



**Qualitative Study Protocol – “La chiclera”:
Understanding Perceptions about Cutaneous
Leishmaniasis in Q’eqchí communities of Alta Verapaz,
Guatemala**

**A detailed account of a qualitative study investigating perceptions and
meanings of cutaneous leishmaniasis and its treatment in Mayan
populations**

María Purificación Moreno Sánchez

Supervisor:

Ass. Professor Cristina Larrea Killinger

Department of Social Anthropology. Universitat de Barcelona

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**UNIVERSITAT DE
BARCELONA**

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1 List of abbreviations

CDC: Center of Disease Control

CHS-UVG: Center of Health Studies. Universidad del Valle de Guatemala

CL: Cutaneous Leishmaniasis

COCODE: Consejos Comunitarios de Desarrollo

GDP: Gross Domestic Product

IGSS: Insituto Guatemalteco de Seguridad Social

KAP: Knowledge Attitudes and Practices

MIS: Modelo Incluyente de Salud

MOH: Ministry of Health

MSPAS: Ministerio de Salud Pública y Asistencia Social

NGO: Non-Governmental Organisation

NTD: Neglected Tropical Disease

OECD: Organisation for Economic Co-operation and Development

PAHO: Pan-American Health Organisation

USAID: United States Agency for International Development

WHO: World Health Organisation

2 Executive summary

Background: Q'eqchí population is one of the major Guatemalan Mayan-Indigenous groups coexisting in Guatemala, and are primarily settled in rural areas of Alta Verapaz. Alta Verapaz is the area most affected by Cutaneous Leishmaniasis (CL)-commonly called *chiclera*-, a parasitic Neglected Tropical Disease (NTD) transmitted by the bite of a sandfly and characterised by ulcerous lesions causing serious disability. Mayan-Q'eqchí different understanding of health-disease-healthcare, together with the profound disadvantages suffered by indigenous rural areas, make the task of controlling a disease as CL very challenging. The Ministry of Health, together with different stakeholders, focuses its strategy on providing free diagnosing and treatment (intramuscular meglumine antimoniate 20mg/kg/day during 20 days), at no cost. Despite the efforts, the incidence is still high and cure rate low, suggesting that the strategy is not being effective. After lack of success in previous quantitative KAP studies intending to explain the issue, it is hypothesised that a qualitative approach would capture Q'eqchí beliefs, perceptions and experiences about CL in affected communities of Alta Verapaz, and the findings would contribute to develop a more inclusive and contextualised strategy to control CL.

Methods: Sub-groups of key informants in communities of Alta Verapaz will be purposively selected to obtain information through individual in-depth interviews and direct observations during field work. Obtained data will be managed and analysed using the qualitative software NVIVO-11, and further narratives will report the findings. An iterative approach will be adopted for ongoing refining of field tools as relevant topics emerge. The protocol is designed to achieve direct participation of the main stakeholders and community engagement.

Discussion: The use of qualitative methods is crucial to improve the control of CL in Mayan communities of Guatemala, through contextualisation and inclusion of the meanings that people give to the disease and its treatment. Although further strategies concerning surveillance and vector and reservoir control would be highly recommended, this qualitative research protocol might be the first step to contribute to improvements in the design of health strategies involving indigenous populations, through the inclusion of cultural and social aspects regarding disease.

3 Political and Cultural Framework

3.1 Country profile

Guatemala is the largest country- with 108,890 km²- and largest economy in Central America, with and a GDP of \$63.79 billion(1). However, the country is ranked 125th out of 187 countries according to the Human Development Index (2). Among the 16.34 million inhabitants in Guatemala, fifty-three percent live in poverty, and 13 percent live in extreme poverty (3). Although the population is divided almost equally between its urban and rural areas-51.6% and 48,4% respectively(1)-, large disparities persist in indicators of economic development, access to health services, and health outcomes, where rural areas are much more disadvantaged than urban areas(4). In addition, deep cultural differences exist since rural population is mainly Maya, divided in several ethnic and linguistic Indigenous groups distributed across the country.

The capability of the Guatemalan government to provide health and education is severely hampered by weak fiscal systems. According to the OECD, Guatemala's fiscal revenues of 12.3 percent of GDP are among the lowest in the region(5), thus the government's overall capacity to offer services financed with public resources, as health care, among others, could be considered as limited. Indeed, Guatemala's health system is characterized by high levels of fragmentation among various public institutions, worsened during the civil war occurred from 1960 to 1996, where the health system was considerably neglected, resulting in a system with severely inadequate funding and poor coverage of health services in indigenous rural areas(4). Although the Peace Accords of 1996 established measures to address the structural causes of poverty, the high levels of poverty and exclusion suffered by vulnerable groups – as Mayan indigenous population - remain(6). Structurally, in the public sphere, the main actors are the MOH (MSPAS – “Ministerio de Salud Pública y Asistencia Social”-in Spanish), responsible for governance and service delivery, and the Guatemalan Social Security Institute (IGSS - “Instituto Guatemalteco de Seguridad Social”- in Spanish), a social health insurance system covering workers in the formal sector. Members of the armed forces are covered through Military Health. Despite a low level of private medical insurance coverage (less than 5 percent), there are many different actors involved in the private sector. This includes both for-profit and non-profit providers such as NGOs and faith-based organizations, and traditional and alternative forms of medicine(7). A summary of the health system structure is provided in **Figure 1**.

Due to the high number of people working on the informal sector, only 25 percent of Guatemalans have some type of health insurance(4). According to the last USAID analysis “The MSPAS is, in theory, responsible for providing services to the rest of the population, but its effective coverage is much lower”(4). Thus, rural community-based organizations, such as health committees called COCODEs (“Consejos Comunitarios de Desarrollo” in Spanish), and networks of community volunteers (“promotores de salud”) trained as health promoters by the MOH, as well as traditional healers (“curanderos/as”) and birth attendants (“comadronas”), are crucial elements regarding health coverage and services delivery for rural population(4).

Currently, the inclusive model implemented by the MOH -“Modelo Incluyente de Salud” (MIS)- seeks to integrate this parallel system into public health regulations, in its efforts to improve the health status of the country. The model reinforces primary healthcare by focusing on horizontalization of programmes and the

of intercultural approaches, equity, social participation and environmental awareness at three levels: individual, familiar and community levels(8).

