



BODY-MAPPING & PEOPLE LIVING WITH CHAGAS DISEASE: TIME FOR ACTION

Miriam Navarro¹, Sandra Parisi², Michael Pritsch³, Zulma Apodaca⁴, Gonzalo Rubilar⁵, Camila Jiménez⁵, Elisa Chilet¹, Boris Apodaca⁶

¹Department of Public Health, History of Science and Gynecology, Universidad Miguel Hernández, Alicante (Spain); ²DAHW (Deutsche Lepra- und Tuberkulosehilfe e.V.), Germany; ³Department of Infectious Diseases and Tropical Medicine, Medical Center of the University of Munich (LMU), Munich, Germany; ⁴Fundación Intercultural NorSud, Bolivia; ⁵DAHW (Deutsche Lepra- und Tuberkulosehilfe e.V.), Latin America; ⁶Hospital Dermatológico, Monteagudo, Bolivia.

Introduction

Body-mapping is a method of telling stories in which the perspective and experience of the narrator strongly contributes to the story's significance. Since 2002, it has been as both a therapeutic and research tool, primarily for people living with HIV/AIDS. These body-maps consist of a series of texts, pictures, paintings, and collages, drawn from stories told by the participants and collected within a silhouette of the individuals' body. **Chagas disease** is one of the 20 **Neglected Tropical Diseases** outlined by the World Health Organization (WHO) and affects 6-7 million people worldwide, resulting in the death of roughly 10,000 people annually. Originally confined to the American continent, Chagas has become a global concern due to international migration resulting in the disease's spread.

Aim

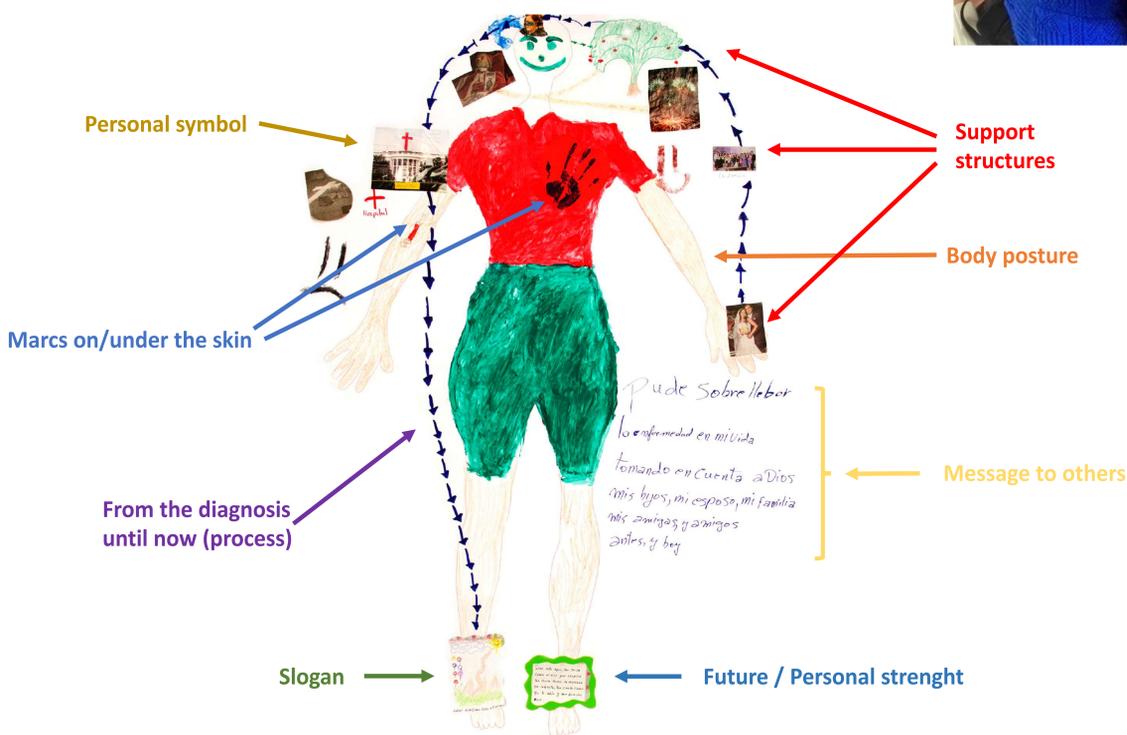
To use body-map storytelling as a **research** and **advocacy** tool for people living with Chagas disease.

Methods

In November 2018, a multidisciplinary team from Bolivia, Germany, and Spain implemented body-mapping in a Chagas hyperendemic region of Bolivia. Three independent sessions with each participant were conducted by one researcher respectively, and the following topics were explored:

- Session 1: pre- and post- diagnosis
- Session 2: living with Chagas disease & gender perspective
- Session 3: resilience and coping.

These sessions were audio-recorded and the transcriptions were analysed and triangulated. After editing photos of the body maps, some life-size maps were printed for upcoming exhibitions. Ethical approval was granted by the University of Sucre (Bolivia) and the LMU of Munich (Germany).



Results

Twelve men (n=7) and women (n=5) living with Chagas disease had body-maps constructed by researchers based on their personal experiences with Chagas. Ages ranged from 24 to 63 years old. Ten were living in rural areas. Most remarkable findings: how participants dealt with the disease according to gender, how their **lives changed** after diagnosis, and **medical pluralism**.

Veterinary ivermectin provided by medical and vet doctors

Will I be **cured**? Which treatment do I take? Wide range of information **sources**: relatives, neighbours, traditional healers...

Two predominant concerns were: **incertitude** and **economic difficulties**. Main support structures were family and faith.

Many people can't afford paying for a **pacemaker** or an expensive **surgery**. Patients are also **excluded from** formal jobs and **bank loans**.

Chagas Body-Maps Exhibitions in 2019:

- Conference on Tropical Medicine & Global Health (April 4-6, Munich, Germany)



- Conference on Tropical Medicine & Int. Health (October 28-30, Ávila, Spain)



Conclusions

This research demonstrates **challenges** that Chagas disease patients face and some of their **unmet needs**. The ultimate goal of exhibiting the body-maps is to **raise awareness** concerning Chagas disease.