identified: severity of the disability; family and community; direct and associated cost; location of referral; negative camp experience; deliberate non-uptake; and procedural problems. Parents often discussed multiple reasons for non-uptake, interrelating socio-cultural, logistical and experiential factors. **Conclusion:** Understanding the reasons for the parents of children with disability not taking up referral is important for the design and implementation of appropriate, relevant and contextual medical and rehabilitative services. The role of Key Informants may be developed from case detection, to include facilitation of effective and efficient uptake of services.

Keywords

Barriers, children, referral, treatment seeking

History

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► Implications for Rehabilitation:

- Programmes to identify children with disability and facilitate subsequent rehabilitation or treatment need to have extensive pre-planned strategies for referral mechanisms and follow up.
- Although Key Informants were not the focus of investigation, the present study suggests that there is potential for the role of the Key Informants to be extended beyond that of a case detection, to inform and facilitate referral processes and encourage the uptake of services.

Introduction

Disability in children is a major public health concern, particularly in low- and middle-income countries, where logistical, socio-economic and cultural factors contribute to a high proportion of health and rehabilitation needs being unmet. As the WHO *World Report on Disability* states, ‘‘People with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. This is largely due to the lack of services available to them and the many obstacles they face in their everyday lives’’ [1].

The UN Convention on the Rights of Persons with Disabilities [2] stressed inequalities in access to services, and served as a call to action to address disability as an aspect of international development [3]. A priority in planning for and providing appropriate and accessible services is the identification of barriers

to care and strategies to overcome them [4]. There now exists a wealth of literature focusing on care-seeking behaviour and associated barriers concerning different disabilities in a range of settings [see for example 5–9]. Although local context shapes the presentation of barriers faced by people with disabilities (as it shapes perceptions of disability itself [10]), common themes are evident. These include logistical barriers (distance from home to clinic, limited access to transport, time constraints); financial barriers (direct costs of accessing services and paying for services received, hidden costs such as loss of earnings due to clinical attendance, limited control over household income and expenditure, the need to prioritise care above other household commitments); social barriers (the influence of family and community, decision-making processes, gender discrimination, education level of the carer, need to prioritise care of a person with disability over other family members); local theories of causation (environmental, inherited, witchcraft, curses, divine intervention); and level of knowledge about appropriate services (no treatment exists, condition cannot be treated, hope that condition will self correct). These factors combine in dynamic ways as determinants influencing care-seeking behaviour and barriers to service access.

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In accepting the existence of such barriers, the current study focuses on a more specific question: why do parents who have previously engaged with health services in relation to their child's disability (and are likely, therefore, to have overcome a number of potential barriers in their care-seeking pathway) not take up subsequent referrals? The study built upon a wider research project focusing on the identification of children with disabling impairments living in the community in Bangladesh using the Key Informant Method (KIM) [11]. Of the children who were offered a referral as part of this project, over 52% did not take up their referral. Quantitative analysis to identify predictors of referral uptake in the study population found that higher monthly income, parental literacy, impairment type and urban residency were associated with increased odds of uptake, although gender was not [12]. These findings meshed with other studies exploring barriers to treatment-seeking for physical disabilities in Bangladesh [13–18], yet no previous research had specifically explored reasons for non-uptake of referral. We therefore conducted a qualitative study focusing on why parents who presented their child at a screening camp did not take up their subsequent referral.

Through the analysis of perspectives and experiences of parents, we sought to identify reasons for non-uptake of referral for children with disability identified through the KIM in Bangladesh. The research will inform the development of KIM-based interventions that better facilitate referral uptake in a developing South Asian context.

Methods

Background

Building on research that shows Key Informants are a successful and cost-effective community mobilisation strategy for the detection of disability in poor resource settings [19–22], the International Centre for Eye Health at the London School of Hygiene and Tropical Medicine and the Child Sight Foundation in Dhaka, engaged in the development, testing, validation and evaluation of the KIM to identify children with disability living in the community in Bangladesh [11]. Working in the Rajshahi division across 15 sub-districts in Sirajganj, Natore and Bogra, Key Informants were trained to identify children with epilepsy; children with bilateral visual or hearing impairments; and children with physical impairments as a result of cerebral palsy, clubfoot and cleft lip or palate. The children were invited to attend a “screening camp”, a locally held day-long clinic, where the child was assessed and diagnosed by a medical team who then referred them if appropriate, to the necessary specialist medical or rehabilitation service. Referrals were largely grouped into five categories according to type: assistive devices, therapy, medicine, surgery and further investigation.

