Community Involvement in A TB Prevalence Survey in Western Kenya

JANET AGAYA

KEMRI/CDC KISUMU
OUTLINE

• Background
• Study site
• Why community involvement
• Objectives
• Methods
• Challenges
• Achievements
Background (1)

- **TB in Kenya**
  - TB major health problem in Kenya
  - Kenya ranks 13\(^{th}\) among the 22 HBC
  - CNR 329/100,000 (2008)
  - HIV key contributing factor (7% HIV prevalence nationally, KAIS; 52% of TB patients co-infected with HIV)

- **TB in Nyanza**
  - Contributes 20% of the national TB burden
  - TB notification of ~400/100,000
  - HIV key contributing factor (15% HIV prevalence; 75% of TB cases co-infected with HIV)
Background (2)

- Conducted a TB prevalence survey
  - To determine prevalence of sm+ and culture +PTB
  - Among pop. ≥ 15 yrs in Gem and Asembo areas
  - Aimed at enrolling 20,000 people from 40 clusters in 1yr
  - Rural population with high TB and HIV prevalence
Study Area, Nyanza Province, Western Kenya

Area combined: 450km²
Pop (2005): 134,000
DSS since 2002
Health research: >10yrs
Study procedures

1. Door to door community mobilization

2. Enrolment in the house
   - Informed Consent
   - Symptom Questionnaire, administered in a PDA
   - Two Sputum Samples taken (spot and early morning)
   - Refer to central site in the village

3. At a central location in the village
   - Chest radiograph (CXR) done
   - Review of CXR by clinical officer
   - Treatment for minor illnesses on-site or referral

If suggestive symptoms:
- The two sputum samples examined by Fluorescence Microscopy
- An additional sputum sample is taken and sent for culture
- If positive TB, notified and registered with TB treatment program.

If any abnormality on CXR:
- If any abnormality on CXR

KEMRI/CDC Research and Public Health Collaboration
Center for Global Health Research
Why Community Involvement?

• Low participation in a cross sectional study may introduce selection bias
• To enhance participation, we required
  – Good collaboration
  – Adequate sensitization
• Community willingness to participate could be influenced by
  – Research fatigue from previous studies
  – Previous adverse rumors
  – Previous adverse media reports about communities being used as “guinea pigs”
  – Stigma related to TB and HIV
Objectives

1. Obtain the communities’ view on the envisioned study procedures
2. Ensure community understanding of the study to enhance their full participation
3. Maximise enrolment of eligible persons within a cluster
4. Ensure community members made informed decisions about their involvement in the study
Methods

1. Focus group discussions
2. Involvement of community leaders/institutions
3. Training of study personnel
4. Home based consenting and enrolment
5. Mobile radiography
6. Follow up of cases
Focus Group Discussions (FGDs)

• Objective, to identify
  – Potential barriers to study participation
  – Best ways to enhance people’s participation
  – How the study will be perceived in the community

• Five categories of people living in each study area were involved
  – Adult males
  – Adult females
  – Community TB volunteers
  – Village Reporters
  – DSS interviewers

• 11 FGDs with 8-12 participants conducted
FGD Findings (1)

Prevailing barriers to seeking TB care

– Stigma, poverty, cultural beliefs, ignorance,

1. Majority were willing to participate because of reduced “costs and convenience”.

– “In this village where I live, if TB testing is brought, I think they can be happy because one or two here have TB. People have TB such that if they hear that the vehicle will come and they will be treated, something done for free, people would come in large numbers.” (Quote from a Female member from Gem).
FGD Findings (2)

2. Barriers to study participation
   – Lack of awareness
   – Staff attitude
   – Breach of confidentiality
     • “When one is going to get tested even for TB, there are those who fear...... he thinks that another disease is going to be detected in his body. The bad one that we hear kills people.” (Quote from a Male member Gem).
   – Sputum production procedure (embarrassing)
   – Community activities
3. Concerns and recommendations
   - Support to the elderly sick/weak participants – provided transport
   - Carrying sputum samples embarrassing - provided opaque bags
   - Doubtful of getting results – provided individual letters

