Integrating Community-Based and Participatory Approaches into Tackling Neglected Tropical Disease in Latin America and the Caribbean

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Abstract
Neglected tropical diseases (NTDs) in Latin America and the Caribbean (LAC) disproportionately impact poor and vulnerable populations, especially indigenous populations and communities of African descent. Community-based and participatory approaches, including community driven development, community directed interventions, and participatory GIS can be used to engage and empower vulnerable populations in NTD control and elimination efforts in LAC. Community-based and participatory approaches that emphasize local “ownership” are paramount to garner broad-based support and achieve sustainability of NTD integrated approaches since vulnerable populations are often poor, disenfranchised, and have limited political and economic power. Building participatory approaches on a development framework, like community driven development, helps to address the mutually reinforcing cycle between NTDs and poverty and gives vulnerable populations the power to make decisions on interventions to improve their health and well being.

Introduction
The substantial burden of Neglected tropical diseases (NTDs) on poor and vulnerable populations in Latin American and the Caribbean (LAC) make these diseases anything but neglected. Brazil, for example, does not consider any infectious disease “neglected,” but instead recognizes that these are diseases of poverty ¹. Not only do these diseases tend to occur in poor settings, but they also exacerbate poverty and destabilize communities ². Based on prevalence and healthy life years lost from disability, hookworm, other soil-transmitted helminth infections, and Chagas disease are the most important NTDs in LAC followed by dengue, schistosomiasis, leishmaniasis, trachoma, leprosy, and lymphatic filariasis ³. In the
Americas, the NTDs are concentrated within pockets of intense poverty, and disproportionately impact vulnerable groups, including indigenous populations, communities of African descent, women and children, peri-urban communities, and populations in conflict and war areas. Current control and elimination efforts in LAC have made important strides, but there exists an urgent need to develop innovative tools to combat NTDs, particularly ones that move away from a vertical, single disease-centered approach to those that focus on a more horizontal population health approach. There is a need to design integrated, inter-programmatic, and inter-sectoral approaches that address the multi-faceted nature of NTDs. The participation of communities, and especially vulnerable populations, within these integrated approaches is critical to assuring the success and sustainability of these programs, and ultimately the elimination of NTDs. This review aims to summarize the burden of disease and outline potential community-based and participatory approaches that are apt to engage vulnerable populations in implementing integrated packages aimed at prevention, control, and elimination of NTDs in LAC.

**Methodology**

English, Spanish, and Portuguese articles were identified by searching PubMed and Ovid database EMBASE using various combinations of terms including “Latin America”, “neglected tropical diseases”, “indigenous”, “urban slums”, “intersectoral approaches”, “community-based”, “participatory”, “GIS”, and “community mapping”. Additional articles were obtained by using references cited within articles identified through these search strategies, as well as publications from the World Health Organization, the Pan American Health Organization, the Centers for Disease Control and Prevention, and the World Bank.

**Epidemiology: Disproportionate Disease Burden**

Globally, NTDs infect 1 billion people and put at least 2 billion at risk, or nearly one in three persons in the world. Disease burden due to NTDs accounts for
an estimated 57 million disability-adjusted life years (DALYs) lost per year\textsuperscript{3, 6}. LAC accounts for 8.8% or 1.5 million to 5 million DALYs of the global disease burden due to NTDs\textsuperscript{3}.

The NTDs in the Americas are concentrated not only within pockets of intense poverty, but also among selected vulnerable populations, especially indigenous populations and communities of African descent\textsuperscript{3}. In some areas women and children may be considered neglected populations due to their limited access to health and social support services\textsuperscript{4}. There is also mounting evidence that populations in conflict areas are disproportionately impacted by NTDs. Other vulnerable groups impacted by poverty and heavily affected by communicable and non-communicable diseases include peri-urban communities (e.g. shanty-town dwellers) and the rural poor (e.g. migratory workers in agriculture, miners, and fishers).

