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Community Participation in Onchocerciasis: A Case Study

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Section A

Contrasting Community-Based and Community-Directed Programs

Community-Based vs. CDTI Ownership, Decision Making

- ✦ *CBTI* is a procedure wherein health providers determine the steps and the schedule to be followed
 - Activities are based in the community but not owned by the community

Community-Based vs. CDTI Ownership, Decision Making

- ✦ *CDTI* is a process built on the experience of community members and thus enhances decision making and problem-solving capacity
 - Activities are both in and of the community

Who Exercises Authority?

- ✦ **CBTI:** Community does not exercise authority over decisions on project design and implementation
 - Project activities, (e.g., treatment dates and procedures) are designed by the agency

Who Exercises Authority?

- ✦ **CDTI:** Community exercises authority over decisions and decides on acceptable method of distribution (e.g., central place, house-to-house) and when to distribute
 - Ensures sensitivity to local decision-making structures and social life



Health worker takes on new role of facilitating community brainstorming

Becoming Stakeholders, Innovators

- ✦ **CBTI:** The community is a recipient of services within limits and rules set by the provider
 - There is no sense of ownership; the project is seen as foreign

Becoming Stakeholders, Innovators

- ✦ **CDTI:** The community is the lead stakeholder in the provision of services, creating a sense of ownership and thus enhancing the likelihood that the activities will be integrated into the community's health agenda
 - There is room for innovation by the community

Instruction or Facilitation?

- ✦ **CBTI:** The educational role of the health worker is to communicate the benefits of the program to the community and provide instructions on how to comply with procedures

Instruction or Facilitation?

- ✦ **CDTI:** The educational role of the health worker is to communicate benefits of the program to the community and then pass on program-management skills to community members

Health Worker Roles and Work

- ✦ **CBTI:** The health worker's workload remains constant and high because year after year he/she must handle all training, logistics, and outreach to every village

Health Worker Roles and Work

- ✦ **CDTI:** While start-up field work may increase the immediate workload of the health worker, in the long term, an empowered community takes more responsibility for program implementation, thus reducing the health worker's workload

Health Worker Attitudes, Beliefs

Express Doubts

- ✦ Low opinion of community involvement
- ✦ But higher for health inspectors than nurses
- ✦ Believe that they—as trained persons—should take major role in management

Health Worker Attitudes, Beliefs

Express Doubts

- ✦ Lack confidence in ability to do community organization
- ✦ Complain—lack of logistical support, (e.g., transportation to reach out to community)

Health Workers Have Poor History of Fostering Community Involvement

- ✦ This is often missing from their basic training
- ✦ Mobilization the most common approach
 - Immunization—transport unions provide transportation
 - Environmental sanitation—boy scouts get out the word

Health Workers Have Poor History of Fostering Community Involvement

- ✦ Suspect communities to hold traditional beliefs too strongly
- ✦ Desire to control programs—because expected to report back statistics that show results

Community Has Own Set of Concerns

- ✦ Health workers rarely visit our village
- ✦ If they come, it is only to tell us what to do
- ✦ When they visit, they expect gifts of foodstuffs
- ✦ During the guinea worm program, they selected the village-based worker for us

Community Has Own Set of Concerns

- ✦ Most of the time, they expect us to come to them when we need help
- ✦ We have complained before to government, but no response has been seen

Intervention Strategy

- ✦ Enhancing Interaction/Communication Stakeholders Meetings (SHMs)
- ✦ SMH includes village representatives, CBO representatives, and local health staff



Community members share concerns and ideas at SHMs

Intervention Strategy

- ✦ SHMs are opportunity to enhance communication between health workers and villagers
- ✦ SHMs serve as a venue for clusters of villages to plan best strategies for CDTI

Intervention Design

✦ Standard CDTI: 2 Districts

- O1 = baseline measures
- X = Standard guidelines followed
- O2 = Follow-up data collection

✦ Enhanced CDTI: 2 Districts

- O1 = baseline measures
- X = Standard CDTI + SHMs
- O2 = Follow-up data collection

Feedback on SHM

✦ Community representatives

- “This kind of meeting will weld all communities together and they will speak with one voice”
- “There has never been a meeting like this, but we enjoyed it ... (because) it is a useful solution to our health problems”

