Focus on Non-Compliance: Populations, Causes & Formulating a Programmatic Response

Session Date: Saturday, October 27

Session Time: 9:00am – 12:00pm

Session Location: Bacchus, 8th Floor

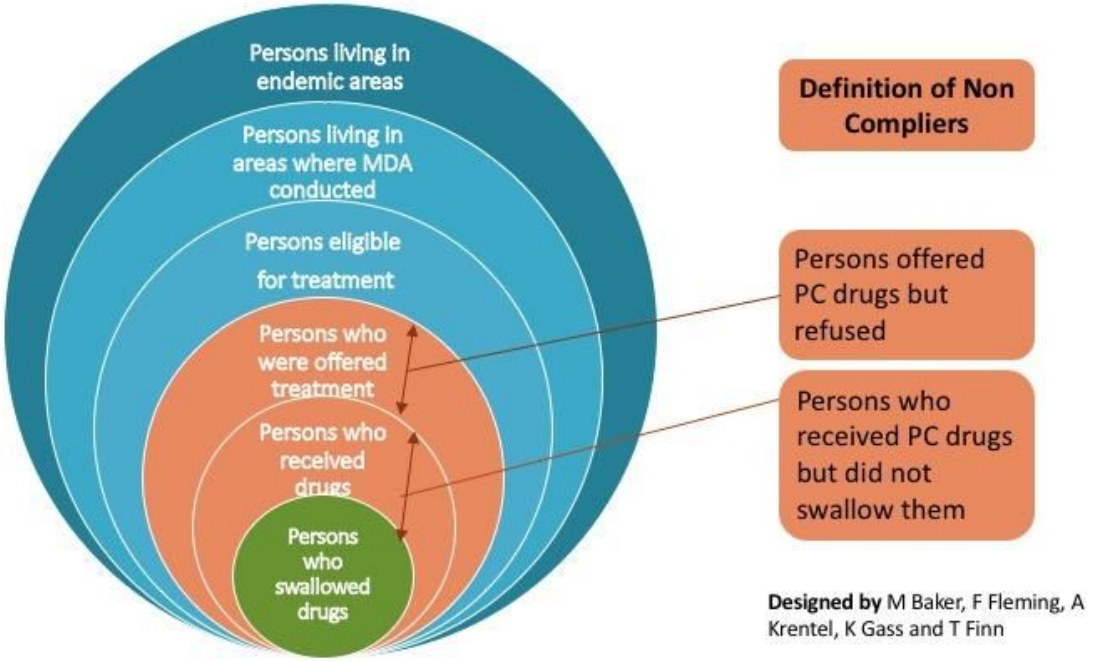
Session Description: Challenges related to low coverage can be defined as supply side (getting the treatment to the population) or demand side (having a population willing to take the treatment). A proportion of people who are offered, or even given, the treatment, do not accept it– they don't show up at treatment posts, they refuse when offered, or they accept the tablets but do not swallow them. This group is what we are calling 'non-compliers' and whom this session will be focused on.

Session Chairs: Margaret Baker, RTI International
Caroline Kusi, The Task Force for Global Health

Session Rapporteur: Chelsea Toledo

KEY DISCUSSION POINTS

The session opened with a presentation from Margaret Baker, who provided a working definition of noncompliers: people who are offered drugs and who refuse them, as well as people who receive drugs but do not swallow them.



Achut Babu Ojha and Ria Larasati presented the situation in the field (in Nepal and Indonesia, respectively) from an implementing program prospective. This was followed by two presentation on

results of research studies: a presentation from Goylette Chami on using network analysis to identify the drug distributors that would increase MDA compliance and a presentation from Alison Krentel on the profile of *systematic* noncompliers.

These presentations generated discussion that focused on the following topic areas: defining noncompliance, noncompliance in practice, communication of side effects, leveraging networks, and systematic noncompliance. Questions from participants and answers from the presenters are summarized below.

Defining Noncompliance

Q: The diagram above assumes that the difference in size between the outermost and subsequent circle represents a disparity in geographic coverage. What if this isn't the case?

A: These circles are not static but can change in size depending on the situation.

Q: What about absenteeism? A sizeable portion of people may not be present to be offered drugs.

A: This group is represented in the gap between the third and fourth circle: people who were eligible, but not offered treatment. These could also be considered as non-compliers – e.g., if they are intentionally avoiding the MDA.

Noncompliance in Practice

Q: There are two groups within the populations in question: adults making decisions on their own behalf, and adults making decisions on behalf of children. Are their reasons for compliance the same?

