

SOCIAL INNOVATION IN HEALTH INITIATIVE

COMPREHENSIVE HEALTH APPROACH TO FIGHT CHAGAS DISEASE

CONTINENT

Central America

COUNTRY

Guatemala

HEALTH FOCUS

Infectious Disease

AREAS OF INTEREST

Health promotion, disease prevention,
cross-sector collaboration

HEALTH SYSTEM FOCUS

Community delivery

COMPREHENSIVE HEALTH APPROACH FOR CHAGAS DISEASE IN COMAPA (JUTIAPA, GUATEMALA), GUATEMALA

Contextualised comprehensive approach to the understanding, prevention, diagnosis and treatment of Chagas disease, involving communities in active participation, health state institutions and non-governmental organisations present in Comapa (Jutiapa, Guatemala).

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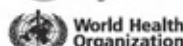


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ABBREVIATIONS

UVG	Universidad del Valle de Guatemala
WHO / OMS	World Health Organization / Organización Mundial de la Salud
IDRC	International Development Research Center (Canadá)
CDC	Centers for Disease Control and Prevention (USA)
JICA	Japan International Cooperation Agency (Japan)
PAHO/OPS	Pan American Health Organization / Organización Panamericana de la Salud
DNDi	Drugs for Neglected Diseases Initiative



CASE INTRODUCTION

Magdalena Medrano is a 46-year-old community leader, a mother with four children who lives in the rural zone of Comapa (in the district of Jutiapa), in southeast Guatemala. When Universidad del Valle de Guatemala (UVG) began its work on Chagas disease in this municipality in 2010, Magdalena became involved in the initiative by taking part in discussions on the disease led by the University's interdisciplinary group, which she has since been invited to join. Thanks to the joint efforts of various institutions and organizations, with strong leadership by the UVG, Magdalena and her family have been able to implement a number of improvements and preventative measures in her home. These include keeping dogs and chickens outside the house, storing grains and maize appropriately to keep out rodents, and setting mouse and rat traps. These measures have helped to protect their living space from "la chinche picuda" ("the blood sucking bug"), which transmits Chagas disease. This vector usually hides in cracks and holes on poorly finished floors inside the home or in walls and palm roofs, wood, adobe (clay) or mud walls – looking to feed on the blood from dogs, birds, rodents and humans. If infected, the insect transmits the parasite through its droppings, causing the disease.

"There were lots of bugs here, but now look, thank God we can hardly see them now (...) We didn't know the bugs could cause diseases, until the projects came and gave us talks about it(...). The hardest

thing about Chagas is not knowing that you are being consumed by the disease, because every day you are getting sicker, and you don't understand why," (Magdalena Medrano, Inhabitant of Comapa) Magdalena explains as she has a good understanding of Chagas. Her oldest daughter was pregnant when she was diagnosed with the disease, during the work to screen for congenital transmission implemented by the UVG. At only 19 years of age, her daughter experienced dizziness, and became very tired while walking around, without knowing what was causing her discomfort. Given the toxicity of the medication available to fight the disease, they had to wait until the end of lactation to treat her. Magdalena tells us that her daughter is now enjoying good health and the child will be tested when he is four years old so that he can start treatment, if he is positive; there is a possibility that the mother could have passed on the disease during gestation or during birth.

Magdalena and her family are some of the people from Comapa to have benefitted from the efforts carried out by the UVG, who have worked in collaboration with other professionals and institutions. Researchers from this university focused on Comapa, as the municipality showing one of the highest levels of bug infestation in the houses, and with one of the highest number of children infected with the parasite across Guatemala (Pennington et al., 2017). This village also had high rates of bug recurrence, even after an intensive

spraying campaign that was carried out nationally, in the 2000s (Manne et al., 2012). However, when working with the Comapa community, the UVG took a different approach from that traditionally used by academic institutions and NGOs within communities, and opted for an interdisciplinary commitment that sought the participation and collaboration of community members, both in the identification of their needs and in developing strategies to meet these. Through the integration of research and intervention projects presented by the UVG to funders and promoters of the World Health Organization (WHO); the International Development Research Center (IDRC, Canada); and the Centres for Disease Control and Prevention (CDC)

of the US, this approach, initiated in 2010, has continued virtually uninterrupted.