Parasite loads are often high within indigenous communities and correlate with poor nutritional status\textsuperscript{7, 8, 9, 10}. Chronic helminth infections have been linked to protein-calorie undernutrition, anemia, and growth stunting\textsuperscript{11}. In Guatemala and southern states in Mexico, indigenous populations suffer from some of the highest rates of soil transmitted helminth infections in the Americas, as well as high rates of onchocerciasis and Chagas disease\textsuperscript{3}. Similarly, the indigenous people of Bolivia and Peru experience high rates of fasciolasis and cysticercosis; those in Colombia are at elevated risk for leishmaniasis, Chagas disease, and yellow fever; and in Brazil, high levels of soil transmitted helminth infections and subsequent growth stunting occur among indigenous populations\textsuperscript{3, 10, 12, 13}. In a study comparing rural Queimadas Indian schoolchildren with urban schoolchildren in southern Brazil, results demonstrated a significant statistical correlation between stunting and the intensity of soil transmitted helminths among the Queimadas schoolchildren\textsuperscript{12}. In Guatemala and Mexico, the indigenous populations who live in coffee plantations are most at risk for onchocerciasis\textsuperscript{14}, whereas in Ecuador and Colombia the disease affects those living on the banks of river shores, primarily people of African and indigenous descent\textsuperscript{15}. In addition to LAC’s indigenous populations, poor communities of African descent, such as those found in parts of the Caribbean, Central America, and Brazil,
suffer from high prevalence rates of NTDs, especially hookworm infection, lymphatic filariasis, onchocerciasis, and schistosomiasis. The unique geography of areas such as the dry and cold Altiplano, the dry and barren Chaco, the isolated Central American highlands, and parts of the Amazonian and Caribbean basins, each represent NTD “hot spots” where marginalized and often impoverished populations of indigenous and African descent live.

The epidemiology of some NTDs, like Chagas disease is shifting due partly to urbanization, migration patterns of the rural poor, an increase in urban poverty, and globalization in areas like the Amazon. Demographic trends suggest that the urbanization of poverty will continue: if poverty rates remain unchanged, by 2015 two-thirds of the poor in LAC will be living in cities, which may impact transmission patterns of some NTDs including Chagas and leishmaniasis. Many urban slums are built on unsecured land, often located in areas prone to natural disasters, such as flooding and landslides, or in close proximity to environmental hazards, such as landfills, all of which can create environments that make the urban poor more susceptible to NTDs. In LAC, leptospirosis is an important cause of morbidity, especially in urban slums. In Brazil alone, more than 10,000 cases of severe leptospirosis cases cluster in the slum settlements which lack adequate sewage systems and refuse collection services. In South America, visceral leishmaniasis is increasingly a peri-urban disease; in these settings, lack of sanitation and sporadic garbage collection provide sandfly breeding sites and increase the risk for leishmaniasis.

NTDs disproportionately result in negative health outcomes for girls and women. Although iron deficiency anemia is multifactorial, hookworm infections are an important contributor to anemia and iron loss in pregnancy in endemic areas. There is also some evidence that schistosomiasis in pregnancy contributes to increased maternal morbidity and low birth weight. It has also been noted that congenital infections with some NTD pathogens can commonly occur. Congenital toxoplasmosis and malaria are the best-known examples, but there is also now evidence that congenital Chagas disease occurs with higher frequency among pregnant mothers infected with Chagas.
Although poverty has contributed to the proliferation of NTDs, evidence is mounting for associations between increased prevalence of diseases, conflict, and systematic violations of human rights. The emergence of cutaneous leishmaniasis in Colombia is linked to several decades of armed and guerilla internal conflict fueled by cocaine production and trafficking. In Colombia, more than 25% of leishmaniasis cases reported in 2004 affected military personnel patrolling conflict areas, representing a three-time increase from the 2003 rate. For civilians living in conflict areas in Colombia, the size and pattern of disease incidence are unknown. In addition, the cycle of poverty, disease, inequality and underdevelopment have at times led to social disruption and civil strife, as was the case in Chiapas, Mexico in 1994 with the Zapatista movement, which saw a concurrent re-emergence of Chagas disease. Conflicts can break down community-health infrastructures, restrict access to health care, limit surveillance, prevention, treatment, and vector control, hamper outbreak investigations due to safety concerns, and reduce donor interest in research. Moreover, the conditions created by war and conflict further perpetuate the neglect of NTDs and marginalization of poor and internally displaced persons with these diseases.

**Community-Based and Participatory Models**

*Community Driven Development: Development Framework*

The most successful integrated, inter-sectoral efforts to date have proven to be those that incorporate concrete, community-based initiatives. Because vulnerable populations are often poor, disenfranchised, and have limited political and economic power, community-based and participatory approaches that emphasize local "ownership" are paramount to garner broad-based support and achieve sustainability of NTD integrated approaches in LAC.

