Validation of the Key Informant Method to Identify Children with Disabilities: Methods and Results from a Pilot Study in Bangladesh

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Summary

Purpose: To assess whether the key informant method (KIM) is an effective method to identify children with disabling sensory or physical impairments, or epilepsy (tonic–clonic seizures), in a low-income setting.

Methods: In one subdistrict each, the Key Informants (KIs) were trained to recognize children with visual impairment, hearing impairment, physical impairment and epilepsy, respectively. In the fifth subdistrict, the KIs were trained to recognize all four conditions.

Results: Of the 2260 children identified by KIs, 1227 attended for examination (54%), of which 911 were diagnosed to have a disabling impairment (74%). KIM had a high sensitivity (average 98%) for case detection in all groups but specificity was lower (average 44%), particularly for hearing impairment.

Conclusions: KIs were able to identify children with epilepsy, sensory and physical impairments. KIM is an effective and low-cost method to identify children with disability in a low-income setting.

Key words: Bangladesh, disabled children, population groups, cerebral palsy, sensitivity.

Introduction

Child disability is a major public health concern, especially in low-resource settings where there is a two-way association: poverty leads to a greater incidence and prevalence of disability, which in turn leads to or exacerbates poverty [1–3]. In low- and middle-income countries (LMIC), the majority of children with impairments are disabled, having less access to medical treatment, rehabilitation and education than their non-impaired counterparts, and are often socially excluded. Many children with disabilities and their families live in poverty and their needs and rights are often neglected [4–6]. There is a paucity of data on the magnitude of impairment in children, although such data are essential for planning appropriate services [7–9]. Bangladesh is one of the poorest nations in Asia with high infant and under five mortality rates (52 and 183 deaths/1000 live-births, respectively) [10, 11]. Reliable data are needed on the causes and disabling effects of impairment in these most marginalized of children in order to plan services that are accessible and appropriate. A formal screening programme is not feasible in LMIC due to the high costs and lack of trained health personne [12].

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A systematic, less expensive method was successfully developed to identify blind children in rural Bangladesh, using local volunteers as trained Key Informants (KIs) [13]. It has also been used in other countries such as Malawi [14], Iran [15] and for children with epilepsy in India [16]. It was found to be particularly useful for those ‘hard to reach’ children; females, multiple disabilities, rural, pre-school or those of illiterate families. The current project was designed to test and validate whether the key informant method (KIM) could also be effective in identifying a range of different childhood conditions; visual, hearing, physical impairments as well as an often disabling health condition, epilepsy (generalized tonic–clonic seizures).

**Objectives**

- To develop, pre-test, pilot and refine KIM for a range of childhood impairments.
- Assess the validity of KIM by estimating sensitivity and specificity of the method using clinical diagnosis by medical specialists as the gold standard.

**Methods**

The recognized framework for disability is the International Classification of Functioning, Disability and Health (ICF), where impairment is described as, ‘A loss or abnormality in body structure or physiological function’ [17]. It is incumbent to note that this study utilized the impairment component of disability definition in relation to functional activity limitations (by examination and Washington Group set of questions) [18, 19]. Hence to assess impairment in children, standardized WHO criteria of bilateral vision and hearing loss were adopted [20, 21], for epilepsy according to history of episodes and whether function was significantly effected with physical impairments.

**Sampling**

The pilot study took place in rural Sirajganj district that is 140 km northwest of Dhaka. Using simple random sampling, five subdistricts were selected. Within each subdistrict, communities were then stratified by rural/urban location, and communities were randomly selected until a total population of 100,000 had been identified in each subdistrict, with 27% being selected from urban areas. In a population of this size, there would be approximately 42,000 children aged 0–18 years.

To determine the sensitivity and specificity of KIM, 50 children who were not listed by the KIs were randomly selected using systematic random sampling i.e. every 10th child in the village where the examination camp was scheduled were identified going house to house until 50 were listed. These children also underwent the same process of medical assessment by specialists.

**KIM process: general**

Trained community mobilisers (CMs) were responsible for identifying potential KIs, with an emphasis on gender and diversity in recruitment. These individuals needed to be literate, and have good knowledge and influence within their local communities and included: teachers, council members, Imams, non-governmental organization (NGO) or health/social workers, local government officials, police, business people, journalists, village doctors, traditional healers.