4. Generally community willing to participate if concerns addressed
Community Entry Process (1)

1. Leaders awareness meetings
   - Health authorities
   - Administrative leaders

2. 2 Community Advisory Boards constituted following predefined criteria
   - 22 and 28 members respectively
   - Trained to link the study and the community
   - Represent the interests of the participants throughout the study period
   - Monthly meetings to report on emerging issues
3. Leaders participation in cluster sampling
   - to enhance their understanding of the process
   - Ability to explain the process to the community
   - Simple random sampling of 40 out of 105 clusters in DSS
     • 1 cluster = 1 - 4 villages, providing ~500 participants
   - Study sample size 20,000 participants
     • Participant Eligibility
     - All persons ≥15 yrs and resident for ≥1 month in sampled cluster
• Community sensitization meetings: meetings were conducted with community organized groups, church leaders, teachers, household members etc to inform them about the study, its benefit to the community, explain expected roles.
Home Based Consenting and Enrolment

(1)

- Home based enrolment
  - To maximize participation
  - To link to DSS data

- In the homes
  - Permission from head of compound
  - Update DSS data - recent migration and deaths
  - Eligible persons given group information
  - Written informed consent obtained from each individual
• Administer symptoms questionnaire
  – Using cough instruction chart
• collected spot sputum samples
• Instructions for overnight sample
  – Referral to a central site for radiography
Mobile field site (MFS) situated at a central site in the village
- Community advised on selection of site
- Public institutions preferred e.g. schools, churches
- At night, equipments stored at a nearby police post
- Community guarded the tents
Mobile Radiography (2)

- Mobile radiography unit locally assembled to meet the study needs
  - Move closer to the people
  - Manage local road conditions
- Consisted of
  1. X-ray machine practix 400
  2. Curix ID camera
  3. Film processor curix 60
  4. a 20KVA mobile generator
Roles of Community Resource Persons

(1)

Provided labour for supportive activities including

- Minor road repairs
- Security of the study team and equipments
- Reminded participants to come for x-ray
- Brought water and food to site
Roles of Community Resource Persons (2)

- Guided the study interviewers in the village
- Provided group orientation on x-ray procedures to participants using visual aids at the MFS
- Maintained order and flow of participants at the site
Follow Up of Cases

- Guided the study team to deliver results to study participants
- Cases referred to health facilities and started on treatment by study nurses
- Follow up was done for those who delayed to report to the facilities
Conclusion

• Community involvement
  – Important pre requisite for the success of such a large survey
  – Prior knowledge of community perceived barriers to participation helps in tailoring procedures

• Important that the entry process is
  – systematic
  – involves the relevant persons
Participant Flow and Tracking at the Mobile Field Site
Mobile Field Site

The daily set up of a Mobile Field Site (MFS) in the village where x-ray procedures were undertaken.
Mobile Field Site

Reception
- Check invitation card
- Log in
- Tracking form

Dispatcher
- Receive tracking form and card
- Log out
- Dispatch incentive

Clinical Office
- Read CXR
- Minor ailments
- 3rd sputum if applicable

Waiting bay 1
- Explanation on X-ray

Changing ‘rooms’

Waiting bay 2
- Await X-ray

Chest X-ray
Challenges in enrolment

Demographic Challenges

Migration/not at home

- 11.4% of the population expected based on DSS information had moved.
- 1% had died
- 24.9% of persons reported to live in the sampled clusters could not be found at the time of survey; reasons:
  - Schooling in boarding schools elsewhere
  - Labour/occupation/economic activities that keep people away from home for the day or longer.
Challenges in enrolment

A. Community related Issues

1. Refusal
   - 10.7% of the eligible participants refused to participate.
   - Some villages were more difficult especially those “over researched” whose negativity appeared to be based on passed experience with other studies.

How addressed
   - Intense community mobilization and promptly addressing any related concerns before and throughout the study period.

2. Religion
   - Strong religious influence predispose people to believe in divine intervention for whatever illness hence hindering participation in modern medicine research.

3. Culture
   - Those deeply rooted in the native culture tend to shun modern medicine related activities.

How addressed
   - Respect for people’s religion and culture and accept their decision.
Challenges Cont.

4. Hostile participants
   - Some potential participants were hostile to the community interviewers despite introduction by a community member hence difficult to consent

   **How addressed**
   - Regular update to the provincial administration or their representative on the team’s movement and activities in the village.

5. Events in the village
   - Events such as market days, funerals and agricultural activities interrupted the availability of participants at home.