The NTDs are both a cause and a consequence of poverty. The fight to control and eliminate NTDs is integrally a fight against poverty. Rather than a strictly disease-centered approach, comprehensive public policies aimed at community development and poverty reduction will be needed to tackle NTD control and elimination in LAC. Improving community health and promoting
sustainable development in vulnerable populations burdened by NTDs will require that efforts be grounded in a participatory model that addresses poverty reduction and places communities at the forefront of decision making and resource allocation, like the community driven development approach.

Community driven development is an approach to community-partnered participatory research that treats poor people and their institutions as assets and partners in the development process and research-informed programs. Community driven development is a way to provide social and infrastructure services, organize economic activity and resource management, empower poor people, improve governance, and enhance security of the poorest. The benefits of using a community driven development approach to reaching vulnerable populations impacted by NTDs are multiple.

Community driven development can function as the founding framework upon which the other participatory approaches, community directed interventions and participatory GIS, are built. These participatory models will contribute to the gains that have already been made by NTD integrated packages, while facilitating community involvement through participatory decision-making, local capacity building, and community control of resources. Incorporating community based and participatory approaches within existing integrated packages can help shift the current disease-centered approach towards more comprehensive public policies aimed at community development and poverty reduction, which are needed to fully address the complexity of NTDs among vulnerable populations in LAC.

**Community-Directed Interventions**

There is an urgent need to develop and scale up strategies that can ensure improved access of poor populations to existing, efficacious health interventions. One such model that has proven effective is community-directed interventions. As defined by the World Health Organization (WHO), community directed interventions are health interventions that are undertaken at the community level under the direction of the community itself. Box 1 describes a community-directed
intervention using community cooperatives to improve malaria control in Colombia and Mexico.

The ultimate test of community-directed interventions’ effectiveness is whether they can improve and sustain the coverage of the target populations with the interventions 36. Coverage with impregnated nets was above 50% in all study areas and the fastest increase of insecticide-treated material coverage was achieved through the exclusive sale of impregnation services (Box 1) 37. Community cooperatives like the Mexico/Colombia project could provide an avenue to form an integrated and intersectoral program between Malaria and NTDs focused on vector control and preventive health education.

Control and elimination programs in LAC that can potentially adopt the community directed intervention approach to increase community participation and ownership include mass drug administration (MDA) for lymphatic filariasis, onchocerciasis, trachoma, and leprosy, deworming programs for soil transmitted helminths, health promotion and education programs, and community surveillance programs for Chagas disease. However, community involvement may vary by country, geographic setting, and target population so community directed interventions must be undertaken in ways that are consistent with local norms, systems, and structures acceptable to the community as well as the functionality of the health systems 2.

**Participatory Mapping and Geographic Information System (GIS) Approaches**

Mapping of disease prevalence and distributions is crucial to any control effort 38. Public participatory GIS has arisen as an innovative approach to make use of digital media in order to engage communities in the process of visualizing, interpreting, and generating geographic information 39. Participatory mapping has great potential to increase our understanding of community health while at the same time generating local ownership of information about community assets that can be used to reduce risk 39. Agriculture cooperatives in Telpaneca, Nicaragua used community mapping, a type of participatory GIS, to settle land demarcation disputes, increase management and control of their lands, and promote resource
conservation and local-state relations. Participatory mapping methods can help indigenous groups in LAC better map their lands, which often have poor cartographic coverage, and in turn better understand and bring attention to the impact and patterns of NTDs. The use of participatory GIS as part of an integrated ecosystem approach for the management and prevention of vector-borne diseases, such as dengue, Chagas disease, and leishmaniasis should be explored. The ecosystem approach assists in characterizing the underlying driving forces that lead to exposure to vectors and advocates for involving the community in all aspects of control programs to enhance behavioral changes.

**Special Considerations for Vulnerable Populations**

Addressing the needs of vulnerable populations is imperative if progress is to be made in controlling and eliminating NTDs in LAC. Communities in LAC are not homogenous; thus the use of community driven interventions, community-directed interventions, and participatory GIS approaches need to be designed to be socially inclusive, giving voice and decision-making responsibility to marginalized groups including women, indigenous populations, people of African descent, peri-urban poor communities, and rural communities. When designing inclusive programs, it is important to understand existing community decision-making processes and the often-complex local political and social contexts.

