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# Looking through the lens of social science approaches: A scoping review of leishmaniases and Chagas disease research

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### ABSTRACT

Scholars have called for increased attention to sociocultural, economic, historical, and political processes shaping Neglected Tropical Diseases (NTDs) ecology. We conducted a scoping review to identify major research themes and the knowledge gaps in social science literature in leishmaniases or Chagas disease (CD). Following the scoping review protocol, we first determined the focus of the review to be centered on identifying research that approaches leishmaniases and CD from social science perspective and was indexed by large, biomedically focused databases. We then searched PubMed and Web of Science using "Leishmaniasis" and "Chagas disease" with "social science" or "anthropology" as search terms. We analyzed 199 articles (123 on leishmaniases and 76 on CD), categorizing them into three main research themes. Sociocultural dimensions of the diseases (leishmaniases=60.2 %; CD=68.4 %) primarily focused on individuals' knowledge, practices, and behaviors, barriers to accessing healthcare (especially in endemic regions), psychosocial effects, stigma, and traditional treatments. Research focused on socioeconomic dimensions of the diseases (leishmaniases=29.3 %; CD=19.7 %) included topics like household characteristics, social capital, and infrastructure access. A final theme, the historical and political contexts of the diseases (Leishmaniases=10.5 %; CD=11.9 %) was less common than other themes. Here, studies consider civil war and the (re)emergence of leishmaniasis, as well as the significance of CD discovery for scientific and public health in Brazil, which is the most common country for research on both leishmaniases and CD that draws on social science approaches. Future directions for research include focusing on how social institutions and economic factors shape diseases education, control measures, healthcare access, and quality of life of people affected by NTDs. Greater attention to social sciences can help mitigate and undo the ways that structural biases have infiltrated biomedicine.

### 1. Introduction

Over the past decades there have been consistent calls for greater contributions of social sciences to ecology and epidemiology of infectious diseases (Janes et al., 2012; Amieva, 2014; Franceschi et al., 2010; Farmer, 2020; Farmer, 2001). Scholars have noted that, although the integration of anthropological and sociological perspectives into Neglected Tropical Diseases (NTDs) control and surveillance programs can provide significant value (Briceño-León, 1990), its potential remains underutilized in contemporary strategies and policies (Bardosh, 2014). Despite the apparent relevance of the social sciences for NTDs, a 2011 review found fewer publications on social science themes or

interdisciplinary research in NTDs than biomedically focused research (Reidpath et al., 2011). This disparity is unsurprising given the differences in number of researchers, funding support, and differences in research and publication practices (Kagan, 2009; Solovey, 2020), however the contributions of social science remain central to understanding the complexities of interactions between humans and infectious disease.

Both leishmaniases and CD are NTDs that disproportionately affect people that lack access to basic sanitary infrastructure and health care – mainly those living in rural areas of tropical and subtropical regions of the world (World Health Organization [WHO], 2022a). Global migration patterns, driven by factors including economic, political, and environmental conditions, have also contributed to the global spread

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and (re)emergence of both leishmaniases and CD over the past decades (Muhjazi et al., 2019; Schmunis, 2007). Transmission of these potentially disabling and life-threatening diseases is a complex and dynamic social-ecological process linking pathogens, vectors, humans, and non-human hosts. Leishmaniases are caused by various Leishmania spp. protozoa and transmitted by sandflies. This group of diseases is endemic in 99 countries and territories of the Global South and has three clinical presentations. Visceral leishmaniasis (VL) has a high mortality rate if untreated, while cutaneous leishmaniasis (CL) and mucocutaneous leishmaniasis (MCL) cause skin ulcerative lesions that may result in lifelong scars and facial disfigurement (WHO, 2022b). Chagas disease (CD) is caused by the protozoa Trypanosoma cruzi, which is transmitted to humans mainly by the blood-sucking triatomine bugs (kissing bugs). The disease is endemic in Latin America, and increased cases around the world have been reported related to non-vector transmission (e.g., blood transfusion, via transplacentally from mother to the newborn, organ transplant). CD is a severe, potentially fatal illness. Most cases are asymptomatic in the initial acute phase, but among people who develop symptoms at this phase between 5 and 10 % will die from myocarditis and/or meningoencephalitis (Dias et al., 2015; Pérez-Molina and Molina, 2018; Rassi et al., 2010). Patients with untreated, acute CD progress to the chronic phase of the disease and 30–40 % will progress to symptomatic chronic cardiac, digestive (megaesophagus, megacolon), or cardiodigestive forms (Dias et al., 2015; Pérez-Molina and Molina, 2018; Rassi et al., 2010).

Research has clearly established that the sustained transmission of leishmaniases and CD to humans is closely related to the social-cultural, economic, historical, and political contexts of societies (Athni et al., 2021). The importance of the social dimensions of the diseases combined with relatively fewer publications highlights the need for a more comprehensive understanding of what is published in large, biomedically focused reference databases and what additional research could fill existing knowledge gaps. In this scoping review, we aim to assess the literature that utilizes approaches common in social sciences to investigate leishmaniases and CD. We first focus on research indexed by large, health/medical focused databases to identify main research themes. Second, we highlight knowledge gaps that exist either due to lack of research or because relevant research is not indexed by health-focused reference databases. This may improve our understanding of how the interactions between people and infectious disease shape our current world as well as highlight how social science research contributes to surveillance and control of NTDs.

### 2. Materials and methods

# 2.1. Literature search for identifying relevant studies

Scoping reviews were developed to identify central research themes and potential gaps in around a focused research topic instead of providing a systematic review of all publications in a general research area (Arksey and O'malley, 2005). Consistent with the method (Arksey and O'malley, 2005), we first determined that the focus of the review would be to identify major research themes in research on leishmaniases and CD that included a social science component and was likely to be visible to biomedical researchers in research databases.

We searched PubMed (ncbi.nlm.nih.gov/pubmed) on January 1st, 2023, and Web of Science Core Collection (WoS) on May 21st, 2023, for social science literature on leishmaniases and CD that had been published prior to December 31st, 2022. We searched PubMed because it is the largest publicly available database focused on health, medicine, and biomedical sciences. Additionally, PubMed indexes health-related research from many languages and databases including the SciELO database. We duplicated our search in the Web of Science (WoS) database, which includes research across the life and physical sciences, social sciences, and arts and humanities from 1900 to the present (Falagas et al., 2008). Our query arguments for the leishmaniases search were

"(Leishmaniasis) AND (social science OR anthropology)" and for the CD search were "(Chagas disease) AND (social science OR anthropology)" because we wanted to capture research from across the social sciences in general and specifically anthropology.

We recognize that there is debate around what is included in the social sciences and that much social science research is interdisciplinary. Because the primary goal of our scoping review was to offer a summary of the research areas and identify knowledge gaps, we relied on the hierarchy of MeSH terms used in PubMed to define social science. This narrowed the scope to: criminology, economics, government, policy, political systems, politics, public sector, quality of life, sociology, medical, physical, and cultural anthropology. In WoS searches, we included leishmaniases and CD records associated with anthropology and terms listed under the social science research area: archeology, biomedical social science, business & economics, communication, criminology & penology, cultural studies, development studies, education & educational research, ethnic studies, geography, government & law, linguistics, psychology, public administration, social issues, social work, sociology, and women's studies.