   **How addressed**
   - Advance team noted community calendar of events upfront and planned accordingly
   - Repeat visits
6. Participant health status
   – Some participants were too sick and required extra time and patience to take them through the procedure

How addressed
   – Provided transport to bring sick participants to the central site and back to their homes

7. Drunkenness and Illicit brew in the village
   – Where local brews were prepared and consumed, it was difficult to communicate with drunken potential participants.

How addressed
   – Sought appointments with such families and made re-visits
8. Illiterate participants
   - Consenting process was slow among the illiterate participants

9. Age of participants
   - The elderly took long to comprehend what the study entailed hence the interviewers took long in consenting.

How handled
   - *Being patient, taking time to ensure comprehension*
10. Fierce dogs:
   - Fierce dogs could hamper access to some compounds

   **How addressed**
   - Guidance by community members familiar with such homes
   - Diplomacy and good community relations made possible to identify such homes upfront.
Challenges cont.

B. Project Management Issues
1. Inability to attain the set enrolment target of 100 participants per day so as to complete the study on time.
   - Initially average enrolment was below 50/day
   - Later increased to average of 80/day with peaks of 90-100

How Addressed
- Increased the number of community interviewers
- Improved efficiency of procedures
- Adjusted to a more realistic goal of 85 participants per day
2. Staff unfamiliarity with mobile equipments

- Both study radiographers and equipment dealers were unfamiliar with use of x-ray and the automatic film processor in a mobile x-ray van hence overlooked critical requirements like ensuring leveling of truck always before commence of operations.
- The study ID card printer was sensitive to size of the card
- How overcome
- Always use spirit level and wooden blocks to ensure level parking of the truck
- understand the printer sensitivity to card size.
3. Maintaining good quality and quantity of sputum.
   - It is difficult for people without respiratory illness to readily give sputum

How addressed

Developed instruction materials on how to give sputum in the right qualities and quantities
Challenges Cont

4. Slow flow of participants at the x-ray unit
   - Due to Participant’s unfamiliarity with X-ray procedures and surprised at technological innovations. extra time was needed to perform x-rays

How addressed
   - Developed instruction materials on x-ray procedure to improve understanding on the same
   - A lay worker explained the procedures to the participants using pictures before entering the unit
5. Equipment breakdown

- Over the study period we lost 14 days working days due to equipment breakdown with one long period of 4 consecutive days.
- This led to overwhelming number of participants on the next functional days.

**How addressed**

- Service agreements for prompt action
- Functional spare film processor in store
- Regulate participants flow
C. Infrastructure

1. Bad roads
   • Inaccessibility due to bad roads and sometimes coupled with bad weather called for the field site to be set in neighboring villages. This could lead to:
     - Interruption by non participants especially if the neighboring village was not sampled
     - Increased the walking distance to the site.
Challenges Cont.

Poor terrain coupled with sparse population
• This made the walk through some villages difficult hence slow down enrolment.

Bad weather;
• The rains and muddy roads and foot paths not only made communication between the compounds difficult but also delayed the start of work

How overcome
• Transported participants to the central site
• Where possible unskilled road repairs with the villagers was done
• Used vehicles to drop and pick interviewers at convenient points in the villages
• Interviewers had raincoats and gumboots
Challenges

Unexpected events

• Some days, sudden unexpected events completely called for a total change of the day’s plan
Challenges Cont.

Administrative challenges

LAB
- Receiving large number of samples
- Huge work load of receiving and processing 150-200 sputum samples per day for microscopy hence delays in giving results.
- Unexpected break down of a florescent microscope part not locally available. It took more than 2 months of this very busy period of time.

DATA
- Consolidating data activities from various data collection points

How over come
- Tracking system in place for all documents used to ensure no data is lost
Achievement

- Good rapport developed
- Enrolled 20,314 in 17 months from 40 clusters
- 8.9% of eligible participants found in their houses at the time of study declined
- >95% gave spot and EM sputum samples
- 92.1% of the enrolled participants presented for radiography
Acknowledgement

• The leaders and community of Asembo and Gem,
• Health authorities in the area,
• All participating public and private institutions such as churches, schools, police posts,
• The KEMRI/CDC field staff
• The Principle Investigator, TB Prevalence Survey
• Dr. Kayla Laserson
• Dr. John Ayisi
Thank you