The UVG initially focused on reducing the probability of re-infestation of the Chagas transmitting vector in the home, aiming to enable inhabitants to take an active role in the management of animals that the bug feeds on: rats, mice, dogs and chickens. They then focused on improving care, diagnosing and treating Chagas in the Comapa medical centre. Finally, they aimed at reducing the transmission of the disease from mother to child, an effort that is currently helping to raise similar questions and strategies regarding the Zika virus, now also affecting the people of Comapa.

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1. INNOVATION AT A GLANCE

Project Details

Project name	Comprehensive health approach to Chagas disease in Comapa (Jutiapa, Guatemala)
Founding year	2009
Founder's name	Pamela Pennington and Sandra De Urioste-Stone
Nationality of funders	Guatemala
Organizations involved	Universidad del Valle de Guatemala, Ministerio de Salud y Asistencia Pública de Guatemala (Área de Salud Jutiapa, Centro de Salud de Comapa)/(Ministry of Health and Public Assistance of Guatemala (Health Area Jutiapa, Comapa Health Centre), Visión Mundial/World Vision, CDC
Organizational structure	Research and intervention University programme
Size	4 - 10 people, depending on the project being run

Innovation Value

Value proposition	Comprehensive and contextualized approach to the understanding, prevention, diagnosis and treatment of Chagas disease, involving the active participation of communities, state health institutions and non-governmental organizations present in Comapa (Jutiapa, Guatemala).
Beneficiaries	Communities from Comapa (Jutiapa, Guatemala)
Key components	Participatory action research strategy, community involvement, mutual respect between diverse participants and disciplines (social sciences and natural sciences), reflective and cyclical process with short-term impacts.

Operational Details

Main income streams	Funding agencies for academic research and intervention projects
Annual expenditure	Total for 2016: \$100.000 USD

Scale and Transferability

Scope of operations	Municipality of Comapa, in the departament of Jutiapa, South East of Guatemala
Local engagement	Working together with the Comapa Health Centre, Área de Salud de Jutiapa (Jutiapa Health Area), the Comapa midwives, Visión Mundial (World Vision), Ibermed
Scalability	The UVG's strategy can be expanded at a national scale, provided it is included in public policy, and that a national programme for the management of Chagas is introduced, which is a medium-term objective of the team.



2. CHALLENGES

Chagas disease, also called tripanosomiasis americana (American trypanosomiasis) because it is mainly prevalent in Latin America, affects approximately 8 million people worldwide, causing around 10,000 deaths per year (WHO, n.d.). Chagas is the highest parasitic killer disease in Latin America, even more so than malaria (DNDi, n.d.). Microscopic parasites known as *Trypanosoma cruzi* are transmitted to humans through contact with the excrements of triatomine insects, commonly known as chinchés. These insects exclusively feed on blood and have been found in the cracks of very poorly constructed houses, mainly in rural adobe or mud wall constructed houses, providing an ideal environment for the bugs to inhabit and reproduce. At night, they seek hot-blooded animals – dogs, chickens, rats, mice and humans – to feed on. The bugs defecate near the place where they have bitten, and the parasite enters the body when the person or the animal instinctively scratches and spreads excrement into the bitten area, the eyes, the mouth, or any other opening of the skin (WHO, 2017).

Chagas disease has two phases – acute and chronic. During the acute phase, which lasts around two months after infection, a large number of parasites circulate in the blood but usually go unnoticed as the symptoms are minor, unspecific or non-existent. In the chronic phase, the parasites remain hidden in the muscular tissues of the heart and the digestive system. Thirty percent of patients suffer from cardiac problems, and ten percent from digestive, neurological or a mixture of symptoms. Over time, Chagas disease can cause death due to arrhythmias or heart failure

as a result of an enlarged heart because of the immune reaction triggered by the parasites (WHO, 2017).