A: In many cases, the father makes decisions on behalf of the entire family. Grandparents and schoolteachers can also act as influencers. A parent's decision for a child not to participate in mass drug administration (MDA) could represent a desire not to impose risks of side effects upon a child.

Q: Urban population coverage has always been an issue for lymphatic filariasis programs. What unique approaches are being applied to address this?

A: The program in Nepal has delivered messages via mass media, and is also creating a 20-30 minute teleplay (a strategy that was successful for leprosy). In Indonesia, achieving urban coverage has proven difficult, especially among certain ethnic groups, who simply refuse the drugs. While urban MDA in Indonesia cost more, there was no additional cost in Nepal.

Q: Is there a social desirability bias in people who receive the drug and don't take it?

A: There is definitely a difference between the Asian and African contexts. In Africa, if people have reported that they've been given a drug, they've probably swallowed that drug. In Asia, the experience is different. This topic is being addressed in a symposium on urban contexts at the American Society for Tropical Medicine and Hygiene meeting.

Q: Coverage survey results often show that very few people were not offered the drugs. Is it possible that the people who aren't reached by MDA are the same people who aren't reached by the coverage survey?

A: The survey used was the World Health Organization's cluster survey, which has a random chance of meeting communities. Researchers are working to refine the existing tools further.

Communication of Side Effects

Q: What are the side effects of co-administration of diethylcarbamazine (DEC) and albendazole for lymphatic filariasis? How do you explain them?

A: Onchocerciasis is not co-endemic in Nepal or Indonesia, so there is little risk of severe adverse events. The messages communicated is that people may experience minor side effects (including dizziness, headache, nausea, and sleepiness) and this should be seen as evidence that the drug is working and killing the parasites. It is true that some people also have no filaria but still have minor side effects. It seems that a greater number of side effects are observed following treatment with DEC as opposed to ivermectin, which explains the differences in experience in Asia versus in Africa.

Discussions also highlighted the importance of communicating on side effects – on the one hand preparing people for what they will experience and being ethically responsible, and on the other hand not scaring them unduly. Strategies such as having health workers available in case of adverse event were also shared.

Leveraging Networks

Q: This presentation suggested that asking community members about their influential contacts can reveal a village friendship network. Does it matter who asks these questions?

A: Goylette Chami's study leveraged lay surveyors. Unless the information is controversial or confidential, it shouldn't make a difference.

Q: What examples do we have of health-literacy-based information education communication (IEC) models that have been used at the community level?

A: Individual knowledge is important, but we've put all our eggs in that basket, neglecting the collective. We need to take a step back and identify health networks, norms, etc.

Also, social networks can be used to stop rumors: If a rumor about MDA gets to an influential person, that person can correct it and get the right information out.

Systematic Noncompliance

Q: What is the prevalence of microfilaria and antigens in systematic noncompliers (SNC)? Are they important reservoirs of infection?

A: Yes. See slide 30 in Alison Krentel's presentation for references.

KNOWLEDGE GAPS IDENTIFIED & RECOMMENDED NEXT STEPS

Participants broke into three groups, identifying the following knowledge gaps and operational research questions.

Epidemiology

1. ***To what extent do the people we miss systematically represent reservoirs of infection? (e.g. gated communities, apartment buildings, middle aged men etc.). What are the profiles of persons often systematically missed AND who represent reservoirs of infection?
    - Questions should be addressed by disease with review articles where several papers on the topic already exist.
2. What are the most common reasons for absenteeism and rejection of treatment?

Social mobilization

3. ***What strategies effectively address fear of treatment and side effects?
4. What rapid research methods can be used to identify barriers and facilitators of (systematic) noncompliance in settings with known challenges in this area (e.g. Nepal and Ache, Indonesia)?
    - How do barriers and facilitators of compliance vary by community and groups (e.g. urban slums, out of school children)?
5. What locally owned innovative interventions, including use of different platforms, improve compliance? – Need for case studies.
6. What communication methods effectively reduce noncompliance? – Need for case studies

Selection of drug distributors How do we identify the best people to deliver the treatment?

7. *** Replicate the social networks methodology in different settings and evaluate with a randomized controlled trial.
8. Would copying model programs from other health interventions that utilize *peer educators* improve compliance with MDA?
9. Are more people treated when drug distributors and beneficiaries share affiliations (e.g. same family units, social support groups, workplace)? And how can this be used in selection of effective drug distributors?

Monitoring and Evaluation

10. Without DOT, how do we verify ingestion of treatment? Can we revise the coverage survey so that it better captures issues around non-compliance:
    - Are we collecting the right indicators (acceptability, intentionality, systematic noncompliance) to improve programmatic reach?
    - Does the current study design reach the 'right' people?

*** *Notes the three priority questions*