**Conclusion**

Building participatory approaches on a development framework, like community driven development, helps to address the mutually reinforcing cycle between NTDs and poverty and gives vulnerable populations the power to make decisions on interventions to improve their health and well being. Furthermore, participatory approaches embrace group autonomy and management under self-determination. When working with vulnerable populations it is also critical to consider the unique geographical, social, cultural, and political contexts that can influence participation in NTD control and elimination efforts and make adjustments accordingly. Not addressing the disproportionate burden of disease in
vulnerable populations means further neglect of the already neglected tropical diseases in LAC. Ultimately, the treatment and prevention of NTDs is an ethical imperative to respond to the fundamental human right to health, particularly for LAC’s poorest and most vulnerable populations, its indigenous populations, people of African descent, peri-urban populations, women and children, and populations in war and conflict areas. True progress toward the goal of controlling and ultimately eliminating NTDs in the LAC region will require successful efforts to integrate poor and vulnerable communities in developing locally appropriate and feasible solutions in their communities.

Tables and Figures

Table 1: Benefits of Community Driven Development.
Source: Reference 33

1. Complements market and public sector activities
2. Enhances sustainability
3. Improves efficiency and effectiveness
4. Allows poverty reduction efforts to be taken to scale
5. Makes development more inclusive of the interests of poor people and vulnerable groups
6. Empowers poor people, builds social capital, and strengthens governance
Box 1. Community Directed Interventions on the Ground: Community cooperatives and insecticide-treated materials for malaria control in Colombia and Mexico

Source: Reference 37

Scope & Background of the Project. Insecticide-treated materials have a mean protection efficacy against malaria episodes of roughly 40% in lower endemicity areas of Latin America and have been shown to have some protection against other vector-borne diseases like Chagas and leishmaniasis. However, scarce human resources limit maintaining and monitoring high insecticide coverage in Latin America. Community cooperatives, which aid in vector control through provision of insecticide-treated materials to community members, can help fill this gap.

Selection of pilot project communities: The Mexican states of Chiapas and Oaxaca, which are malaria endemic, exhibit high poverty, and have a large indigenous community presence, were selected by Mexico’s social security system (IMSS) to participate in the project. The Colombian Ministry of Health and the National Institute of Health selected the poor pacific coast, Chocó department, and the better-off Atlantic coast, Urabá (Antioquia department), to participate. Eight cooperatives were set up in Mexico (5 in Chiapas, 3 in Oaxaca) and 6 cooperatives in Colombia (3 in Chocó, 3 in Urabá). The cooperatives offered one of the following three kinds of insecticide-treated material services: sale of impregnation services; sale of impregnated nets; or production of nets and sale of impregnated nets.

Partners: Mexico—IMSS, community members (mostly women & rural); Colombia—Ministry of Health, community members (mostly women & urban)

Community Participation: All cooperatives had an elected president, secretary, and treasurer. The cooperatives were responsible for marketing the product and administrative and financial control. The respective partners in each of the countries provided continuous support and supervision, which led to development of the infrastructure and corporate identity of the cooperatives. Development of the community, protection of their families, and income generation were among the reasons community members participated in the cooperatives.

Outcomes: Coverage with impregnated nets was above 50% in all study areas. The fastest increase of insecticide-treated material coverage was through the exclusive sale of impregnation services.

Table 2. Strategies to engage Vulnerable Populations in NTD Control and Elimination Programs

Source: Reference 4, 7, and 37

- Identifying subgroups among the poor, especially those at risk of exclusion (i.e., women, indigenous populations, Afro-Latinos);
- Structuring project rules and procedures to promote their participation;
- Determining participatory techniques that can help facilitate their involvement;
- Ensuring that intermediaries (e.g., NGOs, local government) working with communities have experience in working with these groups and using
Box 2. Key Learning Points

- Neglected tropical diseases disproportionately impact vulnerable populations in LAC, including indigenous populations, people of African descent, women, and populations in conflict areas.
- If LAC hopes to control and eliminate NTDs in the near future the unique needs of vulnerable populations must be addressed.
- Engaging vulnerable populations through community-based and participatory models, including community driven development, community directed interventions, and participatory GIS, which address poverty reduction and place communities at the forefront of decision making and resource allocation will help LAC reach their strategic goal to prevent, control or eliminate NTDs by 2015.
- Vulnerable populations are not homogenous in LAC so the proposed community-based and participatory models must be adapted to fit the geographical, cultural, and linguistic needs of each community engaged in NTD control and elimination programs.
- Challenges to implementing community-based and participatory efforts may include overburdening communities with multiple activities, remuneration at the community level, and political will and support.

Box 3. Five Key Papers in the Field

REFERENCES