In Sirajganj and Natore (Bogra was not included in the research as screening camps were continuing at the time of research), a total of 3319 children attended 37 screening camps between November 2008 and March 2010 (67% of children initially contacted by a Key Informant attended a screening camp). A total of 1911 children (58%) were classified as having a disabling impairment, according to the WHO standardised criteria for hearing and visual impairments, incorporating an assessment of activity limitations and, for epilepsy, a history of generalised tonic-clonic seizures. Of those, 1308 (68%) were referred for rehabilitative or medical services, or for further investigation (612 from Sirajganj and 696 from Natore).

Children who had been referred were prospectively traced between 6 and 18 months after their attendance at a screening camp and their uptake recorded in an Excel log, linking children to clinical data via a unique identifier. Of the cases

referred, 413 cases (68%) in Sirajganj (the KIM pilot district) and 272 cases (39%) in Natore did not take up their referral. Across the two districts, an average of 52% of children who received referrals did not act on them after their attendance at a screening camp.

Study site

The qualitative study was conducted in 10 sub-districts where a screening camp had been held. In the district of Sirajganj: Tarash, Shajadpur, Kazipur, Ullapara and Kamarkhand; and in the district of Natore: Lalpur, Bagatipara, Natore Sadar, Baraigram and Gurudaspur.

Participants and recruitment

The study used a three-stage cluster sampling approach. From the Excel log of children who had not taken up their referral in Sirajganj and Natore, 200 cases were selected (100 from each district, 20 cases from each sub-district). Eligibility depended on a diagnosis of: epilepsy, bilateral hearing impairment and bilateral vision impairment; and cerebral palsy, clubfoot, cleft lip or palate). The sample included an equal distribution across type of condition, age and gender.

The child clinical data forms of the 200 cases were then reviewed by the primary investigator and 100 cases were purposively selected (50 from each district, 10 cases from each sub-district), again with an equal distribution of impairment type, age and gender as possible. Half the cases were listed as having an impairment that was non-disabling (i.e. their functionality was high) but had still been assessed as needing a referral by the camp specialist medical team.

Details (name, address, telephone number, age, impairment type, camp attendance record) of the 100 cases were given to two community mobilisers who attempted to make contact with the family by telephone and/or in person, to seek informal permission for the research team to visit. Several families were untraceable (the telephone number given had been disconnected and/or the address was too vague to accurately locate the family). An interview schedule of potential cases was drawn up during fieldwork and 51 participants were interviewed.

Data collection

Data collection was carried out in Sirajganj and Natore in November and December 2010. Core data was elicited using in-depth open-ended interview techniques [23,24]. A broad spectrum of research questions was designed by the research team and used as a semi-structured topic guide. Interviews had seven sections: background, general healthcare, condition or impairment (general, social, functional aspects), previous care seeking, camp experience, referral and follow up, and general conclusions. Specific questions and probes were reviewed and refined during the research period in light of themes arising. Although the direction of each interview was determined by the interviewee and largely focused on issues they self-prioritised, the key topics were addressed in each interview and therefore allowed the generalisation of themes across participants.

All interviews were conducted by the primary investigator with the research assistant translating between English and Bangla. Each interview lasted for approximately 1 h. Audio recordings were not made. This helped foster a sense of trust and privacy and encouraged parents to speak more candidly than may otherwise have been possible.

Interviews were conducted inside the house or immediate compound of the family or that of a relative or a close neighbour, and with as much privacy as possible. Except in two cases, the child

and at least one parent was always present (in one case, the child was working in the fields; and in the other, the child's grandmother, the primary carer, was the interviewee). In addition, parents often asked if another family member, most often the grandmother or aunt of the child, could also be present. The child was included in the discussion and their opinions elicited when possible.

At the start of each interview, it was made clear to the key interlocutor and any accompanying relative(s) present that their participation was optional and voluntary, and would not affect any future referral, medical or rehabilitative service required or received. The study's consent form was read and explained in detail. Informed consent and assent was given by signature or thumbprint of all participating parents and primary carers. Participants were given the opportunity to seek clarification or ask questions about the study.

