

# Referral practices on community based management of sick young infants with Possible Serious Bacterial Infection in Tigrai, Ethiopia: the caregivers' perspectives

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## Abstract

**Background:** The World Health Organization reference standard for sick young infants (0-59days) with Possible Serious Bacterial Infection recommends referral to a hospital for inpatient treatment. However, many sick babies are not recognized to have infection because of non-specific signs. Even when danger signs are detected, hospitalization and life-saving treatment may not be accessible, acceptable or affordable to families in settings with high newborn mortality.

**Objective:** The aim of this paper was to share the experiences from the implementation research focusing on the acceptance, practices, challenges and opportunities of the referral system from the caregivers' perspective.

**Methods:** We conducted an implementation research that involved quantitative and qualitative approaches in Raya Alamata and Raya Azebo districts of Tigrai, Ethiopia. The study populations were Young infants aged 0-59 days with possible serious bacterial infections. We determined the sample size based on the proportion (3.1%) of live births in a year and 854 young infants were included assuming 10% proportion of young infants will develop PSBI. Young infants with one or more of the clinical signs of clinical severe infection and severe chest in-drawing, fever (37.5°C or above), low body temperature (less than 35.5°C) and with movement only when stimulated were included in the study. Health Extension Workers were trained to provide health education and counselling about newborn care, the danger signs of newborns and the need for referral level care for sick young infants. A standard Case Reporting Format was adopted to collect the quantitative data. Qualitative data was collected using 57 key informant interviews and 14 focus group discussions. The study participants were recruited using purposive sampling. The qualitative data were recorded, transcribed verbatim, translated and analyzed using the thematic approach. Quantitative data were cleaned and entered into SPSS version 20 software for statistical analysis.

**Results:** The expected live births in both districts were 13,478 and the actual live births identified were 7857. During the implementation process, a total of 854 of possible serious bacterial infection cases were identified of which 317 (65%) and 537 (63%) were from Raya Alamata and Raya Azebo districts, respectively. Moreover, the incidence of possible serious bacterial infection was 12% and 10% for Raya Alamata and Raya Azebo districts, respectively. A total of 208 possible serious bacterial infection cases were documented in 20 months follow-up in the two districts that needs referral. About 144 (69.2%) of those cases with possible serious bacterial infection accepted the referral, while 64 (30.8%) declined. The main reason to decline the referral for 35 (54.7%) of the families was that "no one was to accompany the infant to the next level of care". The qualitative study findings indicated that the district health office only provide an ambulance transportation of the families with referred sick young infants to the referral hospital, but, it does not take them back home.

**Conclusion:** The study findings revealed high compliance to referral acceptance. This suggests that Health Extension Workers can play a significant role in the community management of sick young infants and eventually improve newborn health and reduce child mortality.

**Key words:** PSBI, sick young infants, implementation research, referral, caregiver, Ethiopia.

## Introduction

Neonatal sepsis, meningitis and pneumonia are major causes of morbidity and mortality in developing countries, resulting in an estimated 700,000–800,000 deaths per year [1]. As it is clinically difficult to differentiate between these infections, they are often identified together as a clinical syndrome of possible serious bacterial infection (PSBI). Signs used to diagnose this syndrome include poor feeding, convulsions, fast breathing, severe chest in-drawing, fever or hypothermia and movement only when stimulated or no movement at all. The World Health Organization (WHO) currently recommends transfer to a referral facility, hospitalization and injectable antibiotic therapy with a combination of gentamicin and penicillin/ampicillin for 7-10 days for the management of this clinical syndrome in young infants up to 2 months of ages [2].

An estimated 10.6 million children under five years of age still die each year from preventable or treatable diseases. Many of these deaths are attributable to the conditions targeted by Integrated Management of Childhood Illness (IMCI): acute respiratory infections, malaria, diarrhea, measles and malnutrition. A large proportion of these deaths could be prevented through early, appropriate and low-cost treatment of sick children in the home or community, with antibiotics, antimalarials or oral rehydration therapy [3].

A referral system at all levels is used as a means to facilitate flow of patient referrals among healthcare providers. It is an important activity in any healthcare system for it is a critical component of quality clinical care. A referral management system is a unique and powerful tool for health providers to keep

track of their patient referrals throughout the care continuum. Its main goal is to improve and streamline communication among primary care physicians, specialists, and any other health providers involved in a patient's care [4].