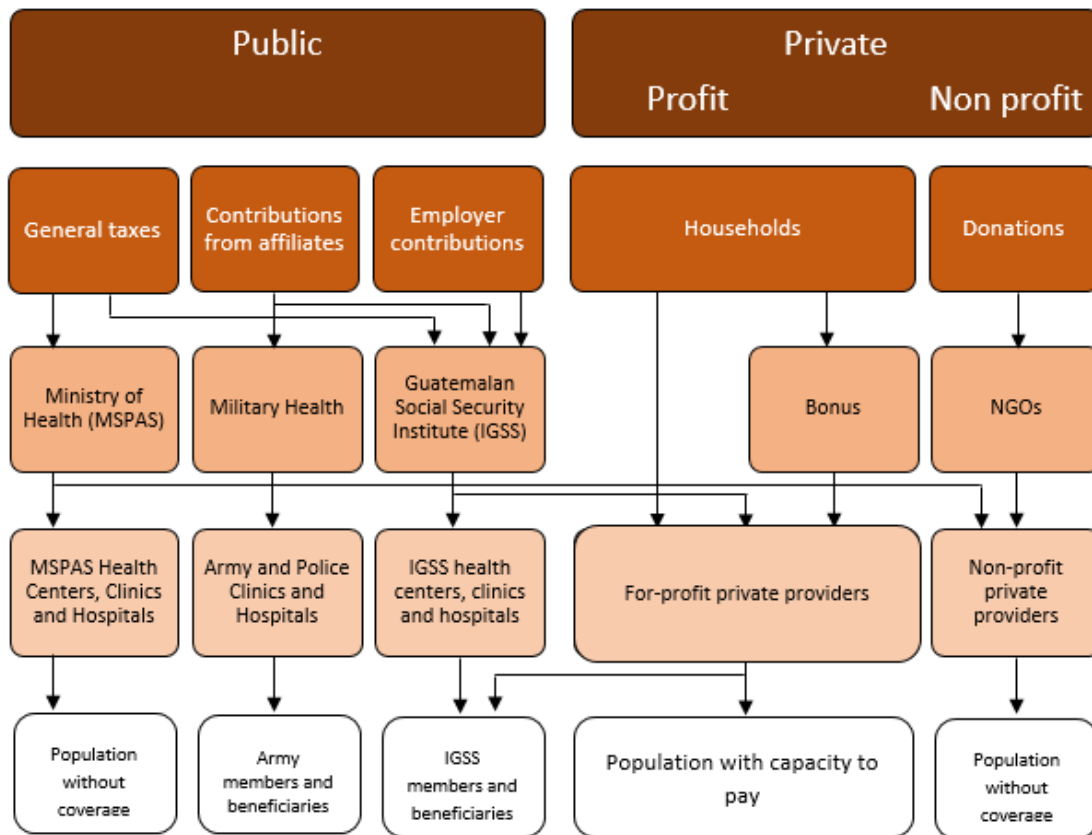


Figure 1. Structure of the Guatemalan Health System(7).

Sector Sources Funds Providers Users

3.2 Mayan Q’eqchí cosmovision

Q’eqchí population

Guatemala has one of the highest percentages of Indigenous population in Latin America(9). There are twenty-two different Mayan groups coexisting in the country -**Figure 2**-. Although they share a homogenous culture, the different groups have kept their particular characteristics, spirituality, and cosmovision(10). At a National level, the Q’eqchí are one of the more numerous groups, representing 11% of the country total population; they are mainly settled in the northern highland department of Alta Verapaz(11).

The Q’eqchí language is the main cultural feature that determines the identity of the group and people are usually reluctant to learn Spanish(12). This factor, along with the social exclusion they have suffered for centuries, has contributed to the maintenance of their characteristics and traditions over time(9).

The respect for nature is the main cultural principle of Q’eqchí and, by extension, of the general Mayan cosmovision(9) . Nature represents an essential component of social and personal self-

comprehension; it constitutes a sacred space that must be respected, given that nature provides all the elements people need in order to survive(9). *Kawá Tzul-Taká*–“*el Dios del Cerro*” in Spanish-, is the main Q’eqchi’ divinity and looks after the requirements of life, “favouring those whose follow the rules and laws inscribed in Nature but punishing those who go against its principles”(13).



Figure 2. Distribution of the different Mayan ethnicities across the country. Took from Journal of Linguistic Anthropology Volume 22, Issue 2, pages E21-E41, 4 OCT 2012 DOI: [10.1111/j.1548-1395.2012.01146.x](https://doi.org/10.1111/j.1548-1395.2012.01146.x)

Disease-Health-Healthcare

According to Mayan cosmovision, the world can be understood as a holism in which each part of the universe relates to each other and coexist in equilibrium(10). In this context, the disease and the health are understood as a duality that exists in an equilibrium which can be dysbalanced by many elements of the universe(14), leading to the appearance of a disease in an individual. The break of the equilibrium can be physical, spiritual or environmental- mind and body, heat and cold, the maintenance of healthy relationships with family, community and nature (14)- and its cause is related with natural and supernatural causes. The result is a variety of symptoms(14).

The classification of “natural” and “super-natural” diseases, is described by Q’eqchi’ population in other terms: *yab’lal*, which people describe as “disease for everyone” or *k’oqob’al*, which is described as “someone is making you sick”(15). *Yab’lal* refers to a class of symptoms everyone experiences in daily life -fever, cough, pregnancy-; their causes are in nature(15)(16). Nowadays, natural diseases are treated both through praying as well as with medicinal plants or *western* medication, depending on the case; for these diseases, patients usually go to the health post, so

people say that natural diseases are cured by doctors(16). Diseases classified as *k'oqob'al* usually follow upon deviant behaviour such as envy, intra-family and neighbour fights, gossip, infidelity, robberies(15)(16), and implies a form of punishment(15). For *k'oqob'al* diseases, the Q'eqchí must be constantly aware of his or her actions and thoughts, as these factors may be the cause of disease; however, a subcategory of *k'oqob'al*, *B'anom yab'ilal*, implies that another person is the cause of the illness, and it most relates to *brujeria* (withcraft)(15).

Regarding healthcare, according to Q'eqchí belief, the nature offers a cure for disease, just as nature produces disease(9)(15). The patient is cured by the intermediation of the traditional healers - "*curanderos/as*" in Spanish-, who have the medicinal plants knowledge, and know the rituals and ceremonies for the treatment and cure of the diseases; the treatment is based both on medicinal plants and religious ceremony(14)(16). Also, in the same family, any member could intervene to cure a sick person, especially the parents and the eldest children. When it comes to a serious illness, then they look for healers to heal the person (16).

With the intervention of biomedical "western" medicine around 1960, the *curanderos* adapted their practices in medicine, and combined their traditional healing with pharmaceutical treatments(16). Moreover, as hospitals and health centers are available, as well as pharmaceutical treatments in health posts, and health promoters who assist remote rural populations, people may have to decide what form of healing they will use.