Data analysis

The primary investigator and research assistant compiled detailed notes during each interview and, at the conclusion of each day, transcribed and annotated these with initial comments. Sections of narratives were translated and transcribed *ad verbatim*. Preliminary analysis was conducted in-country throughout the research process. All data, interview notes and completed case studies were regularly reviewed. Using an inductive approach, initial findings were discussed at the end of fieldwork in round-table forums with the Child Sight Foundation stakeholders in Shajadapur and Dhaka and with collaborative researchers at the International Centre for Eye Health in London.

The primary researcher was responsible for the complete thematic analysis of the interviews using grounded theory [25,26]. Dominant themes were identified through the systematic sorting of data, labelling ideas and phenomena as they appeared and reappeared [27]. Coding and analysis was iterative and by hand. The emerging trends were critically analysed according to the research objectives using a critical-interpretive approach of medical anthropology [28,29].

Ethical considerations

The study was conducted in line with the ethical guidelines agreed with the Bangladesh Medical Research Council and the LSHTM ethics committee, to protect the rights and welfare of all participants. All participants provided informed consent and assent by signature or thumbprint. All data were kept confidential and anonymous. Ethical approval was granted by the London School of Hygiene and Tropical Medicine and the Bangladesh Medical Research Council.

Results

Totally 51 interviews were completed. This was the maximum number possible in the allotted three-week fieldwork period and was sufficient to achieve saturation of thematic findings. All cases selected for inclusion were recorded in the Excel log as not having taken up referral. During the course of interviews, however, it became apparent that the database contained some inaccuracies. Of the 51 interviews, 41 (80%) had not taken up referral since the camp but 10 (20%) had. These latter cases provided valuable background information on late or deferred referral, but were not included in the thematic analysis of non-uptake.

Seven thematic reasons for non-uptake of referral emerged.

Severity of the disability

In a country where the stigma of disability is pervasive, all parents interviewed, discussed the presentation of their child's impairment as being problematic, but not all were regarded as

problems requiring a solution. Several parents thought their child "would grow out of the disability", especially if they had been born with the condition, and treatment was therefore unnecessary. For parents, the severity of a disability was closely linked with functionality and measured in terms of the child's mobility and ability to perform domestic tasks and physical labour such as carrying water, lifting mud and helping with the harvest. Levels of independence and self-care, including praying and eating rice with the right hand, were also used to gauge severity. If such activities could be performed adequately, the likelihood of non-uptake of referral increased. In several cases of neglected bilateral clubfoot, for example, parents claimed the child could "do everything" so there was "no need for treatment". Similarly, a mother whose daughter was visually impaired explained,

My daughter cannot see well so she does not go to school and cannot read. I was very worried that she could not see the Koran, but she has memorised certain parts so she can do her prayers, and I am grateful. She has learnt to help me around the house. Treatment is not necessary for the girl now.

In other cases, medication prescribed at the camp reduced the appearance or severity of the condition and parents concluded that there was therefore no need to take up the referral. For children with epilepsy this was particularly problematic as only a limited amount of medication was prescribed. Several parents asserted that camp medication had stopped or reduced the occurrence or severity of seizures, and some concluded the condition had been cured. Many considered only seeking further treatment or taking up the referral when the episodes returned, and only medicated their child when they perceived the severity of the condition warranted it.

Family and community

The opinions and shared experiences of a child's extended family and surrounding community were highly influential and could determine the course of action adopted. Several parents recalled neighbours advising them not to attend the camp, but "to let the child be". After the camp, some were told not to seek any treatment until the child was older or stronger, or to "just accept the situation" and not take up the referral. Others were told that despite the doctors at the camp giving a referral, treatment would not be effective. A small number of parents were reluctant to seek medical intervention due to the negative experiences of friends and family. One mother concluded,

We saw one child, the neighbour of a relative, who had been operated for *mugur pa* [clubfoot – literally bent foot]. After removing the bandage, the condition was worse and there was infection so they had to amputate the foot. Because of this, we do not want treatment, people forbid us from going further [e.g. taking up their referral].

Bangladesh is a patriarchal society in which male family heads dominate the decision-making process. Whether to act on a referral was usually the decision of the child's father or grandfather. In a number of cases it was evident that whilst the mother wanted to take up the referral, senior family members prohibited it. Discussing her daughter's condition, one mother explained,

The father does not give importance to her treatment. Normally he is not concerned with the children. I took her to the camp and would like to take her to the doctor as they instructed, but it is the father's attitude that prevents it.