For successful referral, there must be geographical access to referral care facilities. Provided referral services are accessible, referral staff must be trained to provide quality care, services must be affordable and must have essential drugs, supplies, and equipment. The most complex aspect of referral care is often the caretaker's acceptance and compliance with a referral recommendation. This is often determined by a variety of factors, including the perceived need of a referral like the disease severity, caretaker or community experience with and the impressions of the referral facility, and the cost (time and resources). In most countries there are two major types of health facilities— primary care facilities and hospitals [5]. Health care systems are often designed to encourage caretakers to first seek care at the primary level and then be referred, if necessary, to a higher level of care. If this reflects actual care seeking behavior, then health care costs for the caretaker will be minimized [6]. In many countries, however, caretakers often bypass primary care facilities and seek care directly at referral care hospitals for illnesses that could be easily treated at the primary care facility [7]. This can overburden the referral facility, and is often expensive for the caretaker and the health care system. The right to the highest attainable standard of health is a fundamental human right. Central to this right in the delivery of health care in a hierarchical health system is the existence of a well-functioning referral system that allows for continuity of care across different tiers of care. Most health systems

in the world are hierarchical, starting with primary care, to secondary care facilities, to the highest level of care, which consists of tertiary level facilities that provide highly specialized services. In most developing countries, however, health referral systems across the various levels of care are weak, which affects the overall performance of the health system and contributes to negative health outcomes [8].

The Ethiopian government, Federal Ministry of Health (FMOH) has recently adopted to implement the community based management of sick young infants with Possible Serious Bacterial Infection (PSBI) where referral is not possible. Cognizant, the Health extension Workers (HEWs) will provide the treatment regimen at the health post level where the families fail to accept referral. To increase the uptake, an implementation research had been deployed in Tigray and all the processes had been followed and documented by the investigators from Mekelle University. In this paper we share the experiences of the implementation research focusing on the acceptance, practices, challenges and opportunities of the referral system from the caregivers' perspective.

## **Methodology**

**Study design and setting:** An implementation research design that involved quantitative and qualitative approaches in Raya Alamata and Raya Azebo districts of Tigray regional state, Ethiopia.

**Study population:** Young infants aged 0-59 days with possible serious bacterial infections (PSBI) and who are permanent residents of the 2 districts were the study population for this PSBI implementation research.

**Sample size and sampling technique:** We determined the sample size based on the proportion (3.1%) of live births in a year. Thus, there are about 8086 ( $= 3.1\% \times 260,844$ ) newborns in both districts. Assuming 10% proportion of young infants will develop PSBI, about 806 young infants were planned to be recruited for the PSBI implementation research. All newborns/ young infants with the clinical signs of PSBI were included in the study.

**Inclusion and exclusion criteria:** Young infants with one or more of the clinical signs of clinical severe infection and severe chest in-drawing, fever ( $37.5^{\circ}\text{C}$  or above), low body temperature (less than  $35.5^{\circ}\text{C}$ ), movement only when stimulated) were included in the study. Young infants with the clinical signs of critical illness (convulsions, no movement at all, and hospitalization in the last 2 weeks, unable to feed) were excluded from the study.

**Follow-up:** HEWs were trained to provide health education and counselling about newborn care, the danger signs of newborns and the need for referral level care for sick young infants. If the mother/family refuses to accept referral of the sick infant to a higher health facility or hospital, the sick infant was treated with simplified antibiotic regimen at the nearest health facility.

**Implementation strategies:** The implementation was designed in such a way that all health posts or HEWs provide simplified outpatient management of PSBI after intensive training, 80% of the sick young infants with PSBI receive treatment and 80% of the sick young infants whose mothers refused referral receive adequate quality treatment at the health post. The implementation strategies would increase recognition of sick young infants at the community by families and health

development armies, referral of sick young infants to health facilities and treatment and management of the sick young infants who cannot seek care at higher level facilities with adequate quality treatment using simplified antibiotic regimen by the HEW.

**Formative Research:** Qualitative study was conducted using key informant interviews and focus group discussions to identify the demand side and supply side barriers of PSBI services utilization and to understand more clearly the complex challenges of the implementation of the management of sick young infants with PSBI. The participants in the qualitative study were mothers, fathers, HEWs, community leaders, religious leaders, women development armies, cluster supervisors, woreda health office experts, health center directors, mid wives and maternal and child health experts from the primary health care units.