This resulted in 3366 total articles (leishmaniases = 1880 and CD = 1486) published before December 31st, 2022. The titles of all the documents retrieved were screened by the first author to include those that clearly (i) investigated leishmaniases and/or CD, (ii) reported primary research or systematic reviews from a social science perspective, and (iii) were written in English, Spanish or Portuguese. We excluded those that did not present original data (comments, perspectives, opinions) or were published outside of peer-reviewed journals (i.e. books, pre-prints, and conference abstracts). The title screening excluded 1561 articles and 40 duplicates on leishmaniases and 1216 articles and 35 duplicates on CD. Our study workflow is summarized in Fig. 1 according to the PRISMA 2020 statement.

### 2.2. Abstract analysis

In the analysis of the 514 remaining abstracts (Leishmaniases: 279; CD: 235), we employed two distinct strategies. For the 449 (Leishmaniases: 243; CD: 206) records/papers retrieved from PubMed, a computer-based method was utilized to automate the first steps of PubMed abstract analysis in order to identify which articles to include in the full-text review. We used RStudio version 1.4.1106 and PubMed. mineR package to identify abstract word frequencies and construct a computer-based content dictionary that enabled us to efficiently analyze this textual information (Bernard et al., 2017). The function readabs() was used to read the PubMed .txt files containing the abstracts retrieved from the leishmaniases and CD searches. The function word.atomizations() was used to tokenize abstract into words and export word frequencies. The first author then sorted the words that appeared in the abstracts into inclusion words for "social science terms group" (examples include perception, socioeconomic, political) and "disease terms group" (examples include Chagas, CD, vector-borne, Leishmania, Kala-azar, leishmaniasis) (see Suppl. S1 Data for full list of inclusion words in each category). The function tdm\_for\_lsa() was then used to generate a term documented matrix (tdm) that was used to identify articles that included at least one word from both the "social science" and "disease" term groups. Leishmaniases and CD abstracts that did not have at least one word from both the "social sciences" and "disease" groups were read by three coauthors (RNB, ST, JVR) in order to confirm they should be excluded (see Fig. 1). The first author then read all abstracts selected as potentially relevant for full-text screening and re-assessed them for inclusion/exclusion criteria (as specified above). When the social science component was not evident from the abstract, the first author read the full text to determine if the social science term mentioned in the abstract was present in the data analysis and interpretation/discussion of results. We did not use automated content analysis for the 65 (Leishmaniases: 36; CD: 29) records/papers obtained from WoS because it was a smaller number of records. Instead, the first

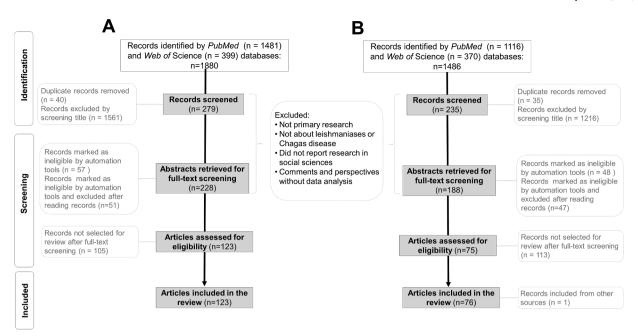


Fig. 1. Flow diagram for identification, screening and inclusion of documents for the scoping review of social science research in leishmaniases and Chagas disease.

author read all abstracts and assessed them for inclusion/exclusion criteria as mentioned above. Other sources (e.g., references from selected articles or studies we were aware of before this review) were also considered to identify relevant themes for our review. These processes resulted in a total of 123 articles that addressed both social science and leishmaniases and 76 that examined both social science and CD retrieved by PubMed and WoS and included in our review (Fig. 1). It is important to mention that research in psychology, economics, and treatment strategies posed a challenge for paper selection during the abstract screening. For example, we decided to exclude research focused on identifying or evaluating depression or anxiety among patients because we determined that clinical research was beyond the scope of this review. This was particularly important in making decisions about what to include/exclude regarding research on how leishmaniases and CD affect quality of life. In economics, we focused on studies that examined the association between socioeconomic status and disease occurrence, risk, progression, or control, and excluded research that focused primarily on economic outcomes such as cost of treatments or assessing cost-effectiveness. Finally, we excluded studies on non-pharmaceutical treatments that solely discussed the effectiveness or cytotoxic activity of a plant or other substance for either leishmaniases or CD.

### 2.3. Text analysis for emergent themes

After the title and abstract screening, a total of 199 articles that included a social science perspective on leishmaniases (n=123) or CD (n=76) were read by the first author (as depicted in Fig. 1 and listed in Suppl. S2 Data). In this step, we drew on principles of grounded theory (Bernard et al., 2017; Bernard, 2006) to identify emergent themes in the published scholarship. Grounded-theory is an inductive, iterative process of reading and coding for themes that allows us to use our background experience in disease ecology and anthropology to identify and code articles into thematic groups (Bernard et al., 2017; Bernard, 2006). The first author developed an organizational database including information on major themes/subthemes for each article and, with the co-authors, discussed and refined the themes throughout data analysis and manuscript preparation Fig. 2. If an article included more than one of our identified major themes, we assigned it to the thematic group that was the primary focus of the publication for the purposes of descriptive

statistics and figures. However, if an article contained multiple themes, we included it in the analysis and discussion of each thematic group. Data visualization was performed with RStudio version 1.4.1106 using ggplot, rworldmap, classInt, and RColorBrwer packages.

### 3. Results

# 3.1. General results

There was more social science research on leishmaniases (61.8 %; 123/199) than CD (38.2 %; 76/199) in our sample and the number of publications on both diseases increased across time. For leishmaniases, the number of publications peaked between 2010 and 2020, with most articles (79.6 %) coming from the last decade (Fig. 3). For CD, most publications also come from last decade (77.6 %), but an abrupt decrease in the number of publications in 2022 is observed (Fig. 3).

We identified three main research themes in our sample of the social science research on leishmaniases and CD (described in Fig. 2). For both diseases, studies about the sociocultural dimensions of the diseases (Group 1) were the most common theme (63.3 %; 126/199 publications). Research investigating the socioeconomic dimensions of diseases' risk, transmission, occurrence, and/or progression (Group 2) ranked second with 25.6 % (51/199) of the documents. The historical and political contexts of the diseases (Group 3) were investigated in 11 % (22/199) of the articles (Fig. 4). In terms of geographic locations, Brazil played a significant role in social sciences research on CD (22.3 %) and leishmaniases (19.5 %). It also emerged as a leading country in overall social sciences research across the three major themes, except for historical contexts of leishmaniases, where the majority of production was in the Middle East and North Africa (Figs. 5 and 6).

### 3.2. Sociocultural dimensions of the diseases - group 1

The sociocultural dimensions of leishmaniases and CD were the main research themes of 60.2% (74/123) of articles on leishmaniases and 68.4% (52/76) of articles on CD (Fig. 4). Subthemes included in this topic are shown in (Fig. 2).