In another case, the eldest son who had become the household head after the death of his father, did not believe treatment was possible for his younger brother's bilateral clubfoot, and persistently dissuaded his mother from taking up the referral. This was in marked contrast to the general view of their village who encouraged her to follow the camp referral and attend the local hospital. Despite community support, the agency of the family head dominated and the child remained untreated.

Direct and associated cost

With only a few exceptions, financial insecurity was a critical issue for all parents interviewed. The perception that a referral would be costly, in terms of both money and time, was the underlying cause of non-uptake in many cases. To act on a referral, the child and their disability required socio-economic priority within the household and the family unit. Many parents explained that it was impossible to sacrifice their limited essential-item expenditure to fund treatment for a child's disability. For many, incurring loss of earnings due to accompanying their child for referral was prohibitive. A father who was the sole wage earner and supported his wife and seven children on 100 Taka (approximately £0.82) per day concluded,

If I take the child to Dhaka for a few days, my family will go hungry. If I do that, they will ultimately die for the one child.

For many parents uptake of referral assumed second place to daily survival. The issue of who would pay for any post-operative care required was a dominant concern for parents whose child was referred for a surgery. Several asserted that they would not act on the referral unless any costs arising were also covered. In several cases where treatment had been sought for the child prior to the screening camp, parents had no intention of devoting further resources to subsequent referrals.

Location of referral

Many parents asserted that the location of the referral centre was the reason behind their non-uptake and several concluded that it was infeasible to take their child to the centre by public transport. This was seen to be a particular problem for parents of children with cerebral palsy and epilepsy who expressed concerns about mobility limitations and the risk of an episode on the road. Other parents were prepared to attend a hospital in the nearest town, but would not consider journeying further. Even referrals to the district capitals were perceived by some to necessitate a journey fraught with complications and unknown dangers. Many mothers would not contemplate travelling alone with their child without a male relative.

Although a network of hospitals and service providers was established in each district, a number of cases required referral to Dhaka. Some parents felt that they did not have the capability or knowhow to make the journey, whilst for many the gulf between their village and the capital was too overwhelming to contemplate, in terms of distance, environment and experience. Frequently made statements included, "we are village people, we don't go anywhere, that city is too far"; "Dhaka is a big city and we don't have people [relatives] there, we don't have the experience to go"; "we don't know the place, nobody in our family has been"; "we wouldn't know how to find the place or the right doctor, so we can't go".

Negative camp experience

For most parents, the possibility of receiving treatment was the main impetus for their attendance at a screening camp.

A significant proportion expected immediate treatment, and a few cases hoped the disability would be cured that day. Receiving a referral was a disappointment for many parents who reported frustration by the lack of direct action at the camp. Dissatisfaction caused by unmet expectations resulted in some parents' non-uptake of referral. In one case, an 18-year old boy had attended the camp, expecting to receive a hearing aid. His aunt explained,

He saw the doctors and they said they wanted to give him a hearing aid, but they didn't give it to him at the camp. They gave him a referral card and said we would have to bring the child to Dhaka. The boy was very angry. He did not want to go to Dhaka. Because they didn't give him the hearing aid at the camp, he didn't trust them to give it in Dhaka. We are very disappointed. If you can give the hearing aid to him here it will be fine, but he does not want to risk going anywhere to collect it.

In other cases, parents complained that medicines prescribed at the camp did not improve the condition, and they were not prepared to follow the referral believing it too would be ineffective. A number of parents of the children with cerebral palsy came to the camp hoping for "a cure from the big doctors" or for advice on daily management of the condition. One mother concluded,

We know there is no cure, but we thought because the camp was special, with doctors from Dhaka, then maybe they could cure her, but nothing happened. They gave us a referral, but there is no point going. We felt sad, it is hopeless.

Choice to not take up referral

A few parents attended camp "to see what was possible", but without any intention of taking up their referral or seeking treatment subsequently. Referrals for rehabilitative services, particularly physiotherapy, were rarely followed and no speech therapy referrals were acted upon. In the case of cerebral palsy, for example, the length of time required to effect a gradual improvement was a deterrent for most parents who could not tolerate the high input-benefit ratio. Most parents tended to discontinue prescribed exercises, even those performed at home, because no immediate result was evident.