4 Background and Rationale

4.1 Cutaneous leishmaniasis in Guatemala

Leishmaniasis is an NTD producing 2 million new cases per year worldwide. It is endemic in 18 countries in the Americas, and Guatemala is one of those. Leishmaniasis is caused by 22 different species of a protozoan parasite of the genus *Leishmania* and is transmitted to humans by the bite of infected female of different sandfly species of the genus *Lutzomyia* (17)- in Guatemala this sandfly is commonly called "mosca chiclera" due to its habitat close to wooded areas where gumtrees ("árbol de chicle" in Spanish) grow-. Its complex transmission cycle comprises not only different species of parasites and vectors, but also reservoirs: leishmaniasis cycle is zoonotic, being necessary the presence of an animal reservoir-marsupials, rodents, dogs- for the survival of the parasite in nature.(17)(18). Moreover, it affects the poorest people with the greatest difficulty in accessing health services(18). The main risk factors associated with the disease are: [1] Socioeconomic conditions; poverty increases the risk of leishmaniasis, poor housing conditions and household sanitation deficits. [2] Malnutrition and immunological status [3] Increase of deforestation caused by the agricultural exploitation-as palm plantations in the case of Guatemala(19)- or settlement in wooded areas where the vector adapts and [4]Environmental changes-temperature, rains, humidity- and climate change(17)(20).

Clinical manifestations depends on the *Leishmania* specie, as well as the immune response of the host(18).In Guatemala, CL ("la chiclera") is the most frequent form of leishmaniasis, and produces ulcerous lesions in the exposed areas of the body, resulting in scars for life and serious disability. The least data available -2015- show a CL incidence of 18,2 cases per 100000 population, and a total of 564 CL new cases in 2015, being northern regions as Alta Verapaz and

Petén the most affected areas(21). Men are more affected than women and 12% of the cases are children under ten years old(21). The most common species causing CL in Guatemala are *Leishmania braziliensis* and *Leishmania Mexicana*(22) and one of the most affected area is Alta Verapaz, indicating the opportunity to intervene in the CL National Program, focused on facilitating access to health services, providing diagnosis through parasite identification and case by case risk-benefit analysis before recommending treatment(23). **Figure 3** shows a summary of the data.

The World Health Organisation (WHO) has assumed the leadership to initiate and amplify the programs of Control of Leishmaniasis in the affected countries(20). Since 2011, through the regional program of leishmaniasis, WHO has addressed the three main problems affecting surveillance, prevention and control of CL in the Americas – [1]scarce and bad-quality epidemiological and surveillance information, [2]problems related to access to diagnosis and treatment, and [3]inadequate vector and reservoir control- and has been proponent of a combination of strategies to contribute to the surveillance, control and elimination of CL in the Americas, which are based on [1]early diagnosis and effective case management -which is the strategy mostly implemented in Guatemala-, [2]vector control, [3]management of the environment, personal and housing protection and the use of residual insecticides, [4]reservoir control and [5]health education and community mobilization(20). Continuing with the Action Plan of Leishmaniasis 2017-2022, WHO has consolidated these main lines of action by specifying indicators to assess its progress(18).

The Guatemalan MOH CL Sub-program- part of the National Program for Vector-Borne Diseases- is strengthened through support from the PAHO-WHO at an international level, and the Center for Health Studies(CHS)-Universidad del Valle de Guatemala(UVG) at a national and regional level together with the Central American Office of Center for Disease Control and Prevention (CDC, Atlanta), and Damian Foundation in detection, vigilance and treatment activities. The strategy consists in organising periodical sessions of diagnosis and treatment delivery in affected communities of Alta Verapaz. People are invited to approach the closest health facility -or multipurpose center- and get a free diagnosis. If diagnosis is positive, they can get the treatment at no cost, as the center is provided with sufficient medicines for treating the total affected population. Due to reasons of cost-effectiveness and availability, most cases are treated with intramuscular meglumine antimoniate -Glucantime®- (17)(20)(24), and the health promoter acts as the administrator of the injections at the multipurpose/health post, in most cases. The standard dose of Glucantime® is 20mg/kg/day, administered by intramuscular injection for 20 days(23). Maintaining an adequate concentration of Glucantime® in the body for a full 20 days of treatment determines treatment success. When the recommended dose is used, cure rate is between 77% and 90% in New World Cutaneous Leishmaniasis (NWCL)—i.e. CL pertaining to species found in the Americas(24)(23).The WHO-negotiated price for systemic Glucantime® is US\$ 1.2 per 5-ml vial of 81 mg/ml which is subsidise by the MOH(20). The diagnosis and treatment strategy is reinforced with provision of information brochures about the prevention and management of the disease (23).

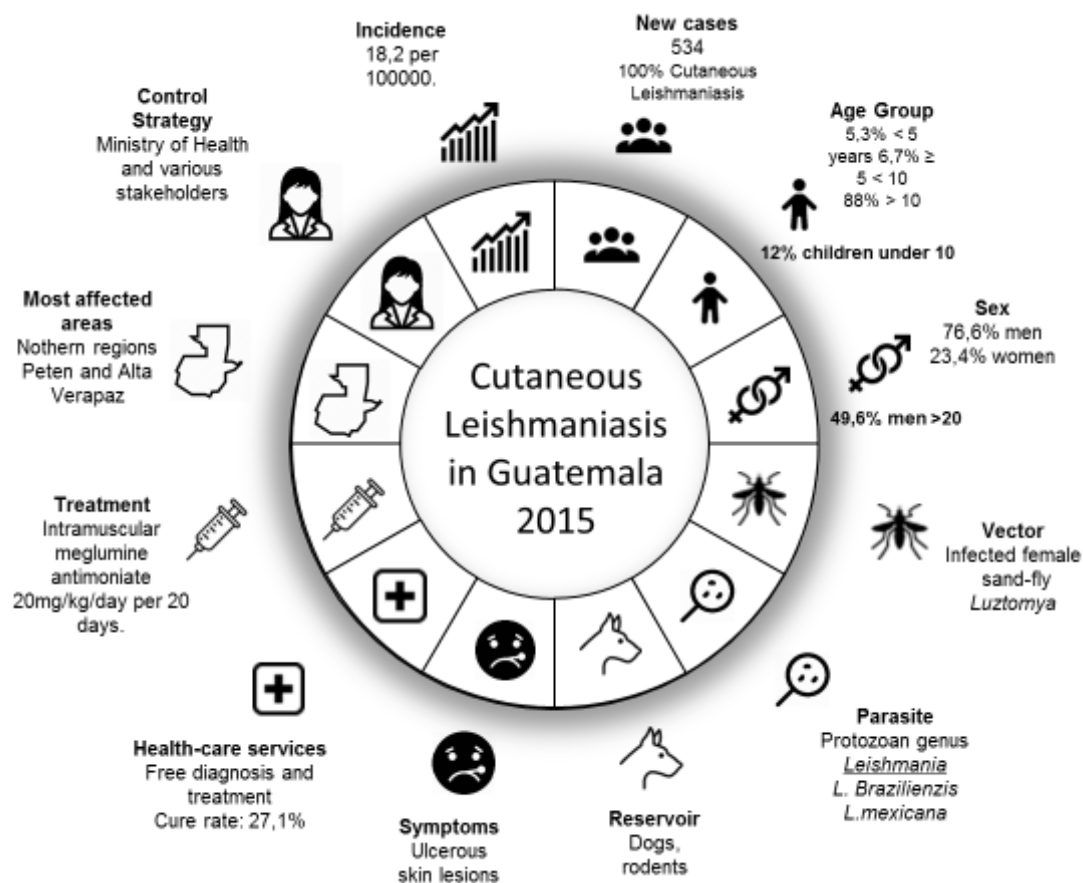


Figure 3. Infographic of Cutaneous Leishmaniasis situation in Guatemala, 2015. Data took from PAHO Report on CL, 2017(21).