Research into people's familiarity and awareness of diseases and insect vectors is a common topic in this research. This is often, but not always, examined with Knowledge, Attitude, and Practices (KAP)

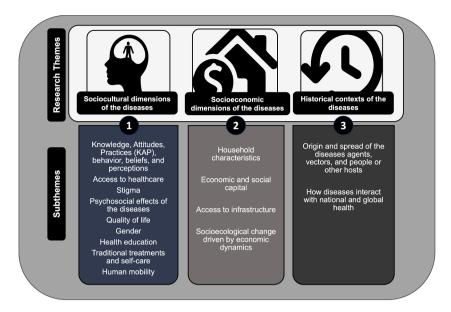


Fig. 2. Major research themes and subthemes identified in social science-based studies in leishmaniases and Chagas disease.

# Social sciences research in leishmaniases and Chagas disease

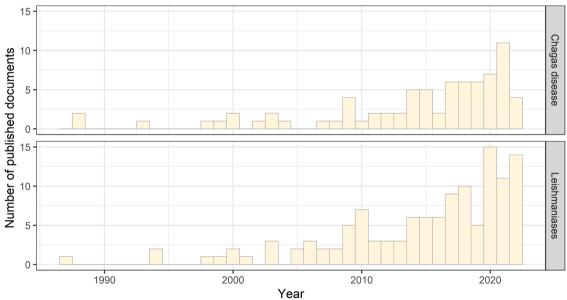


Fig. 3. Social science research in leishmaniases and Chagas disease published over time and indexed by PubMed and Web of Science.

surveys e.g., (Salm and Gertsch, 2019; de Amorim et al., 2015). Research suggests that awareness of leishmaniases, CD, and their insect vectors varies greatly by region, the presence of cases among relatives, the existence of vector/disease control campaigns in the area and individual factors such as age, gender, education level, and socioeconomic status (Salm and Gertsch, 2019; de Amorim et al., 2015; Amin et al., 2012; Mishra et al., 2010; Isaza et al., 1999; Mounia et al., 2022; Parisi et al., 2020; Silva et al., 2020; Martínez-Parra et al., 2018; Conners et al., 2017; Di Girolamo et al., 2016; Hurtado et al., 2014; de Carvalho et al., 2021; Dell'Arciprete et al., 2014; Uchoa et al., 2002; Devipriya et al., 2021; Limongi et al., 2021; Guha et al., 2020; El-Mouhdi et al., 2020; Aerts et al., 2020; Carvalho et al., 2020; Costa et al., 2014). Although the plurality of research on leishmaniases suggests people are well aware of the disease symptoms, some research also finds people's knowledge about the disease, vectors and preventive measures to be very low or inexistant (Akram et al., 2015; Kumar et al., 2009; Garapati et al., 2018).

When people are aware of the disease, some research also suggests that people don't immediately connect the disease to either the sandfly vectors or to measures aimed at minimizing sandflies (Devipriya et al., 2021; El-Mouhdi et al., 2020; Amin et al., 2012; Mishra et al., 2010; Isaza et al., 1999; Patiño-Londoño et al., 2017; Siddiqui et al., 2010). For CD, research suggests that, in general, people living in endemic areas have little knowledge about disease transmission, symptoms, treatment and vectors, even among patients infected with *T. cruzi* or people exposed to high-risk transmission settings (Martínez-Parra et al., 2018; Hurtado et al., 2014).

The link between a person's knowledge or awareness of leishmaniases and CD and disease avoidance practices is not clear in the research. For example, two research articles found that having some knowledge about CL and VL was not associated with practices to prevent the infection (Aerts et al., 2020; Alemu et al., 2013). Instead of a clear association between knowledge of a disease and people taking

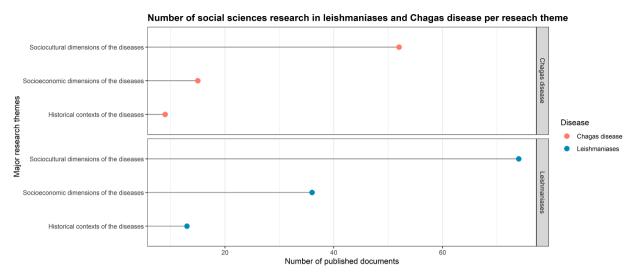
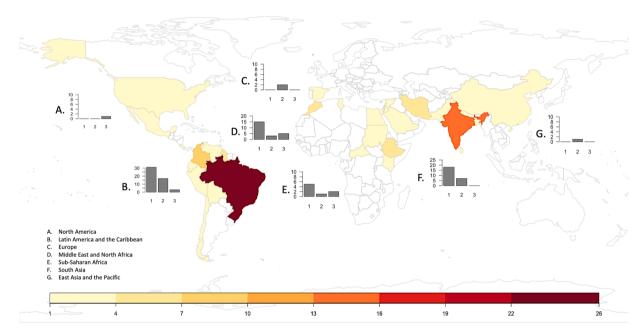


Fig. 4. Total of social science research in leishmaniases and Chagas disease per research theme.

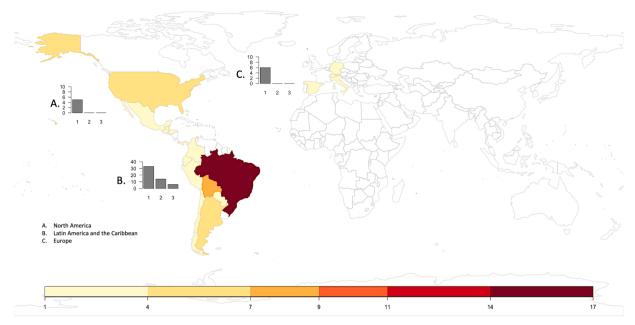


**Fig. 5.** Total of social science research in leishmaniases per country studied and per research theme. The color scale on the map indicates the number of articles published per country. The bar graphs display the total number of articles published per research theme in each region, with the y-axis representing the count and the x-axis indicating the research topics: 1, social and cultural dimensions of the diseases; 2, socioeconomic dimensions of the diseases; 3, historical contexts of the diseases.

preventative measures to avoid the disease, several researchers found that ecological, demographic (gender and age), or socioeconomic conditions were more related to peoples' practices and attitudes towards leishmaniases (Devipriya et al., 2021; Limongi et al., 2021; Pardo et al., 2006; Berhe et al., 2022). Similarly, in communities where people are largely aware of the triatomine bugs as a vectors of CD transmission, this knowledge had little influence on prevention practices, apparently due to factors such as the amount of time that people devoted to patio or corral cleaning or variation in how people feel about kissing bugs and insect bites (Salm and Gertsch, 2019; Ventura-Garcia et al., 2013; Verdú and Ruiz, 2003).