Others chose not to take up referrals due to concerns about taking "strong" medicine for prolonged periods or because of misconceptions about what the referral and possible treatment might entail. A number of parents concluded their lack of trust in biomedical interventions prevented referral uptake. The father of a girl who had been referred for her second surgery explained,

Before my daughter's first operation, the doctor told us the condition would be totally cured. But still now she can only see a small amount. If we were to go for a second operation, I would not believe him if he said it would be cured. I don't want her to have another operation, it is not good for her. We would not have done the first one only for a small improvement.

It was repeatedly emphasised by parents that it was preferable to cope with a known problem rather than risk a referral resulting in treatment that may worsen the condition. This sentiment was most often expressed in relation to surgery. For some parents, the perceived risk that their child may die precluded taking up any referral. In majority of cases, in which surgical referral had not been taken, parents demanded a "guarantee of success" before contemplating the referral.

Procedural problems

In a standard referral procedure the parent would be given a referral card at the camp, and leave their telephone number (or that of a contact person, usually their village chairman or the Key Informant who had invited them to the camp). A community mobiliser would telephone the parent (or contact person) when the referral had been arranged, informing them of the date and location of the appointment. In Natore, parents were told where and when to meet the group transport that had been organised.

In some cases, however, confusion and misunderstanding about the referral process led to non-uptake. Several parents who had received a referral card claimed not to have had further contact since the camp. Cases in which parents had provided a telephone number that was not their own, were often unsure if the community mobiliser had tried to make contact. A number of parents had been instructed to telephone the number on the referral card to confirm the details of their child's referral with the community mobiliser, but several did not take the initiative to telephone and many who had been asked to call reported feeling unease at calling a stranger. The sentiment expressed by one mother that 'I did not know who the number was for, so I did not feel that I could call' was indicative. In Natore, several parents reported that the organised transport did not arrive at the designated place or time. In other cases, parents had been unable to comply with the referral date due to another commitment (such as the child's school exams) or extraneous circumstances (in one case, the child had her first menstruation on the day of the referral). In three cases, parents had misunderstood the referral, and had gone to the wrong hospital or to the right hospital but on the wrong day, and had been turned away.

The majority of parents had the impression that if they had not taken up the referral on the date set, they had missed their one opportunity. Few parents had considered re-contacting the Key Informant or using the telephone number on their referral card to contact the community mobiliser.

Discussion

Whilst there is some indication that referral uptake may be associated with the type of condition and therefore the referral type [12], the dominant reasons for non-uptake identified through this qualitative analysis cross-cut both disability and referral classifications. Although seven themes were delineated, parents often discussed multiple reasons for non-uptake, interrelating socio-cultural, logistical and experiential factors.

The majority of parents attending a screening camp expected the treatment, yet the camps were not initially intended to be of service-providing intervention. Rather, the overall KIM study had been designed to validate the KIM approach, a case detection methodology for specific impairments, in addition to investigating the prevalence of disability among children in rural areas of Bangladesh. That referral rather than service provision was the goal of the study at its outset, may have contributed to the low rate of referral uptake, especially in Sirajganj, the pilot district. The higher rate of uptake in Natore, the study's second site, may partly be attributed to changes made in the referral policy regarding funding treatment and transport. In Sirajganj, parents were asked to make a voluntary contribution to the cost of treatment with the intention that they would be active stakeholders in the referral process, but the initiative caused some confusion and a sense of inequality. In Natore, the policy was standardised to enable free treatment plus free transport and accommodation for the referred child and one accompanying adult. Parents welcomed the idea of organised group transport as it decreased logistical complexities and additional costs, reduced concerns about travel to Dhaka and

fostered a sense of safety in numbers. However, several parents still concluded that facilitating only one accompanying person was impractical and therefore did not take up referral because they were unable to self-fund additional adults whose presence they saw as essential.