Identified KIs attended a 1 day structured training format led by the CMs, consisting of: interactive general discussions on disability, awareness raising topics, disability-specific information using flip chart illustrations, role play with guidance on carrying out KI functions. Once the KIs were trained, they were given 4–6 weeks to list children with the specific impairments in their catchment area and were informed of the date and venue of the KIM medical assessment camps.

**KIM process: for each impairment/condition**

To ascertain whether it would be more effective for KIs to identify only one impairment, or the range of impairments being studied, one impairment was chosen for each of the first four subdistricts, whereas in the fifth subdistrict, the KIs were trained to identify children with all four types of impairment.

A group of experts developed flip charts for each impairment using a consensus approach. In addition, illustrated information sheets were prepared containing key take away messages for case identification.

Initial KI training began in October 2008 and the final KIM pilot medical assessment camps were completed in February 2009. Written informed consent was obtained from parents. Approximately 100 KIs were trained per subdistrict (approximately one per village) and their participation was voluntary without material reward throughout the process.

**Medical assessment**

Most of the specialists (two paediatricians, one ophthalmologist, one ENT doctor, one audiometrician, one physiotherapist and one counsellor) came from Dhaka to attend the assessment camps that lasted for 2 days in each location. They were given training on the KIM study process and completing the clinical data forms. They examined all the children who attended the camp to diagnose the condition, to give advice, information and counselling and refer for appropriate services. They were masked to whether a child was identified by the KI or through systematic sampling of ‘norms’. Costs were supported by the
project, in addition to providing basic primary care medication at the camp site.

Equipment used for vision testing included ophthalmoscope, tumbling E charts, Cardiff cards or torchlight, while otoscope, field audiometer and an OAE (otoacoustic emission) machine were used to test hearing.

**Data instruments**
The child clinical examination form was the principal data collection instrument, consisting of demographic details, income category, parental perception of impairment, activity limitations, school attendance, rehabilitation, clinical history and examination findings followed by referral recommendations.

Data were entered into an Access database and analysed using Stata 11.0 software (Stata Corp, Texas, USA).

**Clinical definitions**
Children were diagnosed as having a ‘disabling impairment’ according to standardized WHO criteria; for vision, presenting vision <6/60 in better eye and for hearing, only children with above 30 dBA in both ears. Epilepsy diagnosis was by history of tonic-clonic seizures within last 3 months. Disabling physical impairment was identified as those with ‘substantial’ (moderate/severe) disability of 6 months duration (or from birth if younger), affecting function i.e. not able to easily do one or more of the Washington Group short set of daily activities.

Ethics Committees of LSHTM (UK) and Bangladesh Medical Research Council provided clearance for the study. The study adhered to the Declaration of Helsinki.

**Results**
Of the 2260 children identified by KIs (Table 1), 1227 attended for examination (54.3%), of which 911 were diagnosed to have a disabling impairment (74.2%), while the majority of other children had milder impairments but did not meet the study criteria. Physical impairments formed the largest group accounting for approximately half of all impairments. Cerebral palsy was the most common diagnosis (295), being responsible for almost half of the physical impairment group and 23% of all children examined. Other frequent physical impairments found were: muscular degenerative conditions (4.8%), club foot (3%) and Cleft lip/palate (2.4%).

Gender analysis showed that 55% males vs. 45% females attended the camps and more boys attended school (53%) than girls (47%). Overall, 46% of the fathers and 40% of the mothers rated themselves as illiterate, while the national literacy rate for Bangladesh is estimated at 52% WFP [22].

The combined approach was more effective in that both the number of children listed by KIs and the

<table>
<thead>
<tr>
<th>Specific impairment covered in each subdistrict</th>
<th>No. of children with specific impairment listed by KI</th>
<th>No. of listed children examined by medical team</th>
<th>No. of children with specific disabling impairment</th>
<th>Percentage of children attending examination camp (%)</th>
<th>Percentage of children with a disabling specific impairment (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual impairment</td>
<td>70</td>
<td>38</td>
<td>54.3</td>
<td>65.8 (49.9–78.8)</td>
<td>29</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>435</td>
<td>149</td>
<td>32.8</td>
<td>51.7 (43.7–59.6)</td>
<td>22</td>
</tr>
<tr>
<td>Physical impairment</td>
<td>459</td>
<td>304</td>
<td>66.2</td>
<td>78 (72.9–82.3)</td>
<td>23</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>93</td>
<td>58</td>
<td>62.4</td>
<td>79.3 (63.2–87.7)</td>
<td>46</td>
</tr>
<tr>
<td>Combined</td>
<td>1203</td>
<td>678</td>
<td>56.3</td>
<td>77.6 (74.3–80.6)</td>
<td>52</td>
</tr>
<tr>
<td>Total</td>
<td>2260</td>
<td>1227</td>
<td>54.3</td>
<td>911</td>
<td>74.2 (71.7–76.6)</td>
</tr>
</tbody>
</table>