4.2 Previous Studies

KAP Study with Q'eqchí population in Alta Verapaz

Although the strategy is put in place in CL affected areas of Guatemala, last data from the National Sub-Program of CL, show that only 27,1% of the cases reach clinical cure(21). Thus, in 2016 a cross-sectional study was performed by the CHS-UVG/CDC in collaboration with the MOH to investigate the issue. The study was carried out in rural areas of Alta Verapaz, and consisted in administering a Knowledge, Attitudes and Practices (KAP) questionnaire to CL patients about CL treatment provided by the MOH at no cost (intra-muscular meglumine antimoniate - Glucantime®-), hypothesising that maybe there were barriers of diverse nature that prevented from receiving appropriately the treatment(25).

The MOH provided the CHS-UVG with data indicating the eleven most prevalent regions of CL in Alta Verapaz. All eleven Q'eqchí Mayan communities were included in the KAP study. Participants were selected only if they had been previously diagnosed with CL by an MOH physician or representative, and with unequivocal access to meglumine antimoniate from the MOH at no cost at the time of the study. Given these including criteria, only thirty-two participants-children and adults-, belonging to three of the eleven communities affected- Sexán, Rubel Ho and Sehubub- were included in the KAP medication study, as shown in **Table 3**.

The KAPs medication questionnaire consisted of four sections: Demographic information; Knowledge surrounding the use of meglumine antimoniate including access to meglumine antimoniate provided by the MOH, administration technique, effects of meglumine antimoniate on lifestyle; Attitude regarding effectiveness of treatment with meglumine antimoniate, and; Practices using meglumine antimoniate(25). Surprisingly, all participants reported receiving the total number of administered meglumine antimoniate ampules from the MOH through their community health promoter(25). However many challenges concerning the KAP-quantitative design, the methodology and field-work were present in the study (26) and are summarised in **Table 4**. Thus, the validity of the KAP study was questioned and therefore, it might not show the real picture of the situation. Authors through time have pointed out that any kind of survey questionnaire may be a non-appropriate method for collecting information in a rural setting in a *non-Western culture*(26). The way the results are interpreted without understanding the socio-cultural context may lead to deliver a narrow understanding of the underlying factors, or even worse, an incorrect interpretation of data(27).

Municipality	Community	Surveyed households	Suspected CL cases	Patients with positive diagnosis and treatment delivered
Fray Bartolomé de las Casas	Sexán	54	34	19*
	Sesamat	32	11	---
	San José Purhulá	21	5	---
Chisec	Rubel Ho	48	8	10*
	Sehubub	43	9	5*
Cobán	Chablaj	47	6	---
Chahal	Valle Verde	42	4	---
	Siguinhá II	21	5	---
Cahabón	Chicoc II	31	1	---
	Pulisibic	19	0	---
	Nuevo Txulen	17	2	---

Table 3. Communities involved in the KAP study: Sexán, Rubel Ho and Sehubub(25).

Challenges	Description	Manifestations
Study design	Topic very narrow Sample size	Topic exclusively focused on Glucantime® 32 participants in a quantitative study is not enough to generalise and reach conclusions
Questionnaire design	The answer is driven by the question design. Assumptions were made	¿What other treatment have you used to treat “la chiclera”? + Closed given answer options ¿What is the most difficult thing to get Glucantime® that is provided by the MOH? + Closed given answer options
Controlling misunderstanding and cultural reinterpretations	Concepts that potentially evoked special meaning and associations in respondents	<<disease>>, <<health>> <<injection>>, <<pain>>
Courtesy bias	Tendency of participants to tell you what they think you want to hear	¿Did you ever share Glucantime® between the members of your family? ¿Do you think that Glucantime® that is given to you by the MOH cure?
General sense of mistrust	Interview atmosphere uncomfortable for participants	Use of smartphones to administer the questionnaires Interviewers were not known by the community Community leaders, prior to the study, asked <i>if we were “the palm people”</i> *

Table 4. Summary of the challenges encountered during the KAP study in 2016.

*The recent grow of palm crops in Alta Verapaz could be seen by Q’eqch’í population as a threat for “maize productivity (considered as sacred), an increase in the level of household-work saturation and, especially, a reduction in women’s spare time”(19)

Implementing an effective CL strategy for Indigenous rural populations, requires a previous profound understanding of CL and its treatment, not only in terms of aetiology and epidemiology, but in terms of the meanings that affected people bring to them(28). Furthermore, qualitative design- as it enables direct and profound contact with individuals and communities in their natural settings- eases the involvement of the communities, which would be another crucial element to develop effective disease control strategies, which consider not only epidemiological data or availability of services, but also cultural, individual and social aspects which surround the problem. Thus, a qualitative design is proposed to explore the perceptions and experiences about CL, its treatment and the current regional control strategy in Indigenous rural communities of Alta Verapaz.

5 Aim and Objectives

5.1 Aim of the study

The proposed study aims to explore the beliefs, perceptions and experiences of people living in Q'eqchí communities of Alta Verapaz, on cutaneous leishmaniasis and its control strategy based on early diagnosis and case-management through treatment.

5.2 Specific Objectives

1. To investigate the beliefs on disease-health-healthcare in the communities, and specifically regarding Cutaneous Leishmaniasis and its treatment.
2. To explore individual experiences and social implications related with CL and its treatment in the communities.
3. To examine the perceptions in the communities about the Ministry of Health's strategy to control Cutaneous Leishmaniasis.

6 Study setting

Alta Verapaz is a northern highland region of Guatemala, where 76.9% of the population live in rural areas, and agriculture is the main economic activity(29). Alta Verapaz is divided in 17 municipalities. Each municipality is formed by several communities, *aldeas* and *fincas*(11). A map of Guatemala and Alta Verapaz can be found in **Figure 3**.