A second research subtheme that emerges from studies on both leishmaniases and CD is how people are able (or unable) to access health care for the diseases. Research often identified peoples' limited knowledge about clinical symptoms, treatments and negative perceptions of health care services as important reasons for not seeking a diagnosis

and/or adhering to treatment for leishmaniases (El-Mouhdi et al., 2020; Boukthir et al., 2020; Nair et al., 2020; Eid et al., 2019; Sunyoto et al., 2018; Bamorovat et al., 2023) and CD (Parisi et al., 2020; Martínez-Parra et al., 2018; Jimeno et al., 2021; Patterson et al., 2018). Additionally, research often identifies structural factors such as long pilgrimages between medical facilities, high costs for diagnosis and/or treatment and poor logistics in the distribution and supply of medicines as important barriers to diagnosis and treatment (Cucunubá et al., 2017; Eid et al., 2019). Several researchers noted that people with CD living in countries like the United States, Spain, Italy, and Germany also experience structural barriers to accessing the healthcare system (Di Girolamo et al., 2016; Valdez Tah, 2021; Forsyth et al., 2021; Ventura-Garcia et al., 2021; Castaldo et al., 2020; Navarro et al., 2017). Research in these countries, often with immigrant patients, identified that the high costs of medical treatment, language barriers, inability to schedule medical appointments outside of work hours, and limited information



**Fig. 6.** Total of social science research in Chagas disease per country studied and per research theme. The color scale on the map indicates the number of articles published per country. The bar graphs display the total number of articles published per research theme in each region, with the y-axis representing the count and the x-axis indicating the research topics: 1, social and cultural dimensions of the diseases; 2, socioeconomic dimensions of the diseases; 3, historical contexts of the diseases.

about immigrant rights and health insurance were all barriers to care (Di Girolamo et al., 2016; Valdez Tah, 2021; Forsyth et al., 2021; Ventura-Garcia et al., 2021; Castaldo et al., 2020; Navarro et al., 2017). There are also challenges within the medical system, like limited knowledge of health professionals about CD, transmission mechanism, diagnosis, or their perception that the disease is related to Latinx ethnicity (Granados et al., 2020; Peniche, 2021).

In addition to structural factors that create healthcare barriers for leishmaniases and CD, research also has investigated how individual ideas, beliefs, and behaviors, as well as the larger sociocultural context, shape how people interact with biomedical systems. For example, researchers note that fear of injections, presence/fear of adverse effects, recommendations from people within the patients' social networks, reliance on traditional (plant-based, chemicals, self-medication) or nonpharmaceutical treatments, and ideas around gender and masculinity influence how people seek treatment for CL and MCL and what kinds of care they prefer and find acceptable (Odonne et al., 2017; Pineda-Reyes et al., 2015; Ramdas, 2012; Odonne et al., 2011; Odonne et al., 2009; Weigel and Armijos, 2001; Weigel et al., 1994). Additionally, fear of physical disfigurement and permanent scars caused by lesions, and fear of disease progression or fatality may influence patient's choice for a conventional pharmacological treatment for CL or MCL (Odonne et al., 2017; Pineda-Reyes et al., 2015; Ramdas, 2012; Odonne et al., 2011; Odonne et al., 2009; Weigel and Armijos, 2001; Weigel et al., 1994).

Non-pharmaceutical treatments of both leishmaniasis and CD is another subtheme of research. Several researchers reported traditional treatments that may be predominantly used as topical application directly on the wound for CL and MCL (Odonne et al., 2017; Pineda-Reyes et al., 2015; Ramdas, 2012; Odonne et al., 2011; Odonne et al., 2009; Weigel and Armijos, 2001; Weigel et al., 1994). Special attention has been given to plant-based treatments in Amazonia, including reports on the use of hundreds of botanical species (Odonne et al., 2017; Odonne et al., 2011; Odonne et al., 2009). Topical use of garlic poultices was also reported as Iranian traditional treatment for CL (Maleki et al., 2018). There is much less research on traditional treatments for CD than leishmaniases. This limited research on traditional or self-care practices for CD included the use of medicinal plants and/or drugs to relieve the suffering (Jimeno et al., 2021; Forsyth, 2018). Opting for self-care or

traditional treatments for CD can be driven by family or friends' influence on treatment choice, patient's narratives from unsuccessful biomedical treatment and/or successful non-biomedical care, no clear improvement of symptoms after initiation of biomedical treatment, and limited understanding about the treatment, and fear of being diagnosed with a diseases linked to death (Parisi et al., 2020; Ventura-Garcia et al., 2013; Jimeno et al., 2021; Forsyth, 2018).

Research exploring the illness experiences of leishmaniases and CD primarily focuses on how experiencing symptoms or receiving a positive diagnosis affect a person's psychosocial health or quality of life (QoL). Research has documented that the skin lesions and scars caused by CL and MCL have psychological and psychosocial impacts including loss of self-esteem, feelings of inferiority, anger, sadness, problems with social relationships, and disliking one's own appearance (Costa et al., 1987; Chahed et al., 2016; Bennis et al., 2017; Khatami et al., 2018). Chronic CD does not result in visible lesions like CL and MCL, but several researchers have found that people with a positive CD diagnosis may suffer from stigma and shame due to the physical limitations that result in loss of work productivity and absenteeism, as well as due to the misunderstood associations between CD, poverty, precarious housing conditions, and rurality. This also leads patients to experience social exclusion when living in a non-endemic country (Valdez Tah, 2021; Dias, 2013; Avaria et al., 2021). Also, a positive diagnosis for leishmaniases or CD can have a profound impact on the overall patient's QoL - including physical, psychological, and social realms (Cavalcanti et al., 2019; Silva et al., 2022). The existing studies on QoL and both CL and MCL in our sample argue that QoL is compromised by inadequate social support for patients (especially those co-infected with other chronic illnesses) due to poor access to health services and stigma. Lack of patient support, in turn, negatively affects the person's mental health, social and professional life and QoL (Nair et al., 2020; Chahed et al., 2016; Alemayehu et al., 2018). Our sample included only two articles that investigated QoL and CD, but both agreed that the overall QoL is compromised by the stigma, mental and/or emotional distress, fear of the future, fear of treatment, physical limitations and related difficulties with employment and professional roles (Cavalcanti et al., 2019; Silva et al., 2022) in patients. However, most of the QoL research into leishmaniases and CD found in this review drew on standardized surveys of symptoms and physical/dermatological

functioning to assess QoL (Cavalcanti et al., 2019; Galvão et al., 2018; Bennis et al., 2018; Hu et al., 2020).

A smaller sample of research has shown how gender dynamics influence stigma and the illness experience of leishmaniases and CD. Several studies focused in the Middle East found that the psychosocial effects caused by CL and MCL lesions are especially salient for young women in areas where lesions/scars are stigmatized, leading to difficulties in relationships, professional achievement, and social exclusion (Chahed et al., 2016; Bennis et al., 2017; Reithinger et al., 2005; Kassi et al., 2008). On the other hand, researchers also found that men experience feelings of anger and guilt related to a CL diagnosis (Khatami et al., 2018). One study found that ideas around masculinity, courage, and physical strength were associated with patients, often men, electing to use a risky chemical self-treatment for leishmaniases (Ramdas, 2012). As with leishmaniases, the psychosocial impact of CD is amplified due to fear and guilt that pregnant women experience after receiving a positive diagnosis for CD because of the possibility of vertical (transplacental) T. cruzi transmission (Avaria et al., 2021).

There is attention to the fact that migration from rural areas in Latin America – where CD is transmitted mainly by vectors – to urban settings both within and outside Latin America can create non-vectoral transmission events such as transmission associated with blood and organ donation or vertical infections (Conners et al., 2017; Ventura-Garcia et al., 2021; Bayer et al., 2009; Vera et al., 1998). Research related to this transmission scenario outside Latin America cautions that stigma associated with CD can lead to discrimination and social exclusion, including racism and xenophobia, towards Latin American or other international migrants (Valdez Tah, 2021). Furthermore, research by Valdez Tah (2021) in the U.S. found that a positive diagnosis for CD in Mexican immigrants living in the U.S. generated a feeling of shame and a disruption of self-image due to the existing stigma around CD. The main reason for migration among CD patients from rural to urban areas (both within and outside Latin America) is the search for work opportunities, improvement of financial situation, political or security reasons (Di Girolamo et al., 2016; Ventura-Garcia et al., 2021; Castaldo et al., 2020; Bayer et al., 2009; Vera et al., 1998) - which is especially observed among women who also have to cope with feeling of fear and guilt due to the possibility of vertical transmission.