Chagas disease is usually described as a silent killer disease not only in Comapa but in many other places, because many people suffer a premature and sudden death, without realizing they are infected. Fatigue and other symptoms that derive from an affected heart are rarely associated with Chagas, and even less so, with the triatomines present in precarious living spaces. Due to the poverty and inequality in rural areas of Latin America, people live in conditions that are underserved and conducive to the development of these type of diseases. Deaths caused by Chagas happen years after infection and may not be reported, and with its neglected status, the disease receives a lot less attention than it should. Chagas is part of the group of neglected diseases, which receives little attention in terms of scientific research, development of drugs, and state interventions to prevent, diagnose and treat. The most conspicuous risk factor is poverty (see Stevens, 2004). *“Health can often be commercial (...) but if someone becomes ill with Chagas, Chagas is not commercial (...) the poorest people are left in oblivion”* (Estuardo Alvarado, Laboratory Coordinator of the Health Area of Jutiapa). There is no vaccine to prevent Chagas disease, so the strategy to deal with the disease focuses on the control of the vector insects that transmit it, and on early access to treatment for infected people (WHO, 2017). In Guatemala, the main preventive practice has been spraying with insecticides.

Efforts in domestic vector control based on insecticides were intensively carried

out in the 2000s as an initiative by the Agency of International Cooperation of Japan (JICA), the Ministry of Health of Guatemala and the PAHO. They sought to eliminate the bug scientifically known as *Rhodnius prolixus* (a non-native insect to Guatemala) which transmits the disease. They also tried to bring the level of *Triatoma dimidiata* infestation — another type of bug that also transmits Chagas — to below five percent in the home. In 2008, the WHO certified the interruption of the transmission of *R. prolixus* in the country (OPS, nd). While the use of insecticides against *T. dimidiata* worked in some localities, over

time, others maintained high rates of infestation of these vectors (Hashimoto et al., 2006; Manne et al., 2012) and despite multiple fumigations, places like Comapa have remained with infestation rates of *T. dimidiata* above 20% (Bustamante et al., 2014; Hashimoto et al., 2006). It became necessary to think of alternative strategies with an emphasis on changes in practice and behaviours, to achieve control of the presence of the bugs in the home, and to improve care for people with the Chagas disease. The work of the UVG was initiated because of this need.

3. INNOVATION IN INTERVENTION AND IMPLEMENTATION

The comprehensive health approach for Chagas disease in Comapa (Jutiapa, Guatemala), is an interdisciplinary group initiative convened by UVG researchers, who have secured funding by linking together research and intervention projects. This has enable them to remain in this municipality tackling the problem with practical solutions, virtually uninterrupted for seven years.

3.1. DESIGN OF STRATEGIES BASED ON THE COMMUNITY'S NEEDS, IDEAS AND REQUESTS

In 2009, the WHO launched a funding initiative from IDRC, to finance Chagas projects which addressed the disease from an eco-systemic, biological and social approach. In response to this, Pamela Pennington, researcher and teacher at UVG, invited Sandra De Urioste-Stone, a social researcher with extensive experience in participatory action research, to be part of the project. They decided to put together an interdisciplinary team bringing together the methodologies of social and natural sciences, equally respecting and valuing the voices of all members in the team.

Under this interdisciplinary premise, they proposed a participatory approach that would not pre-determine the Chagas risk factors but instead, would establish a dynamic dialogue with the communities in Comapa to define with them the focus of the work and the intervention mechanisms. As a result, they first concentrated their efforts on reducing the possibility of vector re-infestation, by making the environment outside and inside the homes less attractive to the bugs: they carried out educational meetings with the communities so they could associate the presence of the vector with the disease, encouraged the families to keep dogs and chickens outside, and promoted appropriate storage for the grains inside the home — corn, beans and sorghum — to avoid the presence of rats and mice.

The second step was to focus on improving the provision of Chagas patient care services. Thanks to a collaboration between Ibermed (Spanish NGO) and the Health Area of Jutiapa (Comapa is part of this district), the UVG team trained a person at the Comapa Health Center to diagnose Chagas disease with rapid testing, perform electrocardiographies and provide treatment. This had not been

done before, despite the fact that the medicine is free and is donated to Guatemala by PAHO.

With discussions with the community, it became evident that a concern shared by both men and women was the possibility of the congenital transmission of Chagas, that is, transmission from the mother to child in gestation. Therefore, the third phase of the intervention involved identifying cases of Chagas transmission at the time of delivery. The majority of expectant mothers in Comapa prefer to have a home birth with the support of a midwife. Therefore, the UVG team approached the Comapa midwives and were able to jointly design a care programme where pregnant mothers were referred to the Health Center to give birth and receive diagnostic tests for Chagas and other diseases. The midwives were instrumental in getting the mothers or other family members to take babies when they are one month old to the Health Center to determine whether or not they had the disease.