This year -2017-, four communities of Alta Verapaz are going to be visited by the Ministry of Health, in collaboration with the CHS-UVG, to perform diagnosis tests for CL and to provide the *centros de convergencia* (multipurpose centers) with sufficient treatment. These communities are "El Rosario" and "San José de la Pasión"(municipality of Chahal); and "Rinconcito del Norte" and "Lomas del Norte"(municipality of Chisec).

Thus, our study will initiate with these four communities. The timing of field work will be worked out with the MOH and CHS-UVG staff, so logistics, coordination and collaboration will be improved and participants' recall bias during the interviews will be minimised. However, if time and resources are sufficient, more communities with different patterns of diagnosis and medication delivery would be added for comparison purposes.

6.1 Chahal

The municipality of Chahal is located at the northeast of the department of Alta Verapaz, in the region called Franja Transversal del Norte, with a territorial extension of 672 km²(30). El Rosario y San José de la Pasión are both in the northern part of the municipality. To reach the municipality of Chahal starting from the capital city, there are three routes, at 364 km, 373 and 375 km respectively; the three routes are made up of asphalted road sections and terraces passable all year round(31).

According to last census Chahal has a total population of 16,853 people(11). The population is predominantly rural (77%) and the majority of the population belongs to the Q'eqchí linguistic and cultural community, representing 94% of the population (11). Concerning the employment

situation, a high percentage of the population who works, develops activities in agriculture (69%) and for the livestock activities 11%(30).

The Municipality has only the public health center located in the Municipal Headquarters, and all other populated places do not have permanent health services, but health promoters work voluntarily in multipurpose centers (*centros de convergencia*) providing general health care services and assisting with health promotion, protection and recovery actions(31).

6.2 Chisec

The municipality of Chisec, is located to the northwest of the department of Alta Verapaz, with a territorial extension of 1008 km²(32). The communities of 'Rinconcito del Norte' and " Lomas del Norte " are to the west of the municipality.

The municipal head of Chisec, is located at 290 kilometers from the Capital city, on a totally paved road, until arriving at the parceling Raxruhá and at 76 kilometers from the departmental capital.(32)

According to the last population census the Municipality has a population of 82,231 inhabitants where 89% live in the rural area (11). The indigenous Mayan Q'eqch'í ethnic group predominates, representing 91% of the population(11).Concerning the employment situation, a 64% of the population who works, do it in agriculture activities(32).

To assist the total population, one public health center is located the east neighbour municipality -Raxruhá-; three dispensaries of the "Episcopal Pastoral Social Conference", and two private medical clinic located in Rubelsanto village also operates and deliver health services(32). The rest of locations are also assisted by health promoters at multipurpose centers.



Figure 3. On the left, Alta Verapaz is highlighted in the map of Guatemala. On the right, the location of Chisec and Chahal. The dots indicate an approximation of the location of the communities under study. From left to right, Rinconcito del Norte and Lomas del Norte in Chisec; and San José de la Pasión and El Rosario from left to right in Chahal.

7 Study Methodology

7.1 Study Design

A qualitative study with sociological and anthropological research approaches will be conducted in the four selected communities, where existing cases of CL will be previously confirmed by the CHS-UVG, using clinical and parasitological diagnosis, and meglumine antimoniate will be provided by the MoH to the *centros de convergencia*. Sub-groups of informants of the communities will be purposively selected to obtain information through individual in-depth interviews, designed according to the aim and the objectives of the study. Additionally, ethnographic observations during field work will be compiled. Obtained data will be analysed using the qualitative software package NVIVO-11. An iterative approach will be adopted—in which data collection and analysis take place simultaneously—for ongoing refining of field tools as relevant topics emerge.

Engaging stakeholders

Early in the project, I wrote to main stakeholders -CHS-UVG and MOH- informing them of the study and inviting them to comment on the proposed protocol and asking for advice given their extensive experience with CL in rural areas of Alta Verapaz. This led to a personal contact in Ciudad de Guatemala from late March to mid-April 2017, and a one-on-one explanation of the proposed protocol. CHS-UVG informed effectively about the strategies followed at a national level to control CL, as well as previous unpublished research on the topic. They also responded reflectively on a wide range of issues of local concern (eg. the way to approach community leaders for permission and to achieve community engagement), the validity of assumptions underlying the study (e.g. mayan beliefs on health, disease and healthcare), logistics issues (e.g. to identify a potential team, to adjust the study to the communities they are going to visit this year, or coordinate timetables with them for potential fieldwork), the methodology (advise with interview procedures, especially about how to approach individuals, adapt the language to participants, the need of both men to interview men and women to interview women, and the need of Q'eqchí translators and how to find them), and advise on funding, having the opportunity to speak about the project to the representative of the CDC-Central America Regional Office of Guatemala, main funder of CHS-UVG projects. These conversations added greatly value of the research and promoted the interest and collaboration of CHS-UVG/CDC. On the other hand, the MOH expressed its full support since the beginning of the contact and its great interest on the project, as it fits very well with its values stated in the recent model "Inclusive Health Model"(MIS), in which including indigenous approaches in health plans is a priority. They also remarked the relevance of the study as Alta Verapaz is a department prioritised in the MIS. These conversations led to a further contact with the Leishmaniasis Sub-Program coordinator (Program of Vector-borne Diseases), who provided me with the national manual of procedures for the prevention and control of leishmaniasis ("Manual de Procedimientos para la prevención y el control de las leishmaniasis" in Spanish)(23) and the educational brochure they provide to people.

7.2 Data collection

7.2.1 In-Depth Interviews

We plan to conduct in-depth interviews with purposively selected informants. The aim of in-depth or unstructured interviews is to collect information on the experiences of the individuals using a flexibly structure to enable respondents to discuss their point of view using their own stories, rhythm and language(33). In in-depth interviews four common topics will be covered:

- 1) Perception about disease, and specifically about CL
- 2) Individual experiences with CL and social implications
- 3) CL treatment choices and perceptions
- 4) Perceptions of the MOH strategy, health workers and procedures in health facilities

The interviews will explicitly aim to capture contextual issues that may have shaped the CL experiences. The “in-depth” approach is thought to be the most appropriate method to understand these issues, as they enable participants to elaborate their own narratives and the interviewee enough time to develop their own accounts of the issues important to them and to link their accounts to additional topics that the researcher might not have considered when designing the topic guide (33). This approach was carefully chosen after considering the potential feelings and thoughts of participants; due to poor literacy and little or non-comparable previous experience of interviews designed as research tools, choosing a more structured method could create feelings of nervousness or distrust that would hamper the achievement of quality information. Therefore, although in-depth approach requires a later interpretive epistemological approach, it might allow for the most comprehensive interpretation of data(33)

Participants and sampling methods

Purposive sampling method will be used to select participants who can best describe the phenomenon. In order to achieve the maximum diversity of information, key-informants directly and indirectly related with the disease and the treatment will be recruited:

- People directly related with the disease: Patients with confirmed CL diagnosis or suspected CL cases (no confirmed diagnosis but skin lesions present).
- Closed family member of the patient living in the same household: decision-makers or carers.
- Health workers trained by the MOH to apply the MOH strategy: Community health workers (*promotores de salud*).
- Community professionals who treat diseases and know the rituals and religious ceremonies related with health: Traditional healers (*curanderos/as*).