Other aspects of the referral procedure remained non-conducive to referral uptake and in both districts parents expressed a degree of confusion and misunderstanding about the referral process. The lack of information, limited communication and inadequate support mechanisms were procedural weaknesses that, in addition to socio-cultural, logistical and experiential factors, contributed most to non-uptake of referral. In response, operational recommendations were made that addressed the reasons for non-uptake identified through the qualitative analysis of parents' perspectives. For example, significant disparity was found between what attending parents expected and what was offered at the screening camps. It was therefore recommended that in their introduction to the camps, Key Informants should convey a more accurate message that reduced the expectation of receiving curative treatment and introduced the concept of referral for medical or rehabilitative services, or for further investigation. We contend that whilst the invitation to a camp must encourage attendance, it should not create false impressions that may subsequently impact negatively upon referral and services uptake. A busy camp was a challenging environment for parents to absorb new and important information. More effective communication was needed to convey explanations about the camp procedure, the health condition or impairment, treatment options and the referral process. It was recommended that instructions be simplified to ensure clear take-home messages were offered and reinforced at all stages. Finding appropriately qualified counsellors proved difficult in Bangladesh, but their contribution was seen as an essential component of the camp. It was therefore recommended that time and resources be spent on strengthening the counselling. In addition to modifying transport and cost, it was also recommended that a more extensive network of service providers (particularly for rehabilitation) be developed in each district to reduce logistical pressures of access.

Through the course of our study, it became apparent that further to being a strategy for case detection, KIM has the capacity to minimise the potential for non-uptake, thereby improving service provision after the screening camps. Its development may include monitoring referral uptake, tracing cases registered for the camp and implementing sustained follow up. As liaison between parents and service providers, Key Informants could improve communication, make bilateral contact easier and help facilitate attendance, particularly in 'hard to reach' cases. They already raised awareness in the community, and could promote additional health education regarding disability, the availability of medical and rehabilitative services, and the importance of timely access, particularly targeting the involvement of male decision makers and household heads. Key Informants could also offer appropriate and proportional explanations to facilitate positive experience sharing as a powerful advocacy tool to encourage uptake of service, and most importantly, as trusted members of the community, support parents throughout the referral process. That parents attended a camp in response to a direct invitation from a Key Informant suggests some degree of willingness to engage with health services. The implementation of the KIM should capitalise upon this and better promote and facilitate referral uptake if the health and wellbeing of children with disabilities is to be not only measured, but also improved. This has positive implications for the development of services in a wider context, both beyond Bangladesh and in relation to other conditions.

Limitations

We sought to minimise potential limitations inherent in an interview-based qualitative methodology by using experience researchers, employing protocols that were designed to be pragmatic and by deploying resources efficiently. Inevitably, some limitations remained. We elected not to use audio recordings to enable participants to speak more openly. It was not possible, therefore, to produce full transcriptions and back translations of interviews.

Issues of language and culture were mediated by using a local research assistant, familiar with the study, interview framework and ethical considerations, who translated between English and Bangla throughout. Risks associated with misinterpretation present in consecutive translation, were reduced by using strategies to improve accuracy. The researchers planned translation and interpretation styles in advance, and decided how to best capture colloquialisms, abstractions and idiomatic expressions. We used short units of speech and careful phraseology that was refined during the finalisation of the interview-question framework. During the interviews, the research team validated sections of narratives that were transcribed *ad verbatim*, and certain responses were reiterated to the interviewee for clarification and confirmation.

It is possible that interviewees expressed what they perceived to be appropriate or socially desired responses. This is a risk in most interview-based qualitative research, but was not judged to be a major limitation as interviews were conducted informally, in private and were not recorded. In addition, the semi-structured interview format allowed questions to be asked in multiple ways and responses triangulated. The study focused on non-uptake of referral and did not, therefore, elicit the views or experiences of families for whom referral had resulted in a positive outcome.

Conclusion

Structural barriers inherent in a developing context limit parents' ability to act. In many cases, those least likely to take up referrals are those least able to. Alongside the identification of socio-demographic and logistical variables that impact referral uptake, qualitative research of this kind helps us to understand in more detail the lived realities and decision-making processes that parents of children with disability face. This is important for the design of appropriate, relevant and contextual healthcare policy and programming. We have, therefore, gone some way to answering the call for operational research to improve the health of people living with disabilities, by identifying reasons for non-uptake of referral services and suggesting strategies to overcome them through the integration of the needs and ideas of the intended beneficiaries [4]. In light of this, future research must further evaluate the role of Key Informants and the KIM, not only for case detection, but also in supporting the effective and efficient uptake of medical and rehabilitative services.

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Declaration of interest

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