A small but important area of research that emerged in the articles included in our review evaluated public health educational information about leishmaniases and CD. For example, Pimenta and colleagues evaluated the audiovisual educational materials on leishmaniases in Brazil to understand their effectiveness as tools for health education (Pimenta et al., 2007). Based on their analysis of 14 videos, they caution that the materials did not stimulate critical reflection on the social determinants of leishmaniases. Instead, the videos promoted some ideas that lead to patients experiencing stigma such as emphasizing the debilitating effects of lesions. In contrast, a study on using animation and games for CL health education showed positive effects on critical thinking and preventative behaviors among adolescents (Alidosti et al., 2022). We found no research evaluating the educational materials aimed at VL and very little focused on CD. Our search included evaluation of a game focused on preventing CD and the social role of Brazilian scientist and community health agents (Piancastelli et al., 2021). A recent literature review focused on CD and education (Sanmartino et al., 2020) found most resources emphasize biomedical aspects of the disease but some contained themes related to the sociocultural and political dimensions of CD (Sanmartino et al., 2020). Overall, the research suggests that health education materials focused on leishmaniases and CD should continue to be aware of stigma and the social and political dimensions of the diseases.

## 3.3. Socioeconomic dimensions of the diseases - group 2

The second most common theme we identified in research explores how socioeconomic drivers explain disease occurrence and/or

mortality, risk of infection, and disease progression. These account for 30.1 % (38/123) of all leishmaniases publications in our review and 19.7 % (15/76) of all CD publications (Fig. 4). Socioeconomic drivers are assessed through a host of measurements including household characteristics (housing structure, overcrowding [number of inhabitants per house], income, material assets [car, moto, radio], economic and social capital (educational level, Human Development Index [HDI], Gini inequality index, caste system), access to infrastructure (piped drinking water, sanitation, electricity, garbage collection, healthcare services), and/or larger socioecological change driven by economic dynamics. These factors were assessed independently (Viotti et al., 2009; Sheets et al., 2010) or combined as a measure for socioeconomic status (Chaves et al., 2008; Brito et al., 2017; Fernández et al., 2019a; Fernández et al., 2019b; Ribeiro et al., 2021).

Household characteristics, including type of housing materials (e.g., mud, wattle, bamboo, thatch roof, etc.) and surrounding environments (refuse piles, wet soil, etc.), income level, and the amount of material assets were found as risk factors for transmission and/or occurrence of VL (Sheets et al., 2010; Ribeiro et al., 2021; dos Reis et al., 2022; Adhikari et al., 2010a; Boelaert et al., 2009; Thakur, 2000; Andrade et al., 2022) and CL cases (Wijerathna et al., 2020; Mashayekhi-Ghovonlo et al., 2015; Rodríguez-Morales et al., 2010; Shahryari et al., 2023; Amane et al., 2022). Additionally, occurrence of canine VL is associated with houses without masonry walls and houses with a dog kennel (Veloso et al., 2021). For CD, house structure (e.g., adobe-cracked wall, presence of wood, tile, brick piles), crowding (number of residents per sleeping quarter), and lower reported income was found to be important risk factors for triatomine bug infestation (Zamora et al., 2015; Gaspe et al., 2015; Bustamante et al., 2014) - and, hence, risk for CD infection. House structure was also highly associated to distribution of CD cases in Latin America (Mischler et al., 2012). In a case control study, non-infected individuals performed more skilled activities, had fewer job changes, and were involved in less heavy occupational activities than CD's cardiomyopathy subjects (Zicker,

Research also points to associations between measures of socioeconomic status, educational levels, and risk of leishmaniases and CD. Associations were found between VL cases and lower educational and literacy level, lower HDI, and higher Gini index Brazil, India and Nepal (Sheets et al., 2010; Ribeiro et al., 2021; dos Reis et al., 2022; Adhikari et al., 2010a; Boelaert et al., 2009; Andrade et al., 2022; Valero and Uriarte, 2020; Almeida and Werneck, 2014; Adhikari et al., 2010b). Associations were also found between CL cases in Brazil, Iran, Venezuela, Morocco and Ethiopia and lower HDI, higher Gini index, lower educational levels (Rodríguez-Morales et al., 2010; Valero and Uriarte, 2020; Gonçalves et al., 2020; Eshetu and Mamo, 2020), residence in rural areas, and movement to endemic regions (Amane et al., 2022). Conversely, one study (Rodrigues et al., 2019) found a positive association between municipality HDI and CL cases in Brazil. Also, low castes with VL have were reported as having poor access to the treatment and twice higher odds to be 'late presenters' at healthcare facilities in Bihar, India, compared to the rest of castes (Martínez et al., 2012). Higher VL lethality was found in Brazilian municipalities with lower HDI (Donato et al., 2020). Researchers investigating dispersion of triatomine bugs as a proxy for CD risk found that levels of schooling and lower municipality HDI were associated to areas of higher dispersion/presence of triatomine bugs in houses (Brito et al., 2017; Bernardo-Pedro et al., 2019) in Brazil. Low educational level was strongly associated to chronic CD progression (Viotti et al., 2009) in Brazil and related to possible outbreak of CD oral infection in Brazil (Monsalve-Lara et al., 2021).

Another important area of research is the links between access to infrastructure and occurrence of leishmaniases and CD. On the whole, research found less access to infrastructure was associated with occurrence/progression of the diseases. For example, impaired access to sanitation services, healthcare, running water, electricity, garbage

collection system, and/or urban mobility were associated with VL cases in Brazil and India (Ribeiro et al., 2021; Boelaert et al., 2009; Donato et al., 2020; Rocha et al., 2018). The health system performance was negatively associated with incidence of CL in Brazil (Rodrigues et al., 2019); in Morocco, CL cases were associated to rural habitation and absence of sewage system (Amane et al., 2022). Individuals with CD living in Brazilian municipalities with fewer physicians per thousand habitants and lower primary health care coverage had higher chances of experiencing CD cardiovascular events (Ferreira et al., 2020) in Brazil. Similarly, low rate of cardiomyopathy progression in patients with chronic CD was observed in patients with private medical insurance coverage (Viotti et al., 2009) in Argentina. Also, fetching drinking water from rivers or wells without pumps were associated with the distribution of CD infection in Bolivia (Mischler et al., 2012). Dispersion/presence of triatomine bugs in houses was also found to be associated with areas where a higher percentage of the population that did not have access to adequate sanitation (Bernardo-Pedro et al., 2019).

Two studies in our sample explored the deforestation as a product of socioeconomic inequities (Chaves et al., 2008; Guerra et al., 2019). They discuss how habitat modifications force change in people's lifestyles such as economic/subsistence activities that expose them to a higher risk of infection (Chaves et al., 2008; Guerra et al., 2019).

