Research letters

Coping with paediatric referral—Ugandan parents' experience

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Referral of severely ill children to hospital is key in the Integrated Management of Childhood Illness (IMCI). In rural Uganda, we documented the caretakers' ability to complete referral to hospital from 12 health facilities. Of 227 children, only 63 (28%) had completed referral after 2 weeks, at a median cost of US$8·85 (range 0·40–89·00). Failure to attend hospital resulted from lack of money (139 children, 90%), transport problems (39, 26%), and responsibilities at home (26, 17%). Children with incomplete referral continued treatment at referring health centres (87, 54%) or in the private sector (45, 28%). Our results show that cost of referral must decrease to make paediatric referral realistic. When referral is difficult, more specific IMCI referral criteria should be used and first-level health workers should be empowered to manage severely ill children.

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The Integrated Management of Childhood Illness (IMCI) strategy classifies sick children into mild, moderate, and severe groups. Children with a severe classification receive initial treatment and urgent referral to hospital.[1] However, low completion of referral is a major problem resulting from difficulties for health workers, patients, households, and communities.[2] Although the problem has been investigated in other regions,[3] there have been few studies on constraints for referral and coping behaviours in sub-Saharan Africa.[2] In rural Uganda, we studied to what extent caretakers were able to complete the referral process as advised by IMCI, reasons for not doing so, and alternative treatments sought among the unreferred.

	Number of children referred and followed up	Number who completed referrals	Number lost to follow-up
Classification*			
Severe pneumonia/ severe disease	88	29 (33%)	27
Possible serious bacterial infection	66	13 (20%)	12
Severe febrile disease	63	19 (30%)	22
Severe malnutrition	13	3 (23%)	6
Severe anaemia	18	4 (22%)	5
Severe dehydration	9	3 (33%)	7
Severe complicated measles	3	2 (67%)	1
Severe persistent diarrhoea	5	1 (20%)	1
Severe dehydration in infant	1	0 (0%)	0
Dysentery in infant	2	1 (50%)	0
Mastoiditis	1	0 (0%)	1
Other non-IMCI conditions	6	2 (33%)	0
Danger sign			
Convulsion at present or by history	52	13 (25%)	19
Not able to breastfeed	4	4 (100%)	4
Lethargy	4	2 (50%)	4
Vomiting everything	9	4 (44%)	2
Age-group			
Infants aged 1 week to 2 months	71	15 (21%)	14
Children aged 2 months to 5 years	156	48 (31%)	55
Sex			
Boys	122	32 (26%)	29
Girls	105	31 (30%)	40
Total	227	63 (28%)	69

*As classified by the Integrated Management of Childhood Illness (IMCI).[1] A child may have more than one severe classification and thus appear in several rows.

Table 1: **Completion rates for different types of referral in children**

Through random sampling stratified for region, we chose four IMCI implementing districts. District medical officers identified 12 health facilities that had no inpatient beds, were not adjacent to hospitals, and where health workers, clinical officers (with 3 years' of basic training), nurses (18 months), nurse assistants (3 months), and local health assistants (2 years) could take part in the study. These facilities served catchment populations of 5000–10 000, and were located in the least served halves of the districts, with a median distance to their primary referral hospitals of 34 km (range 7–80).

Sick children younger than 5 years were managed according to IMCI during the 3-month study period. Overall, 369 (10%) of 3869 children up to 5 years needed referral; detailed reports of symptoms and classifications are given elsewhere.[4] As directed by IMCI, severely ill infants received initial treatment and were referred immediately to hospital.[1] The local health assistant made home visits 2 weeks after referral, to document subsequent actions and experiences. Caretakers unable to complete referral were asked open questions about reasons and alternative actions taken. All health workers had been trained on the IMCI strategy 1–3 years before our study, and received the IMCI management manual "*Annex E. When referral is impossible*". No additional management instructions were given to those who could not complete referrals during the investigation.

18 focus group discussions were undertaken with neighbourhood caretakers about referral of severely ill children. Sessions were tape-recorded, transcribed, and analysed manually for content and themes. Health workers and health assistants were trained on study methods and supervised every month. Quantitative data were analysed with EpiInfo, JMP, and STATA 8, by use of commands for clustered data. This study was approved by the Uganda Ministry of Health and the ethics committee of Karolinska Institutet, Sweden (34903-263).

Of 296 referred children, 227 (77%) could be located after 2 weeks. Median age was 8 months (1 week–54 months). 69 children (23%) were lost to follow-up with a range of 0–61% in different centres. More girls than boys were lost to follow-up but this difference was not significant.