However, considering the iterative nature during the study, new/different informants could be included at a point of the study to capture the maximum diversity of information.

Inclusion criteria

- General inclusion criteria

- Children between 12 and 17 years of age or adults, 18 years or older living in El Rosario or San José la Pasión (Chahal) or Rinconcito del Norte or Lomas del Norte (Chisec).
- Fluent Spanish and/or Q'eqchí speakers
- Specific inclusion criteria:
 - Participants must be (one of the following):
 - Cases of CL (clinic and parasitological diagnosis or suspected cases)
 - Relatives of patients living in the same household
 - Health workers working in the communities
 - Traditional healers of the communities

Sample size

The four subgroups mentioned were identified as important informants. Typically, 4 interviews per setting (municipality) are conducted with each sub-group to attempt to gain enough information about the topics within sub-groups and to be able to identify differences between sub-groups(34). However, data collection will continue until the point of data saturation (i.e. when no more new information emerges from the data)(34). The **Table 3** shows a summary of the sample size.

Informants	Municipality of Chahal		Municipality of Chisec	
	El Rosario	San José de la Pasión	Rinconcito del Norte	Lomas del Norte
CL confirmed or suspected cases	4	4	4	4
Relative of patient	4	4	4	4
Community health workers (usually they will be no more than 1 worker per community)	From 1 minimum to total of them	From 1 minimum to total of them	From 1 minimum to total of them	From 1 minimum to total of them
Traditional healers (usually they will be less than 4 per community)	From 1 minimum to total of them	From 1 minimum to total of them	From 1 minimum to total of them	From 1 minimum to total of them
Total	Minimum of 40 interviews			

Table 3. Sample size by sub-group of informants

Engaging the community

Community leaders must be asked for permission by the investigators, to perform a study in their communities, as well as constituted authorities through ethical approval. Community leaders are called *cocodes*, which refers to the fact that they preside the COCODE (35). To effectively engage the community leaders and community inhabitants a previous information process will be undertaken: the study investigator will be accompanied by a worker of the Ministry of Health known by the *cocode* to each community. He will be properly informed about all the aspects of the study through an information sheet (**Annex 1**). He will be also provided with informative posters to be distributed in the community, explaining the study and encouraging to participate (**Annex 2**). This previous engagement process is thought to be useful to promote trust and willingness to participate in the communities. Then, the recruitment process will begin.

Recruitment

When the period of field-work get closer, community leaders will be contacted again. Providing an outline of the participant recruitment guidelines (**Annex 3**), they will be asked to begin identifying potential participants.

Participant's recruitment on site will follow several steps summarised in **Figure 4**. These steps aim to minimise perceptions of applying pressure on people to participate and to promote willingness to get engaged.(36)

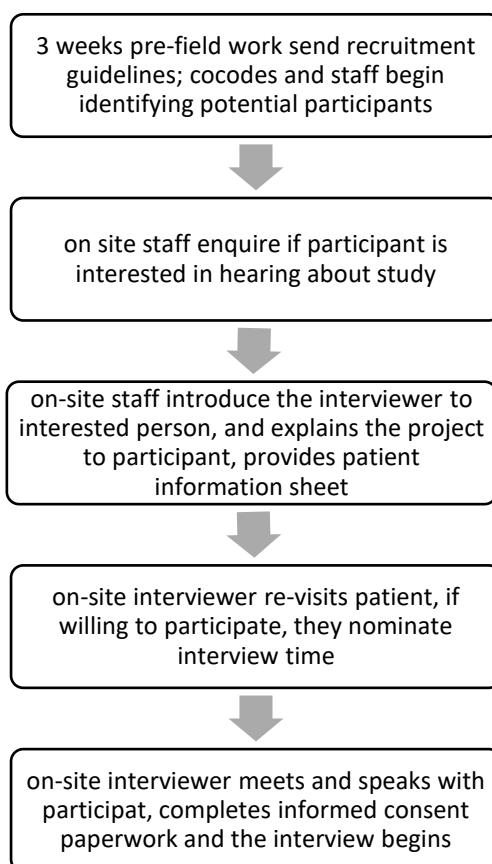


Figure 4. A scheme of the recruitment process.

Performing interviews

In-depth interviews were planned primarily to facilitate the participation and flow of the conversation. Although the in-depth approach does not require a specific schedule for the interviews, some questions were designed to help the interviewer to achieve valuable information about the topics. Thus, the 'Interview forms' (**Annex 4**) will be used more as a reminder than a script(36): the interviewers will be encourage to allow the participant tell its own story and achieve a natural flow and a 'conversational' atmosphere without sacrificing the common themes and the objectives of the study. They are thought to have an approximate duration of 45-60 minutes, and will be conducted at a comfortable setting for the participant, as their home, health center, etc. At the place, the participant, the interviewer, and a translator if necessary will be present. Investigators of CHS-UVG with experience in the communities highly recommend to assign a woman interviewer for female participants and a man interviewer for male participants, and the same for translators. This recommendation is based on previous experiences in the field.

The final data for each interview will comprise a record of the interview, a document including direct observations noted by the interviewer during the interview, and the 'Interview form' including demographic information.

7.2.2 Ethnographic approach

Direct observations will be performed in the period of fieldwork. The aim is to capture information of what participants actually do, think, say- which may differ from the information *reported* by the participants during the interviews- through a reflexive process of observation throughout the field work(34). By this ethnographic approach we intend to get a more comprehensive interpretation of data. Field observations will be compiled in a field-diary, including the team anthropologist's direct observations, as well as unsolicited comments or conversations with/between participants, thoughts, interpretations of situations, hearings... Notes gathered by other team members will be also analysed. These notes will be transcribed electronically and added to NVIVO database for further analysis.

7.2.3 Team debriefing sessions

Due to the iterative character of the study, daily debriefing sessions are needed with all field workers and weekly meetings with the study investigators. The purpose of the debriefing meetings during data collection are:

- "For field staff to update each other on progress with data collection
- For field staff to discuss key findings from data collection so far, including differences and similarities
- For field staff to discuss any problems/changes with the interviews and refine the tools
- For field staff to get an idea of whether new ideas are still emerging or if saturation has been reached on key topics
- To provide a daily/weekly record of proceedings".(33)

7.3 Data Management and Analysis

7.3.1 Data management

Identification

Each participant will have its own identification number. This will be written on the interview form, in notes taken, and will be used to name audio files and transcript documents. The identification number will be ID-XYX, being X a number between 1 and 4 referring to the four communities of the study. YY is a number between 01 and 99, allocated randomly to the participants of each community.