In sum, research on leishmaniases and CD that considers the association between socioeconomic factors and disease finds that lowered socioeconomic status (measured by the many factors mentioned above) affected odds of infection, but the magnitude of these effects varied. Only a few studies reported no clear associations between some of these mentioned socioeconomic factors and self-reported cases of CD (Llovet et al., 2011), canine VL (Veloso et al., 2021; Meheus et al., 2013), or the spatial distribution of CL (Hernández et al., 2019) and VL (Rocha et al., 2018). Researchers have examined the impact of 'poverty' on VL lethality (Donato et al., 2020), as well as the incidence of CL (Amane et al., 2022; Gonçalves et al., 2020; Moya-Salazar et al., 2021) and VL (Adhikari et al., 2010a; Adhikari et al., 2010b); however, the definition of poverty is either absent or limited to income (Adhikari et al., 2010a). Finally, the majority of research on both diseases was carried out in Latin America (Figs. 4 and 5).

### 3.4. Historical contexts of the diseases - group 3

A final research theme focuses on the historical and political contexts of CD and leishmaniases. In the full dataset, 10.5% (13/123) of leishmaniases articles and 11.9% (9/76) of CD articles addressed the origin and/or spread of the diseases (Fig. 4).

Research on the origin and spread of these diseases primarily draws on historical documents, art, archeological material, and/or paleopathological/paleoparasitological data. Paleoparasitological data and historical documents suggests that leishmaniasis was prevalent in humans in antiquity and spread all over the world during early human migration (Steverding, 2017). The oldest documented examples of *T. cruzi* infection in humans are from Chinchorro individuals dating to from ~7000–9000 years ago found in modern day Chile, suggesting that American populations lived with insect vectors throughout history (Aufderheide et al., 2004; Guhl et al., 2000; Ferreira et al., 2000). Archeological, ethnohistorical and molecular data shows that the spread of leishmaniases and CD have always been tied to human activity and driven by social, cultural, economic, and political patterns (Aufderheide et al., 2004; Guhl et al., 2000; Ferreira et al., 2000; Costa et al., 2009; Altamirano-Enciso et al., 2003; Zink et al., 2006).

While the first two research themes cut across both leishmaniases and CD research, there is more research attention to the role of war and political disruptions on leishmaniases than CD. For example, a cluster of research examines how war and political conflict and population displacements associated with conflict are associated with the emergence/re-emergence of leishmaniases. Here, researchers have investigate the increased incidence of either cutaneous or visceral leishmaniasis and the

occurrence of civil war, conflict, or experiences with political terrorism in Middle East and North Africa (Muhjazi et al., 2019; Berry and Berrang-Ford, 2016; Ozaras et al., 2016; Du et al., 2016; Jaber et al., 2014). This also shows how the effects of conflicts spread beyond geographic boundaries as outbreaks were recorded in regions under conflict and in countries hosting immigrants/refugees from conflict zones (Muhjazi et al., 2019; Berry and Berrang-Ford, 2016; Ozaras et al., 2016; Du et al., 2016; Jaber et al., 2014). In a telling example of how complex these socio-politically driven shifts in disease ecology can be, Cannella et al. (2011) show how a small U.S. cluster of CL caused by Leishmania panamensis, among East Africa men who immigrated to the United States could be traced to the men following human trafficking routes and becoming infected while traveling through Central America to the United States. The identification of the parasite responsible for the infection highlights the potential public health and political implications of this frequently used smuggling routes (Cannella et al., 2011).

A final study in this subtheme illustrates how interactions between war, violence, and CL extend after the conflict passes. In their research on the legacy of leishmaniasis and conflict in Colombia, Pinto-García (Pinto-García, 2022a) highlights that combatants and their military dogs are still affected by CL that they acquired during military operations in Colombian forests. The current public health approach to controlling leishmaniases in military dogs often involves euthanasia, which ignores the important roles that dogs play to identify risk by scent and the emotional bond between the dogs and their human companions during the trauma of armed conflict. The author proposes new, non-violent practices of care that consider the life-saving role of military dogs and the emotional bonds they form with their human companions, while also discussing the war-imposed values that prioritize human life over non-human life (Pinto-García, 2022a).

There is also an important body of scholarship that discusses how the historical and political contexts in countries affected by leishmaniases and CD shape public health. Numerous studies highlight the profound impact of Carlos Chagas' discovery of Chagas disease (CD) on Brazilian science, public health, and politics (Amieva, 2014; Kropf and Lima, 2022; Coutinho, 1999; Kropf, 2008; Kropf et al., 2003). These studies emphasize how the discovery of CD advanced scientific knowledge, led to public health interventions and underscored the importance of addressing NTDs within the broader context of social and economic inequalities (Kropf and Lima, 2022; Coutinho, 1999; Kropf, 2008; Kropf et al., 2003). Overall, the research shows how the history of CD's discovery framed the project of nation modernization in Brazil, promoting scientific advancement, initiating public health measures, addressing social inequalities, and emphasizing the role of governance and political commitment (Kropf and Lima, 2022; Kropf, 2008). Despite the scientific progress achieved, Amieva (2014) points out the remaining gap between scientific knowledge and the everyday reality of affected populations and illustrates how CD is both a medical and social problem that needs sustained and systematic involvement of social sciences to control the disease. Beyond Brazil, Wijeyaratne et al. (1994) and Okello et al. (2015) highlight the interconnectedness of history, political context, and public health agendas that shape the control of leishmaniases and other NTDs and the national development, like in some African countries (Okello et al., 2015).

In summary, research in this theme highlights that human movement has always spread pathogens with people. However, global migration like colonialism and current market driven migration under conditions of rapid global transportation are on a different scale so likely to generate novel disease dynamics – requiring, therefore, investigations on the historical and political contexts underlying these disease dynamics and public health.

### 4. Discussion

This scoping review shows there has been increased attention to social science research in both leishmaniases and CD over the past 20

years, especially with respect to three major research themes from our sample of articles that included social sciences research on either leishmaniases or CD. The disparity in the number of leishmaniases (n =123) studies compared to CD (n = 76) is interesting because, while they are both NTDs, they have different global distributions and epidemiological characteristics, with leishmaniases being broader distributed and comprising more diverse social landscape. The leishmaniases are a group of potentially severe and disabling diseases (WHO, 2022b) with three different, clinical manifestations caused by various Leishmania parasites across 99 countries and territories. In contrast, CD is a disabling, life-threatening illness endemic in Latin America - although the transmission of T. cruzi in European and North American countries have increased in recent decades. This is due to the movement of infected people to regions where CD is not endemic, enabling non-vectoral mechanism transmissions e.g., blood transfusion, congenital, and organ donation (Dias et al., 2015; Pérez-Molina and Molina, 2018). Despite that, Brazil is the location of the most social science publications on leishmaniases and CD, whereas other countries with significant burdens receive comparably less research attention from the social sciences. This may be, in part, due to the fact that the discovery of CD by Carlos Chagas in Brazil in 1909 led to a socio-political agreement on its importance and recognition as a significant social and public health problem in Brazil. This lead to increased scientific production about parasitic diseases, which together with the size of the Brazilian territory and its strong universities helps to explain Brazil's higher research output (Coutinho, 1999).