Feedback on SHM

✦ Community representatives

- “The interaction (with health workers) was very encouraging because they asked us many questions; we too asked them some questions”
- “Before (the health workers) had not been coming to our village, but since that day, we believe that the meeting will yield fruit”

Health Worker Feedback

- ✦ “This kind of meeting will support the program as communities were carried along from the start”
- ✦ “I am able to know many people from the villages through this meeting”
- ✦ “The meeting enabled villagers to see themselves as somebody useful in primary health care delivery; it improved my knowledge as a health worker”

Health Worker Feedback

- ✦ “Villagers and health workers had freedom of speaking; the villagers recognize me more and are coming to me”

Section B

Results of Enhancing Community-Directed Treatment

Community Participation

✦ Enhanced Arm

- “We contributed money to buy biros, notebooks, drug box, and drugs to treat side effects”
- “We provided means of transport for CDD”
- “We mobilised villagers to use the drug”

Community Participation

✦ Regular Arm

- Similar contributions as above, but ...
- Twice as many negative responses, “There was no meaningful role played by the community”

Community Participation

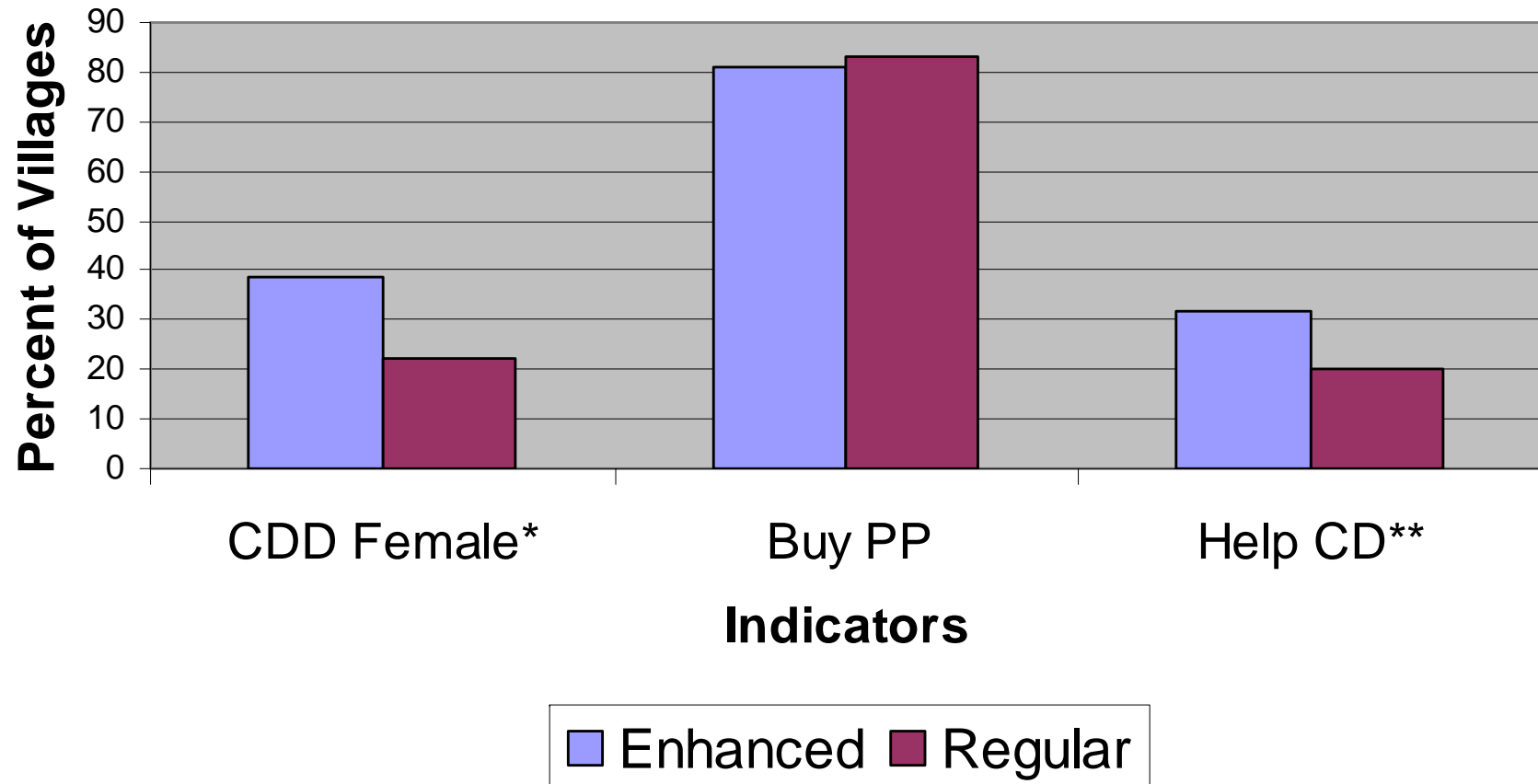
✦ Regular Arm

- More conditional responses:
 - “We are supposed to ...”
 - “We should ...”
 - “We are expected to ...”

Some Changes from Enhancing Participation

- ✦ More female CDDs
- ✦ Slightly more help in cash and kind to the CDD
- ✦ No difference in whether stocked village drug kit with paracetamol and piriton

Indicators of Enhanced CDTI



Perceptions of Interaction

- ✦ “I now can see health workers at least once in every month; they don't come regularly like that before”
- ✦ “Before, there was a wider gap in the communication between the health workers and the villagers”

Perceptions of Interaction

- ✦ “I was able to know that I can go directly to (the Onchocerciasis Coordinator) to ask for the drug any time. We all discuss freely at the meeting; there was no head or tail (leader or follower)”
- ✦ “People now have confidence in health workers. Formerly, many didn’t believe in them because we thought health workers used trick us”

Perceptions of Interaction

- ✦ “I don’t think that there was a good relationship before the meeting, but immediately after there is a positive reaction”

Some Skepticism Remains

More Especially in the Regular Arm