The association between the identification number and the participant will be kept into a password protected document only available for the study investigators.

Storage

A tape recording will be switched on at the start of the interview and another field worker will make notes of the responses and non-verbal behaviour during the interview as well as notes about the setting and atmosphere of the interview.

Collected data (audio files, notes, observations, transcriptions...) will be transferred each day to a password protected central database at the CES-UVG, and only study investigators will have access to the information in the database. Audio recordings will be destroyed as soon as the accuracy and completeness of the transcriptions have been verified. The rest of study materials will be stored in this password-protected database for 3 years-according to the CHS-UVG ethical committee- after the study and then destroyed(37).

Transcription and Translation

Transcription

Audio files will be transcribed carefully in the language of the interview and then translated if needed. All typed records will be kept in password protected computer hard drives and in a password-protected back-up drive. Transcribers will be familiar with the theoretical perspectives of the study and will ensure this is reflected in the approach to transcription(34). The transcription will include word-for-word transcription, recording all hesitations, pauses, and incomplete sentences. The transcription will be read against the audio file by a supervising member of the research team to check for accuracy(38).

Translation

Transcripts will be translated from Q'eqchí into Spanish. Translators will be familiar with the objectives and the methodology of the study. Quality criteria will be comprehensibility (especially relating to culture-specific concepts), appropriateness (in content and approach) and accuracy (faithful to the source text and key facts) (39)The original text will remain in the document. The translation will be also cross-checked to identify possible errors. Then, translated transcriptions will be exported to NVivo qualitative data management software for coding and analysis.

7.3.2 Data analysis

Methods

Interview transcription, field notes and direct observations will be entered daily as a project in NVIVO, a software for managing and analysing qualitative data. NVIVO allows multi-level coding of a text(40). 'Coding' refers to the process of allocating any text against a set of identified analytical categories ('nodes' in NVIVO terminology) such as themes and subthemes, or topics. So, transcripts and field work notes and observations will be coded line-by-line, and then later themes and subthemes will be developed by grouping the base coding together.

The coding process will involve several preparatory steps:

1. A selection of interview transcripts will be analysed by the researchers; crucial themes and points of interest will be identified and discussed so the priorities for coding process will be set.(36)
2. Using NVIVO, investigators independently will code a set of these interviews using the original four common topics. This will act as a basic framework and identifying further themes/sub-themes(36).
3. Then, the coding from each investigator will be compared and through a process of deleting, merging and re-definition, a consolidated 'coding dictionary' of nodes will be produced.(40) (41)
4. At this point, all transcript will be coded against the set of nodes produced. The coding process has both a deductive dimension (with the four common topics as an organising framework) and an inductive (ground-up) aspect, where additional themes and sub-themes emerged directly from the data (42) so new nodes, themes and sub-themes can merge through the analysis(42) (NVIVO is a flexible software and allows to add, delete ad redefine at any point during the analytical process) (41).

Quantitative data

Quantitative data collected in the "Interview Forms" will be organised in an Excel sheet and then imported into NVivo as a new casebook, to be linked with the relevant transcript and audio files. Descriptive statistical analysis will also be performed on the data in Excel, as NVIVO lacks of statistical analysis capacity.(40)

Development of theoretical constructs and narratives

When all the interviews, field notes and direct observations are fully coded, everything will be analysed by the research team. This will include detailed observation of the differences in the emerging concepts according to the subgroups and the different characteristics of the participants.(33)

After this reflective exercise, the research team will develop a narrative that will relate the preconceptions and objectives of the study to the subjective experiences of the participants. The aim of the narrative will be to translate these subjective experiences into theoretical

constructs, which will serve to bring new knowledge to the original conceptual framework, (33)(34), as well as to give recommendations for the public health strategy.

8 Ethics

Ethical approval will be obtained from the Ethics Committee of the Center for Health Studies of Guatemala, by submitting the correspondent application. The ethical committee specially focuses on ensuring application of ethical principles concerning research, promoting research priorities in line with institutional policies of the Universidad del Valle de Guatemala and Ensuring the quality and consistency of the research projects(37).

Informed Consent Materials

Confidentiality and privacy will be ensured with an informed consent process followed with study participants(43). After providing enough time to consider all the information and solve doubts, a written informed consent will be obtained from them(37). For minors, age 12-17, an informed assent process will be completed in addition to parental/legal guardian consent(37). The participant will be also verbally informed and a signed informed assent will be required to ensure the participant understand all the aspects of the study.(37)

The informed consent process will be conducted personally at a convenient location (health center, office, residence) and in the most comfortable language for the participant (Q'eqchí or Spanish), using a translator if necessary. If the potential participant cannot read, an impartial witness will be present during the entire process. After providing information answering any queries, the participant will be asked if they can give their written consent using consent form. If they cannot write or sign, an alternative fingerprint will be proof of written consent.

Informed consent and informed assent forms can be found in **Annex 5**.

The community-based orientation of this study, ethically requires the communication and feedback during the study, and dissemination of key findings upon project completion among participants, as well as other individuals and institutions in the communities(44).

9 Dissemination of results

The dissemination plan will consider some key points:

- Goal: what are the objectives of the dissemination?
- Audience: orient the language, methodology and information level towards the needs of the audience
- Medium: what is the most effective way to reach your audience?
- Execution: when should it occur?(45)

The use of flyers, posters, brochures, or research briefs about the study and findings might offer a concise and visually-appealing way to disseminate information to broad audiences(45). Furthermore, an interactive activity with study participants will be considered to achieve their feedback, which is important not only to clarify the findings with them, but also to ensure the

quality of the research and possibly obtain new information (46). Thus, a local event, seminar or community meeting will be a potential method for informing the community. Additionally, a letter and an oral thanks to the participant is an important ethical component(45).

On the other hand, a research report oriented towards the publication in a peer-reviewed journal is also expected, so purposive writing to publish in potential journals will be made.

Finally, as the Ministry of Health is fully involved in the CL strategy, an evidence-base policy brief might be a powerful tool for communicating research findings to policy makers(44), and build a more effective strategy, assuming that the experiences and perceptions analysed influence the success of the disease control strategy.

10 Team

Lead researcher: Study design, development of interviews, overall supervision of project activities, coordination of data management and analysis, elaboration of reports, manuscripts and scientific presentations, dissemination of findings to different audiences. Experience with Social Science and qualitative research.

Anthropologist: Study design, development of interviews, responsible of communications with local and central health authorities, main ethnographic observant, help to adapt the dissemination of findings to different audiences. Experience with Mayan population.