**Case finding (home visits) for young infants:** All births in the study communities were identified by the women development army or the HEWs as immediately as possible after delivery. Cases of PSBI were identified by HEWs, if a family calls and informs the HEW that a child has PSBI and requests a visit or directly visits the HEW's home/health post. Cases were also identified during routine and scheduled PNC visits made by HEWs to promote essential newborn care in the first six weeks (on days 1, 3, 7 and 42) of life. During these visits, HEWs measure temperature, record respiratory rate, look for chest in drawing and dangers signs of newborns. During the home or facility visits, the HEWs provided standard advice regarding newborn care as described in the WHO/UNICEF Joint Statement on home care of newborns [1].

**Referral of young infants with PSBI:** All caregivers of babies with a diagnosis of PSBI after assessment by the HEW (at the facility or at home) were counseled about the need for hospitalization for their baby. HEWs had to explain to the mother the need for referral, and get her agreement to take the young infant to the referral level care. The HEWs had to prepare a referral note and explained who to give that note to at the referral facility. The HEW counseled mothers about the activities to do on her way to the referral facility such as keeping the young infant warm and breastfeeding. The sick young infants were given the first dose of antibiotics (gentamycin IM and oral amoxicillin) by the HEWs. When mothers of young infants refused hospital referral, despite the best efforts of the HEW, they were offered treatment with the simplified antibiotic regimen (two days injectable gentamycin plus twice daily oral amoxicillin for seven days or seven days injectable gentamycin plus twice daily oral amoxicillin for seven days).

**Administration of treatment:** Injections and first daily dose of oral medicine were administered by the HEW and the second oral dose for the day and the rest of the oral amoxicillin doses were administered by the mother. The families were required to bring the young infant to the health facility for gentamycin injections. When young infants vomited within 20 minutes of oral amoxicillin dosing, the mothers were counseled to re-administer a complete dose.

**Training and standardization:** All health extension workers and nurses working in the catchment health centers were trained on clinical signs of PSBI in young infants and undergo standardization exercises for identification of young infants with PSBI. Refreshment trainings and six monthly re-standardization sessions were provided for

all HEWs and supervisors during the study implementation period.

**Demand generation and awareness creation Activities:** trainings were provided to create demand for community based newborn care, to increase the health seeking behavior of mothers of sick young infants and to trace and report sick young infants in the communities. These include community meetings through existing local platforms such as women development groups, community based forums and the one-to-five women networks. Moreover, messages regarding the referral and treatment and management of neonatal sepsis at the community level were promoted during the ongoing activities such as the village health and nutrition days, immunization clinics and through community mobilization or sensitization workshops for women development groups and the one-to-five networks.

#### **Data Collection**

Data were collected using standard case reporting forms (CRFs). The data collection was done by the HEWs through home visits and self referrals and includes data on all births as well as follows up of the sick young infants and deaths within the first two months of life. The six CRFs (CRF 1 to CRF 6) were field tested and revised after pilot testing for six months in the study communities. The HEWs list the pregnancy cohort or pregnant women (CRF 1), complete baseline information and PNC visits (CRF 2) at enrolment for every enrolled infant, complete the sick young infant assessment form (CRF 3), complete the follow up and treatment form (CRF 4), complete the treatment and outcome for referred or hospitalized infants (CRF 5) and adverse events/death reporting form (CRF 6). Daily treatment and assessment records were maintained by the treating health worker. All

completed forms were checked by study supervisors and core team members for completeness before they were entered into the computer.

#### **Data Management**

Individual health posts were responsible for their own day-to-day data management activities with a close support from the field supervisor. Data quality checks and cleaning were carried out at the field on a monthly basis with the support from the field supervisor. The cleaned data was sent every month to the central data base in Mekelle. The core team had its own data management team, including a data manager and team of data entry clerks. The data entry clerks enter data from paper forms sent from the field into the data management system, which stores the data in a data base. The data manager together with the supervisor and the study team checked for inconsistencies in information across different case report forms. Inconsistencies were resolved in consultation with the supervisors and if necessary with the core team of the study.