3.2. RANDOMIZATION BY GROUPS. ETHICAL ISSUES AND CYCLICAL REFLEXIVITY

Randomization by groups or conglomerates is an increasingly common method in health research. It involves defining 'social units' — homes, hospital rooms, neighbourhoods, schools, etc. — and applying a random intervention on a group of these, while leaving others without an intervention. Despite its benefits in the evaluation of interventions in public health, this method raises difficult ethical problems that challenge researchers, ethics committees, regulatory bodies and sponsors (Weijer et al. 2011).

Recognizing the need to evaluate the impact of their projects, in order to deliver on a national scale in the future, the UVG group opted for this method of intervention, which is comparable to

randomized controlled trials (RCTs) in clinical research (see De Urioste-Stone et al., 2015). The group also used it as an opportunity to reflect on the challenges of ethical practices, in order to take action. *"It forces us to think about how to scale [the intervention] so that the whole group can receive it,"* says Pamela Pennington, as she conveys how the ethical need to extend their initiative to the non-operated areas of Comapa led the team, through an exercise of constant and cyclical reflection, to create strategies to make possible the gradual scaling up of its initiative to municipality level.

3.3. USE OF EXISTING COMMUNITY PLATFORMS

UVG is not the only institution working in Comapa. Rather, it is part of a group of entities which includes, amongst others, the University of San Carlos ([see SIHI case study on an eco-health approach to fight Chagas in Guatemala and beyond](#)), World Vision and Ibermed. These institutions have collaborated with state health entities to respond to Chagas and other problems associated with poverty and inequality. UVG's work in Comapa builds on previous efforts by institutions like JICA, which not only worked on fumigation of vectors but also produced educational strategies and materials — leaflets and posters — on Chagas disease.

World Vision, an NGO focused on children, has a well-established community platform in Comapa. For example, the UVG does not see World Vision as a competitor, but as a collaborator, which is why they worked together when implementing this project. In this regard, Denis Corleto, Manager of the World Vision Development Program in Comapa thinks that: *"The situation in Comapa has changed over the last 6 years, and it is not due to one single institution, but to the fact that many of us are worried (...) together we are stronger"*.

4. ORGANIZATION AND PEOPLE

The comprehensive approach that the UVG that developed since 2010 in Comapa, is the result of the merger and commitment of a group of academics and field technicians. They conducted this work thanks to research and intervention proposals about Chagas disease, financed by international agencies such as WHO, IDRC, and CDC. This group is led by Pamela Pennington, a Guatemalan biologist trained in the United States. Sandra De Urioste-Stone co-led the initiatives undertaken by UVG, especially in relation to community-based participatory strategies in Comapa. The team is composed of other biologists, people trained in ecotourism, anthropology and sociology, and field

technicians with extensive experience in community work in rural areas of Guatemala. On the basis of participatory work, and with an intentional lack of a vertical hierarchy, team cohesion has been a fundamental strength. Jorge Sincal's (field technician of the UVG) view on this is that: *"The unity amongst the team is very important (...) There is no difference because he has graduated from University, or because he is a technician (...) They take me into account, my opinions are heard, and that is what also makes a team work, because one feels trusted, one feels that if I can give an opinion, it is because I can do things, and I am taken into account".*

5. RESULTS AND IMPACT

Through their work in Comapa, the UVG demonstrated that strategies which combine traditional ways of controlling vectors – pesticide spraying, community education and rodent control – are able to reduce the risk of Chagas transmission within the houses. The participatory and community-based approach was essential in achieving this, together with the use of culturally appropriate educational tools, and working in conjunction with state health entities and other institutions present in Comapa. Through the community-based intervention, the UVG team was capable of increasing knowledge regarding Chagas disease among community members, achieving behavioral changes for triatomine a rodent control, reducing rat infestation, and highlighting the importance of prioritizing households with tiled roofs. The UVG team was also able to promote collaboration among a diverse group of actors including communities, private

business, government agencies, non-governmental organizations and universities (De Urioste-Stone et al. 2015).