Research assistant: study design, data management and analysis, elaboration of reports, coordination of field work, help with manuscripts, scientific presentations, dissemination of results to different audiences.

Field investigators: identifying and recruiting participants; assisting with field organisation and data collection; interviewers. Anthropologist highly preferred.

Transcribers/translators: primary responsibility for conducting transcription and translation of all relevant field documents. Q'eqchí-Spanish bilingual speakers.

Support from Ministry of Health: staff from leishmaniasis Sub-Program, Program of Vector-borne Diseases, MOH. Role: Coordination of activities to health authorities, reviewing of reports and manuscripts, dissemination of findings.

11 Timeline and resources

The study is planned for one year. It is divided in phases distributing in time according to **Table 5**. Concerning resources and funding, research activities related with CL have been developed in the CHS-UVG. The CHS is in a cooperative agreement with the MOH of Guatemala(MSPAS), the Centers for Disease Control and Prevention CDC, Atlanta, United States), which is the main funder of the Center. Specifically, the Division of Parasitic Diseases and Malaria, Global Health Center Centers for Disease Control and Prevention, CDC, Atlanta GA, USA, has previously funded CL-related projects.

Activity	Month											
	1	2	3	4	5	6	7	8	9	10	11	12
Ethics Committee approval and refining the protocol	■											
Training and preparation prior field work. Recruitment process		■										
Field work: interviews and ethnographic observations			■	■	■	■						
Data management and preparation for data analysis				■	■	■						
Data analysis and narratives elaboration						■	■	■	■			
Dissemination of results at community level										■		
Report preparation for different audiences											■	■

Table 5. Time-frame for the study

12 Discussion and conclusions

Cutaneous leishmaniasis is a neglected tropical disease affecting vulnerable Mayan-Q'eqchí population in Alta Verapaz, Guatemala. Currently, there is limited knowledge about the socio-cultural context of Mayan-Q'eqchí people and how this affect the individual experiences related with disease and healthcare. This knowledge gap hinders the success of treatment and control initiatives that the MOH and other stakeholders develop to change the CL scenario in the country. Identification of the rural Mayan population meanings and perceptions that surround CL might contribute to the effectiveness of the current MOH control strategy based on early diagnosis and case management through treatment.

In this research protocol, a qualitative methodology was chosen to investigate an example of how cultural beliefs and perceptions can crucially shape the attitudes and practices of people towards healthcare. The focus on reinforcing the importance on cultural differences when designing health strategies, as well as on involving the community to contribute to the improvement of current plans, aligns with the priorities of the MOH model-MIS-which is based on highlighting the cultural relevance when it comes to health plans, in the sense of recognising, respecting and interacting with Mayan points of view(8). In fact, the central research question was considered significant by the MOH and the CHS-UVG, two key stakeholders in the control of CL. The protocol process purposively allocated substantial time and dedication in creating a collaborative atmosphere between the research, main stakeholders and community. Building these participatory relationships added great credibility to the protocol, as well as improved the probabilities of success.

The methodology clearly reported how data will be collected and converted into more complex coding structures and then narrative explanations. The study design also featured triangulation-

conventionally understood as a quality indicator of qualitative research(46)- at different levels, including sources of data (in-depth interviews and ethnographic observations systematically recorded in diaries) and categories of informants (patients, family, health workers and traditional healers). In the context of previous studies, quantitative approaches through KAP studies could also be part of a further level of triangulation. Other quality indicators, such as respondent validation- through the dissemination of results to the community members, resulting in possible generation of further original data added to the study-, or a clear and reflexive methodology statement, assure the validity of the study (46). Part of this reflexivity consists in considering the limitations of the study. First, the studied communities are Q'eqchí speakers as mother tongue. Although Spanish is widely spoken, Q'eqchí is the most comfortable and fluent language for communication(10). Even if interviews will be performed in Q'eqchí with the help of a translator, the use of more intermediaries together with the difficulties in finding qualified translator may deteriorate the accuracy of the information collected; also, some ethnographic observations will be missed by investigators due to the lack of understanding. Second, people who are shy, lacking in confidence, or confused are less likely to get engaged in this research process; the results of the study are therefore less likely to capture the whole picture of the issue. Third, although multiple subgroups and participants reduce the potential for bias, the study design has a limitation insofar as the interviews remain a partial account of the real interviewee experience, as they are *reported* perceptions, attitudes, behaviours... Although ethnographic observations could overcome this limitation, due to time constraints, they may also reflect a partial view of the situation.

This study is thought to contribute to the effectiveness of one of the proposed WHO strategies to control leishmaniasis(20)(18), based on early diagnosis and effective management of cases through treatment. However, many other challenges must be addressed at a regional level: difficulties during the development of this protocol in finding reliable epidemiological data of CL in Guatemala this protocol show that this kind of information is not adequately available for use in decision-making processes. Furthermore, although this study might contribute to the effectiveness of the current strategy, access to diagnosis, treatment and care of CL cases is still not sufficient for the Guatemalan affected population(21); structural problems are at the base of this challenge, as scarcity of properly trained health workers to diagnose, treat and follow-up CL cases, scarcity of infrastructure -eg. health centers- and materials for diagnosis-eg. laboratories-, geographical barriers to access health services and lack of integration of proper promotion, communication and education in health, and deficient social mobilization to control CL. Moreover, actions going beyond diagnosis and treatment must be implemented to increase the chances of success in the control of CL(17)(18). In Guatemala, the vector and reservoir control is not performed in a sustained, systematic and standardized manner(18). Strategies focused on vectors and reservoirs might reduce the transmission in an efficacious way(20).

On the other hand, all strategies suggested by international organisations, do not address properly the subjective perceptions, beliefs and priorities of the individuals directly or indirectly affected by the disease. This novel research is the first proposal aimed at understanding rural Q'eqchí experiences of CL, in order to highlight socio-cultural differences that must be considered for adequate disease management, in a such diverse country as Guatemala.

Overall success of this study depends on the quality and relevance of the research outputs, as well as on empowering participants and involving stakeholders. Both achievements are crucial

to take a vital further step: that our findings are translated into evidence-based public health actions that address the difficulties suffered by rural indigenous population, and improve quality health approaches in terms of equity and solidarity.

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15 Annexes

Please, click on the annexes

[Annex 1. Information sheet for community leaders and study participants.](#)

[Translation in English.](#)

[Annex 2. Informative poster for distribution in the communities.](#)

[Translation in English.](#)

[Annex 3. Recruitment and selection guidelines for community administrative staff.](#)

[Translation in English.](#)

[Annex 4. Interview forms with example questions and demographic information.](#)

[Translation in English.](#)

[Annex 5. Informed consent for adults and Informed consent and Informed assent for under 18.](#)

[Translation in English.](#)