After 2 weeks, only 63 children (28%; 95% CI 15–40%) completed referral as advised, at a hospital or health unit with inpatient facilities (table 1). The median facility referral completion rate was 24% (range 14–67%). Referral completion rate did not differ significantly according to age-group (table 1, p=0·26). 31 children completed referral the same day, 23 the next day, and seven after 2–7 days; no referral time was available for two children. The median journey time to the

	Number of caretakers cited (n=152)
Lack of money	137 (90%)
Transport problems	39 (26%)
Other children at home to care for	23 (15%)
Hospital far from home	15 (10%)
Hospital services are not good	3 (2%)
Father was sick at home	3 (2%)
Husband not around waiting for his opinion	2 (1%)
Improved after first treatment	2 (1%)
"No alternative but to remain"	1 (1%)

Reasons given are thematically coded responses to the question "What made it impossible to go to the health unit your child was referred to?"

Table 2: **Caretakers' reasons for not completing referral**

referral centre was 1 h (range 20 min–6 h) and 25 children were transported by bicycle, 19 by minibus-taxi, 11 by motorcycle taxi, three by boat, two by car, one by bus, and four on foot. Some children used more than one mode of transport.

The median cost of completing referral was US$8·85 (range 0·40–89·00), with no difference between the sexes. Treatment such as drugs and fees for care was the main cost ($6·00, 52% of the mean cost $11·50); transport ($1·80, 16%) and other costs such as food and supplies ($3·70, 32%) made up the rest. Cost contributes to delay: "if you do not have the money you have to look for it first. Sometimes you may even have to spend a day or two looking for the money for the treatment. If you have coffee then you first sell it before you go", according to one woman in a focus group. Focus groups associated referral centres with long waiting time (even for referred children), harsh health workers, inadequate drugs, and language problems.

164 (72%) children did not complete referral for various reasons (table 2). Poverty hindered referral completion to a much greater extent than transport problems. Women needed permission from their husbands before referral. Instead of going to hospital, 87 (53%) children were treated at referring health centres either immediately or on subsequent visits, where local health workers had to do their best. Another 45 (27%) children were treated at private clinics, 15 (9%) at home, nine (5%) at another health centre, and six (4%) by traditional healers; no report was available for two.

According to focus groups, ordinary bicycle transport was available everywhere and at any time. Ambulances were not considered reliable because caretakers needed to buy fuel to travel, and there were no means of effective communication between the home, health centre, and hospital to call for the ambulance.

During follow-up, parents reported that ten children (4%) had died. None of these deaths was in children who completed referral on the same day (p=0·36). Community members suggested several solutions to the referral system: improved transport by use of special bicycle ambulances at local parishes; more effective communication by use of mobile phones in health centres and consistent use of a referral letter; improved health services, especially at the first level, to avoid need for referral; and income generation for women.

Implementing the IMCI strategy in first-level health facilities increases the volume of referrals. Before IMCI implementation, 0·6% of children[5] were referred in Tanzania. Under IMCI, referrals rose to 6–7% of children aged 2 months to 5 years and 50–80% of infants younger than 2 months, in Tanzania and Uganda.[4] Our study shows that 72% of referrals are not completed in rural areas of Uganda, which is worse than the 42% documented in Ecuador.[3] Most of these children were treated at the referring health centre or at private clinics. Private clinics were generally located within participating communities, and lacked capacity to manage severely ill children, such as providing oxygen or giving blood transfusions.

Health facilities in this study were representative of half the Ugandan districts' facilities where hospital access was most difficult. We relied on local health assistants without transport for follow-up interviews, and although loss to follow-up might have introduced selection bias, children lost to follow-up would probably have had the most difficulties to complete referral.

Clearly, non-completion of referral has more to do with practical constraints than a refusal to comply. To go to the health centre counts as a kind of referral already after community options are exhausted; going to hospital is then unrealistic. Poverty is the main cause of low completion of referral: mean referral costs of $11·50 are far too high when 37% of Ugandans live on less than $1 per day.

Efforts to improve hospital care must include reduction of patients' costs. Although more resources are needed to address affordability of referral care, consistent use of referral letters,[3] prioritising referred patients, polite reception, and implementation of bicycle ambulances should be attainable at the present level of funding.

The IMCI strategy introduces strict referral criteria based on symptoms with good sensitivities and lower specificities,[1] especially for sick infants and patients with a history of convulsions.[4] When referral is difficult, more specific criteria could be used, even at the cost of lower sensitivity. Health units need drugs, equipment, training, and permission for local health workers to manage some of the present IMCI referral classifications, which are likely to go beyond the existing IMCI manual's "*Annex E. When referral is impossible*".

First-level health workers should be empowered to care more effectively for severely ill children already in their health centres.[4] Health worker care is probably better than insisting on hospital referral and the possibility of receiving worse care if children do not make it to hospital compared with that in the health centre.

Contributors

All authors participated in design, execution, analysis, and write-up of different parts of the study. S Peterson had the main coordinating responsibility for study analysis and write-up and J Nsungwa-Sabiiti for study logistics. All authors had access to the study data and agreed to submit for publication.

Conflict of interest statement

None declared.

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