The UVG's initiative, as well as generating evidence for this type of comprehensive approach to be extended nationally, had a series of other benefits which impacted on the welfare of the people from Comapa. On the one hand, their work contributed to better interaction between vector control activities carried out by the municipality, and medical care offered to Chagas patients by the Comapa Health Centre. On the other hand, UVG's work enabled the Health Center to assume an active role in the care and treatment of the people affected by the disease: before, there was little or nothing done. There is now written material on Chagas widely available at the Centre. Leaflets and posters on Chagas produced by the Agency of International Cooperation of Japan (JICA) before its retirement in 2005 have been recirculated, there is a trained

person in charge of diagnosing the disease, and the maternity unit has adapted and taken on the screening – diagnostic testing of mothers and babies. Clara Escobar, Head of the Nursing Maternity Area at the Health Centre of Comapa, says that *"with pregnant women we did not have this active search, and now, through the Universidad del Valle, the search is being done, we have found many children of positive mothers who*

have been studied, and mothers have also been treated."

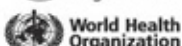
The scope of the work done by the UVG included establishing productive interaction with the Spanish NGO Ibermed, which has distributed portable electrocardiograph machines to enable better management of heart disease, which in places like Comapa is often associated with Chagas.

6. SUSTAINABILITY AND SCALABILITY

The initiative under the leadership of Pamela Pennington, Sandra de Urioste-Stone and her interdisciplinary team, is based at a university and operates under this philosophy. It depends on the attainment of funds, through research and intervention proposals presented to funding agencies. Its sustainability has been possible thanks to the will and commitment of this university group to remain close to the Comapa community and in making a concerted effort that has resulted in increased improvements in dealing with Chagas.

While there are limits in terms of financial sustainability, the strategies they have carried out can be expanded at a national scale and maintained over time; provided they are integrated into public policy, and a national programme for the management of Chagas is established. This has been established as one of the team's objectives in the medium-term. The

production of evidence demonstrating the effectiveness of interventions (De Urioste-Stone et al., 2015) has been regarded as a first step in generating strong arguments to scale-up the initiative. In addition, the work carried out with local health entities (Jutiapa Health Area and Comapa Health Centre) has proven to be fundamental in the initiative's success, and to be replicated in other areas of Guatemala. The UVG will seek to take its ideas to a national level to develop a programmatic commitment that can effectively reduce morbidity and mortality caused by Chagas. It highlights, however, that any programme implemented at a national level must take into account the particularities of each community affected by bug re-infestation, to adapt the strategy, and facilitate its success in each context.



7. KEY LESSONS

Over the years, through their work in Comapa, the UVG team has learnt the importance of sharing results with the communities. Through sustained communication before, during and after interventions with the people of Comapa, the communities have valued the work carried out and given feedback to establish new goals and future action plans. Establishing a communication plan with communities from the start of the programme is considered to be a fundamental element that should be included in budget planning. Similarly, the inclusion of community leaders with a long-standing respect and involvement within the community, as well as identifying key members within each group of participants, has been of pivotal importance for the success of the projects (midwives, in the Health Centre, in the Health Area of Jutiapa, etc.).

Mutual respect between disciplines and participants has been another strength of the UVG initiative. Everyone is equally important, whether they have different training or vision of the problem, or different practices, knowledge, motivation, interpretations or concerns about the communities and state

personnel who operate locally. This is usually not the case of less informed interventions in regards to the context of the community, usually coming from state institutions and organizations with a different vision. *“When the people from the university come here, they start going to people’s houses and getting involved in how people in Comapa live, how they think, what they do, what they want, and what they can do to overcome this situation. They tell us [the state health institutions] what is happening in the community”,* comments Elsa Berganza, epidemiologist from the Health Area in Jutiapa.

In addition, for researchers in the natural sciences such as Pamela Pennington, the inclusion of social sciences from the very beginning of the projects and throughout subsequent stages, has become essential. Others in her team also recognize the value of interdisciplinarity, so much that they continue to work in this way beyond the UVG projects, and those who are not necessarily trained in the field of biomedicine are still interested in the subject of health.

CASE INSIGHTS

1. Participatory and interdisciplinary (or ideally transdisciplinary) approaches to health issues offer communities the opportunity to become deeply involved in understanding their problems and finding solutions.
2. Research and intervention projects based in academic institutions can establish reliable relationships with communities, and make far reaching transformations by connecting projects, allowing for the extension of the work and presence, beyond the project's limitations of time and budget.
3. Intersectoral collaboration involving state institutions is fundamental in articulating the proposed and implemented initiatives with established proceedings and regulations, as well as innovations in existing state processes to generate change at a larger scale.



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