Research that uses "Knowledge, Attitude, and Practice" (KAP) or "Knowledge, Attitude, Behavior, and Practice" (KABP) frameworks was common in this review. KAP research is a method developed by international aid organizations in the 1950s and 1970s, first applied to family planning and later to general health conditions (Launiala, 1970; Nichter, 2008; Manderson and Aaby, 1992; Green, 2001). KAP-oriented research in infectious diseases has strengths including the ability to provide insight into cultural and social factors, inform targeted public health interventions, and improve healthcare utilization (Launiala, 1970). However, this survey approach also draws on the assumption that information on a person's knowledge, attitudes, and behaviors/practices related to a condition/issue can be used to gain information about health-seeking practices and provide new insights into how disease control can be achieved (Nichter, 2008). Furthermore, in KAP-focused research, researchers commonly assume that an increase in knowledge about a disease will lead to a change in behavior (Launiala, 1970). This assumption has led to the use of KAP survey data to plan activities aimed at behavior change, based on the idea that there is a direct relationship between knowledge and behavior (Launiala, 1970). In fact, several publications (Salm and Gertsch, 2019; Aerts et al., 2020; Alemu et al., 2013; Ventura-Garcia et al., 2013; Verdú and Ruiz, 2003) suggest that the practices and attitudes to prevent diseases are not clearly associated with knowledge about the diseases and the risk of transmission. Instead, a person's socioeconomic conditions, cultural values or beliefs, and/or demographic factors such as gender are also important in shaping KAP patterns in a community e.g., (Salm and Gertsch, 2019; de Amorim et al., 2015; Mounia et al., 2022; Parisi et al., 2020). This highlights that KAP-focused studies must consider sociocultural contexts of the research location (Launiala, 1970) in order to strengthen intervention strategies. In addition, our results highlight how intervention studies should also be followed by the post-intervention assessment of KAP. We found three CD educational intervention studies in our review and in all of them the disease knowledge was improved after intervention/campaigns, but none assessed whether people's behavior, attitudes and/or practices afterwards were improved (Granados et al., 2020; Araujo-Jorge et al., 2021; Marco-Crespo et al., 2018) as observed in a few VL studies (Srinivasan et al., 2018; dos Santos Lobo et al., 2013; Magalhães et al.,

It is not surprising to find that a significant subtheme in the social science research related to leishmaniases and CD examined barriers to

accessing healthcare. The social sciences have made important contributions to this topic highlighting the financial, social, and historical reasons why patients can't or don't embrace medical care for a host of infectious diseases (Farmer, 2001). Nevertheless, the focus on leishmaniases and CD in this review also points to important contributions to understanding vector-borne, zoonotic diseases. Like other infectious diseases, the costs of diagnosis, treatment, and long journeys to health services are documented in the research conducted in endemic areas of Latin America included in this scoping review (Parisi et al., 2020; Jimeno et al., 2021; Patterson et al., 2018; Vera et al., 1998). However, it is important to note that a large portion of CD studies focus on barriers to accessing health care in countries where CD is not endemic (Valdez Tah, 2021; Forsyth et al., 2021; Ventura-Garcia et al., 2021; Castaldo et al., 2020; Navarro et al., 2017; Granados et al., 2020; Avaria et al., 2021; Rapp, 2021; Forsyth et al., 2018). Although difficulties in accessing health care are an equally important issue for all people affected by CD, we note that more research is needed on populations residing in Latin America, where ~4 million people are infected with the parasite and ~70 million are at risk of transmission (Pérez-Molina and Molina, 2018).

In addition to identifying important barriers to accessing biomedically-focused healthcare, research that considers how people draw on local treatments, healers, and social relationships when suffering from an infectious disease has made important contributions to understanding the illness experiences (Young, 1976) and treatment strategies (Nichter, 2008) for people around the world. The focus on leishmaniases and CD in this review illustrates again the value of this thread of research across multiple diseases. For example, with research on leishmaniases, there is often a discussion of the use of local, non-pharmaceutical (often plant-based) treatments, but the number of studies that go beyond investigating the possible biomedical applications of these treatments is small. While there is scholarship on how people self-treat for diseases like malaria (McCombie, 2002), this review suggests important dimensions of local treatments and responses to non-mosquito borne diseases like leishmaniases and CD – although there are more studies focused on this topic for leishmaniases than for CD in our review. For example, despite the 'invisibility' of CD, some publications noted traditional/self-treatments for managing the symptoms of CD (Parisi et al., 2020; Jimeno et al., 2021; Forsyth, 2018). Another aspect that draws attention is the issue of gender in utilizing treatments outside of conventional, biomedical medicines. For example, norms of strength and masculinity are implicated in research on why men are discouraged from seeking medical help or elect to use dangerous chemical treatments (Isaza et al., 1999; Ramdas, 2012); on the other hand, the added burden of a CD diagnosis and possibility of placental transmission during pregnancy provides an added burden when the role of family and women's roles are linked. These themes cross-cut research on NTD's as illustrated by Wharton-Smith et al. (Wharton-Smith et al., 2019) research showing women affected by five NTDs in Ethiopia postpone seeking medical attention because of gender-based power dynamics, including their reliance on men for covering healthcare costs or needing their husbands' approval to seek and receive medical care. Besides the insufficient research on gender inequality in healthcare, there is also limited information about gender disparities in knowledge about leishmaniases and CD. Varying levels of KAP regarding leishmaniases have been observed between men and women (Limongi et al., 2021; Mishra et al., 2010; Isaza et al., 1999; Mounia et al., 2022; Devipriya et al., 2021; Wenning et al., 2022), but the reasons for these disparities among gender are unclear.

Stigma is embedded in sociocultural norms and constantly reinforced by institutions like governments, media, industry, and religion (a.k.a. structural stigma), which in turn affects individuals differently based on characteristics such as gender, ethnicity, income, or age (Brewis and Wutich, 2019). For example, the stigma and, therefore, its psychosocial impacts, affects patients with both leishmaniases and CD, but we found in our review that women bear a disproportionate burden of the

consequences of public stigma (e.g., difficulties for marriage and for finding a job) and self-stigma (e.g., fear or guilty of vertical T. cruzi transmission). In their book, Brewis and Wutich (2019) illustrate how societal perceptions of poverty related to sanitation campaigns and infectious disease control influenced the allocation of resources, policies, and interventions. They also argue that the negative effects of stigma tends to be strongest when a condition acquires a social meaning that results in the perception that people are morally responsible for their condition, thus shifting the focus from social and political causes to individuals' responsibility (Brewis and Wutich, 2019). An example of this with leishmaniases and CD is the frequent association of these diseases with low economic status. The majority of studies focused on investigating the socioeconomic drivers (measured by emphasis on household characteristics, economic and social capital, and access to infrastructure) of the diseases instead of research-oriented to the links between wealth, power, colonialism, slavery, politics, disordered urbanization, and the dynamic transmission of leishmaniases and CD. Many studies in our reviewwith a few exceptions (Fernández et al., 2019b) -also did not adjust the estimates for other co-occurring inequalities like gender, age, or ethnicity, which can introduce bias and impact the magnitude of the observed effect of socioeconomic status in the odds of the diseases. Our review suggests that further attention to how and why economic status is linked to disease risk can help better understand how stigma, wealth, power, and health are interconnected.