*Similarly to KI listed children, not all of the randomly listed 50 children from the subdistrict camp village attended.*
number who attended camps was greater than the sum of the other impairment groups (Table 1). KIs had more chance of being active in listing children with a range of impairments than when just one type is the focus. In addition, CMs reported greater work satisfaction with the combined approach as it meant they could offer assistance to a majority of children with impairments in a community, instead of focusing on one type to the exclusion of others.

Some form of action/referral was required for ~80% of the children examined (e.g. medication, assistive devices, rehabilitation, surgery, investigations).

### Sensitivity and specificity
KIM had a high sensitivity (Table 2) in all groups (average 98%) but specificity was lower, particularly for hearing impairment, where a significant proportion attended due to a chronic discharging ear, which did not meet WHO criteria of bilateral disabling hearing impairment. For physical impairment, it was not possible to avoid picking up some ‘non-disabling’ conditions when children were not screened until the medical examination. The numbers of non-KI listed children was small and low prevalence in sensitivity and specificity may not be truly indicative at this pilot stage. It was observed that both positive and negative predictive values were high in all impairments, except with hearing impairment where the positive predictive value was low. The high predictive values indicate that the extent of over referrals did not appear to be a cause for concern except for hearing impairment. However as stated, most of those did experience some ear morbidity which required medical examination.

Across the groups an average 45% of KI listed children did not attend camps due to a wide range of reasons identified in a follow-up survey of 235 children (Table 3). After the pilot phase, two further medical assessment camps were held for a random sample ($n = 104$) of these children. The characteristics of gender, age, income or nature of impairment were not found to differ from those who had attended.

### Discussion
The results of the KIM camps indicated that using KIs was successful in identifying a range of specific impairments in children. The study criteria used meant that those with confirmed diagnosis had moderate to severe impairments, while milder forms that did not cause activity limitations were not included. The results are comparable with the Ten Questionnaire screening (TQS) tool widely used to...
identify children with disabilities, internationally, which was found to be a good tool for identifying severe cases [23, 24]. However, some authors feel it has limitations as it does not provide information on degree of impairment or type of services required [7]. The TQS was also used in the large United Nations Children’s Fund (UNICEF) Multiple Indicator Cluster Survey (MICS) studies [4, 25] but the identified children were not followed up as intended with a medical screening to confirm diagnosis. One study in North India had a second phase medical evaluation, but the study was limited to only three villages [26]. The KIM study has the advantage of including specialist medical screening, parent/child reported degree of activity limitations and detailed referral information. A significant limitation, however, was that intellectual disability was not included in the study, as there was a lack of consensus for KI detection and no appropriate referral services were available in the districts.

The large proportion of children listed by KIs but not attending camps is of concern and efforts have are being made to address this in other districts. Strategies have been identified to improve communication in subsequent KIM phases such as staggered registration to reduce waiting time, improved communication channels, maintaining fixed dates for camps in advance and increased guidance for KIs in the training workshops.

Gender overall did not appear to play a major role, although there were some differences in the results; the 55% male to 45% female attendance ratio is reflected in two household disability surveys in Bangladesh [27, 28] where 44% and 42% females were found to have disability, respectively.

An important aspect of the field work was to establish prior links with local disabled persons organizations and NGOs where we could learn what resources were available locally and they could participate in the KIM process. A Dhaka Task Force of disability stakeholders and providers is involved with the project to take it forward and use the results for advocacy purposes, approaches advocated by others in the field of disability statistics [4, 19].

The study showed that KIM is effective in identifying children with disability and that a combined approach to the specific impairments was the better option. It is an appropriate, low-cost method of case detection through community participation, using a sustainable network of volunteer KIs. It is thus a more suitable option in resource poor settings for case detection and follow-up than a household survey.

References