#### **Data Analysis**

**Quantitative data:** Data were cleaned and entered into SPSS version 20 software. After checking for missing data, outliers and invalid values, descriptive analysis was conducted to report frequencies, coverage and proportion of sick young infants with clinical severe infection, critical illness, pneumonia, local bacterial infections; treatment failures; proportion referred to referral level care; proportion that did not accept referral; proportion of sick young infants treated by HEWs; proportion able to complete treatment; proportion that did not improve and needed higher level care; proportion that were cured along with relevant information regarding PSBI management and treatment at the community level.

## **Qualitative data**

### **Data collection and methods of analysis:**

A qualitative research design enabled the exploration of the opinions, beliefs, deeper feelings and understanding of program managers, health workers and community members related to identification, classification and treatment of possible serious bacterial infections when referral is not possible. The main technique of data collection employed was 46 in-depth interviews (IDIs) with program managers, health workers and community members. The study participants were recruited using purposive sampling from the following categories: Regional Health Bureau experts, Woreda Health Office Experts, Hospital NICU Staff, Health Centre Staff, Health Extension Workers and community members (mothers and women development groups). The In-depth interviews were recorded using digital recorders. Demographic information was written down on paper during the interview and later entered into a spreadsheet. Interviews were conducted by one qualitative researcher. All interviews were conducted in Tigrigna, the local language in which the interviewees felt most comfortable with. Daily debriefing sessions occurred between the study coordinator and field teams to assure quality assurance and strong communication amongst the study team members. Moreover, after each round of in-depth interview, the interviewers met to discuss the main findings and potential

difficulties. This step allowed for the opportunity to remind study staff of the objective of the interviews and of particular topics for the following round of interviews. It also served to develop emerging topics and to adapt the related questions. The qualitative data were recorded, transcribed verbatim, translated and analyzed using the thematic approach.

### **Ethical considerations**

The study protocol and all associated data collection instruments and consent forms were approved by the Institutional Review Board of the College of Health Sciences at Mekelle University. Oral informed consents were obtained for participation in the study, the home visits for pregnancy and birth, enrolment, treatment as well as for follow-up visits.

## **Results**

The expected live births in both districts were 8086; whereas the actual live births identified were 7857. During the implementation research period, 317 (65%) and 537 (63%) of PSBI cases were identified from Raya Alamata (two days regimen) and Raya Azebo (seven days regime) woredas, respectively making a total of 854 (63%) PSBI cases from the expected births. Moreover, the incidence of PSBI was 12% and 10% for Raya Alamata and Raya Azebo districts respectively (Table 1).

Table 1: Expected and actual Live births, and actual coverage of PSBI cases among sick young infants from Raya Alamata and Raya Azebo districts, Tigrai, Northern Ethiopia, 2016 – 2017 (N = 7857).

Parameter	Raya Alamata	Raya Azebo	Total
Actual LBs identified (n)	2576	5281	7857
10% of PSBI from expected LBs (n)	491	856	1347
10% of PSBI from actual LBs (n)	258	528	786
Actual PSBI cases identified in the site (n)	317	537	854
Coverage from expected LBs (%)	65	63	63
Coverage from actual LBs (%)	123	102	109
Incidence of PSBI (%)	12	10	11

### Referral acceptance

A total of 208 PSBI cases were documented in 20 months follow-up of the implementation research in the two districts that needs referral to the next higher level of care. The majority 144(69.2%) of those cases with PSBI who were referred by the HEWs to the next level of care accepted the referral after a

series of counseling and referral was supported and facilitated, while 64 (30.8%) declined despite the continuous reinforcement of the referral and were treated by the HEWs with simplified antibiotic regimen as an outpatient at the health post level (Table 2).

Table 2:- Proportion of referral acceptance status among families of sick young infants with PSBI in two districts of Tigrai, Northern Ethiopia, 2016 – 2017.

Referral acceptance by the families of an infant with PSBI	Response	Frequency	Percent
	Yes	144	69.2
	No	64	30.8
	Total	208	100.0

The majority, 35 (56.5%) of the families with PSBI children declined referral for no one was to accompany the infant to the next level of care. About 8 (12.9%) of the families declined referral because the

hospital was too far from their home. Similar number 8 (12.9%) of the families also reported that they were not able to afford for transportation costs (Table 3).