- ✦ “Health workers only came for immunization”
- ✦ “There was no interaction; we never see them”
- ✦ “Health workers unlikely to come after research team concludes work”

Some Skepticism Remains

More Especially in the Regular Arm

- ✦ “We don’t see the effect of the HWs”
- ✦ “We don’t see them anymore”
- ✦ “We didn’t see HWs. It was the researchers that usually came and took care of us”

Willingness and Commitment

- ✦ In both arms
 - “We are ready and very willing to continue taking this drug; this we will do through mobilizing our community members”
 - “We are capable to continue using the drug because we benefited. We want it on a regular basis. Many people used it”

Willingness and Commitment

- ✦ But more respondents in Enhanced Arm mentioned steps already taken to plan for future

Health Worker Performance

- ✦ Observed that they can facilitate training and meetings
- ✦ CDTI internalized
 - Our role is to visit community leaders
 - We should allow them to select CDD for themselves
 - My role is to train the CDDs
 - We gave the village a free hand

Health Worker Performance

- ✦ Those in Enhanced Arm report undertaking more essential CDTI activities—planning, managing supplies, supervision

Health Worker CDTI Attitude

- ✦ Communities are capable of managing ivermectin—increased
- ✦ Oncho control best run at district (not state) level—increased
- ✦ Community involvement saves HW time—increased

Health Worker CDTI Attitude

- ✦ Health workers cannot handle distribution, overworked—increased
- ✦ Health workers don't believe in CDTI—decreased

Health System/Policy

Advocacy Needed

- ✦ Local government (LG) chairmen and councilors were positive for future support
 - The LG is ever-ready and willing to support all programs aimed at improving the health of the community, including ComDT

Health System/Policy

Advocacy Needed

- ✦ LG Health Department observed
 - Frequent change in councils
 - Logistical and financial support in some LGs
 - Lack of current vote or interest in others
 - But still ready to continue, expand

Conclusions: Sustaining CDTI

- ✦ Communities are capable of implementing and sustaining ComDT
 - Resources provided for procurement, side effect management, CDD support, etc
- ✦ CDDs are capable of distribution, record keeping
- ✦ CBOs have potential

Conclusions: Sustaining CDTI

- ✦ Health staff are also capable
 - Able to facilitate, interact with community as partners
 - Manage training, drug supplies, etc
 - Express positive attitudes toward CDTI