Research into public health interventions, stigma, and QoL show that these concepts are connected. We found in this review that some health education materials for leishmaniases and CD may contribute to the stigmatization of these diseases by portraying patients as victims, fostering fear, or reinforcing stereotypes instead of promoting health education. The experience of social exclusion, rejection, shame, fear, and guilt drives patients' mental illness and impacts their QoL (Brewis and Wutich, 2019). The World Health Organization (WHO) defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 2023). The conceptual and, hence, methodological issues used to measure QoL have been discussed in this regard, particularly the limited symptom-focused approach extensively used by some clinical researchers (Gladis et al., 1999). Most QoL-based studies screened in this review were based on generic methods designed for other diseases and, hence, focused to physical symptoms – i.e., impacts of dermatological, psychiatric, digestive, or cardiac symptoms on patients' physical disfunction (e.g., Dermatology Life quality Index or Minnesota Living with Heart Failure questionnaires). Although it is agreed that leishmaniases and CD impacts patient's physical, psychological, and social realms, most QoL studies are still limited to symptom-focused approaches. Therefore, it is crucial to devise target methods that can assess the impact of leishmaniases and CD on patients' lives using a clear, comprehensive definition of QoL that goes beyond just physical constraints and symptoms. In addition, it is important to develop strategies that promote individuals' acceptance and empowerment in dealing with these diseases on a daily basis, while also ensuring accessible and effective healthcare services; this approach should go beyond solely focusing on restoring functional capacity (Cavalcanti et al., 2019; Silva et al., 2022; Galvão et al., 2018; Bennis et al., 2018).

Given the amount of social science publications available that explore the influence of factors such as history, wealth, power, colonialism, racism, and patriarchal systems on infectious diseases, including how global development, migration patterns, and settlement patterns impact vector-borne diseases (Athni et al., 2021; Coimbra Jr., 1988; Briceño-León and Galván, 2007; Aguilar et al., 2007), we were surprised by the lack of attention given to historical and political contexts of leishmaniases and CD in this review. We can think of two possible explanations for this. First, it is possible that this research has been published in books or book chapters not commonly indexed by biomedical reference databases. For example, the classic work "La Casa"

Enferma: Sociología de la Enfermedad de Chagas" (Briceño-León, 1990) that asserts how wealth and power contribute to sustained-transmission of CD. This explanation is also supported in recent books highlighting how colonial history has shaped the scholarship. For example, the books "Epidemic Illusions: On the Coloniality of Global Public Health" by Eugene Richardson (Richardson, 2020) and "Critical epidemiology and the people's health" by Jaime Breilh (Breilh, 2021) argue that current public health interventions ignore the structural inequalities that perpetuate health inequalities and call for a decolonization of public health by acknowledging the unequal power dynamics and hierarchies that have shaped the discipline. Second, relying on the PubMed and WoS databases restricts our scoping review to the joint social science and biomedical literature on leishmaniases and CD and omits a substantial portion of relevant studies that are not indexed by these databases, such as the history and sociopolitical contexts of the diseases or issues about pharmaceutical-centered public health strategies to address the diseases e.g., (Barbeitas, 2019; Benchimol and Junior, 2020; Pinto-García, 2022b; Pinto-García, 2019). Therefore, our review reminds scholars that searching exclusively in biomedical and health focused databases such as PubMed or WoS can overlook important research from the social sciences, arts, and humanities that is relevant to our understanding of human diseases. This may be particularly important when examining the role that history, power, and politics play in shaping economic and structural inequalities and how these inequalities relate to leishmaniases

Although recent reviews have called (Athni et al., 2021) for increased attention to how warfare and violence have spread infectious disease across history, our review also found limited original research on how civil war or other conflict-terror can shape occurrence, distribution, emergence, and re-emergence of leishmaniases and CD. Indeed, exploring how infectious disease shapes society and our understanding of what it means to be human is a theoretically important question to the social sciences. For example, recent work on Cholera in Zimbabwe, Simukai Chigudu (Chigudu, 2020) shows how political and economic disruptions from the 1990's onwards set the stage for how ideas of citizenship informed how people experienced the 2008-09 cholera epidemic. This review demonstrated how conflict and violence extend beyond people in conflict zones. The link between CL and civil war through the example of soldier dogs in Colombia - illustrates how the effect of NTD's extend into multispecies interactions and illustrate the critical role of animals in people's well-being (Rodríguez et al., 2021). Surprisingly, no study was found that assesses the effects on people's well-being resulting from the euthanasia of their dogs as a measure for controlling VL – one of control measures carried out in some countries.

Our review has limitations. First and foremost, it is plausible that our chosen keywords might have resulted in the omission of certain pertinent papers e.g., (Romay-Barja et al., 2021; Guiu et al., 2017; Iglesias-Rus et al., 2019; Minneman et al., 2012); searches with additional keywords like 'qualitative' or 'focus group' could have yielded a more extensive collection of literature for our review. However, our primary objective was to conduct a scoping review that offers a synthesis of the principal research themes covered by large, biomedically focused reference databases rather than an exhaustive examination of the literature. Despite the possibility of some papers being overlooked due to our keyword selection, we believe that our sample captures major research themes. Finally, because PubMed also includes health-related research indexed by the SciELO database (which is focused on Latin America, Portugual, and Spain), our review may also have missed other relevant publications from Africa, Asia, Australia, Europe, or the Middle East. These limitations serve as a reminder of the necessity for interdisciplinary, open-acess research that transcends traditional database boundaries.

### 5. Conclusions

It is well established that the social factors underpin the

disproportional effects of NTDs diseases on minoritized populations. This scoping review on leishmaniases and CD highlights three major research themes that are found among research using social science to investigate leishmaniases and CD: sociocultural dimensions, socioeconomic drivers, and historical contexts of the diseases. Each of these shows the need for continued attention to these themes in research on NTDs and all infectious diseases. The common oversimplification of these diseases with 'poverty', the use of 'educational' materials featuring images of afflicted patients with lesions, or the generalization that 'poverty' is linked to lower knowledge and, consequently, less effective disease prevention practices can exacerbate the structural inequality and bias related to the diseases and result in delayed treatment and therefore greater harm to patients. Future research on leishmaniases, CD, and other NTDs in all endemic regions could address how social sciences can improve health education, control measures, access to healthcare, and/or quality of life while actively mitigating, rather than exacerbating structural bias and potential patients' distress associated with these diseases. Additional attention to how the interaction between people and NTD's influences individual disease risk but also informs our understanding of history, sociocultural conditions, and multispecies interactions will also continue to make both applied and theoretical contributions to the social sciences and public health especially if incorporated in traditional databases. Social sciences research will guide us in unraveling these intricacies and avoiding simplistic assumptions, thereby promoting a more informed and effective approach to disease prevention and management in an everevolving world.

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# Supplementary information

**Suppl. S1 Data.** Full list of words used for automated abstract analysis.

**Suppl. S2 Data.** Full list of all social science publications in leishmaniases and Chagas disease included in the review.

# CRediT authorship contribution statement

Raíssa Nogueira de Brito: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. Susan Tanner: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Project administration, Resources, Funding acquisition, Writing – review & editing. Julie Velásquez Runk: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Project administration, Resources, Funding acquisition, Writing – review & editing. Juliana Hoyos: Data curation, Formal analysis, Methodology, Writing – review & editing.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

# Data availability

We have provided all data in supplemental materials.

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### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.actatropica.2023.107059.

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