**Table 3:** Proportion of reasons for not accepting referral to hospital; among families of sick young infants with PSBI from Raya Alamata and Raya Woreda districts of Tigrai, Northern Ethiopia, 2016 – 2017.

Reasons for not accepting referral to hospital	Frequency	Percent
Hospital is too far	8	12.9
Parent unable to accompany the infant	35	56.4
Cannot afford transport	8	12.9
undecided whether will accept referral	7	11.3
Other	4	6.5
<b>Total</b>	<b>62</b>	<b>100</b>

In the qualitative study, participants were asked to provide their understanding about the efficiency of the existing referral system and direct referral from a health post to a hospital as an option. The majority of the participants stated that though the district office is doing better to support quality care to the mothers and children, so as to get the appropriate care at a hospital level, transportation is considered a big issue where many families with sick young infant could not afford and thereby decline to go to the referral hospital. Among the findings from the qualitative study one participant indicated that *“the district health office only provide an ambulance transportation of the families with referred sick young infants to the referral hospital, but, it does not take them back home”*. Furthermore, participants clearly stated that *“as they are having many elder children at home where no one is to take care, they preferred to get the treatment at the health post”*. These findings complement with the results from the quantitative study.

## Discussion

Significant reductions in neonatal morbidity and mortality must be made to reach the Sustainable Development Goal for under-

five morbidity and mortality. Though community based management of sick young infants with PSBI is proved for its effectiveness by different literature, the gold standard management is that PSBI cases should be referred to a hospital for quality treatment. From this implementation research we have learned that majority, 69.2% of families with sick young infants with PSBI accepted the referral counseling provided by the health extension workers. Moreover, 30.8% declined the referral and were treated at the health post level. The reason of referral declination for the majority, 50.9% was that lack of companion of the sick infant followed by lack of money to afford transportation and the hospital was too far to reach.

Moreover, in this implementation research the capacity of the health extension workers who were well trained and strictly supervised have brought a change in the health seeking behavior of the community which is reflected by the increase in the referral acceptance of the families with sick young infant which is the main objective of the implementation research. The health extension workers are health cadres their main role is in health promotion, disease prevention, and treatment of uncomplicated and non-severe illnesses such as malaria,



pneumonia, diarrhea, and malnutrition [9]. The community based management of sick young infants is an additional task that was given to them recently.

Transportation problem was identified as one of the reasons of declination from referral acceptance in the families with PSBI. This was also supported by the findings from the qualitative study that families were not able to afford the transportation cost to reach to the hospitals. Similarly, literatures from Ethiopia and Nigeria pointed out that transport as a key constraint in achieving the child and maternal health goals in most of the developing countries in Africa. Transport and Health are inextricably linked. The WHO/UNICEF describes the consequences of inadequate transport for delivery of basic health care to the most impoverished – usually rural areas have few or no health care facilities or the means to transport people for medical assistance. Studies on the accessibility of referral hospital care have repeatedly confirmed the existence of a steep distance-decay function, in countries such as Ethiopia and Nigeria [10, 11].

Families also indicated that distance of the referral hospital as one factor that prevented them not to accept the referral recommended by the health extension workers. It is obvious that the rural populations in the two study districts are scattered with bad topography. This problem together with the inability to cover the transportation cost made the families to decline from the referral. A number of studies have indicated that public hospitals in many poor countries like Ethiopia disproportionately benefit the impoverished community because of lack of accessibility to the community [12, 13]. Another reason for the declination of referral of the families with sick young infant was lack of companion from the family members believing that a sick infant does not get cured in hospitals.

## **Conclusion and recommendation**

In conclusion, appropriate referral is undoubtedly one of the main factors in determining the quality of health care at different levels. Relatively we found high compliance to referral acceptance. This suggests that HEWs can play a significant role, within the community management of sick young infants, to improve newborn health and reduce child mortality. Transportation cost and distance of referral hospitals are the main reasons of declination from accepting a referral after counseling. Moreover, lack of companion of the referred sick young infant is among the obstacles of referral acceptance. Therefore, it is recommended that the Tigray regional health bureau/district health office arrange round trip transportation to families with sick young infants who are referred to the next level of care. Furthermore, engagement in awareness creation of family members on the importance of referral for a better management of the sick young infants with PSBI should be in place.

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