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# Revisiting Chagas Disease and its Cardiac Implications: an Integrative Review Study for Nursing Practice

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# **Abstract**

Goals: The aim of this study was to identify relevant aspects found in the literature regarding nursing actions in caring for adults with Chagas cardiomyopathy.

**Methods:** An integrative review was performed. The research was guided by the question: "What information and actions should nurses know about when taking care of adults with Chagas cardiomyopathy?"

**Results:** Eleven articles were identified, published in the last 10 years. This study showed that: patients with Chagas cardiomyopathy have more severe symptoms than with other etiologies of heart failure and higher prevalence of indications for artificial heart pacemakers; there is a knowledge gap among health professionals regarding this disease; and these patients face prolonged hospital stays until heart transplantation with a consequent drop in their quality of life, calling for interventions with a focus on self-management of the disease.

**Conclusions:** Chagas disease has shown an increase in prevalence in non-endemic and developed countries. The planning of nursing interventions that result in improved quality of life, symptom control, and increased adherence to pharmacological and non-pharmacological therapy is essential in the care of patients with Chagas disease.

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#### **Keywords**

Nursing; Chagas Disease; Chagas Cardiomyopathy.

# Introduction

Chagas disease (CD) is characterized as an anthropozoonosis. It was first described in 1909 by Carlos Chagas, who identified the etiologic agent Trypanosoma cruzi, an intracellular protozoon with flagella; transmission occurs through a number of vectors, Triatoma infestans, Rhodnius prolixus, and *Triatoma dimidiata* being the most common [1, 2]. Chagas disease is considered a transmittable disease with higher prevalence in rural and urban areas of developing countries. The World Health Organization considers it to be one of the 13 most neglected diseases due to lack of incentives for research to develop new drugs for it [3]. Chagas disease occurs in endemic and non-endemic areas, with wide distribution in Central and South America. One epidemiological study showed that there are 16 to 20 million infected people and 23,000 deaths per year, and that there is a trend toward higher incidence in individuals in worse economic situations [4, 5, 6].

Several government entities and surveillance organs made efforts to eradicate the vector that transmits the disease; according to a publication by Moncayo, the incidence of new cases decreased from 700,000 cases annually to 40,000 cases with a significant reduction in mortality from 45,000 to 12,500 cases. However, the disease was not completely eradicated. One cause was the existence of various vectors and reservoirs as disease transmitters with a certain potential for resistance to insecticides. Others were reduction in efficiency in tropical areas, small changes in human habits, and inadequate controls on blood transfusion in some countries in South America [7].

Many other countries considered non-endemic regions have had patients with serology for Chagas disease, probably secondary to migration of these patients from endemic areas. However, there are studies showing that some vectors present are able to transmit the disease. Other factors related to the transmission of Chagas disease to non-endemic re-

gions are blood transfusion, organ transplantation, and vertical infection [8, 9, 10].

The Center for Disease Control and Prevention estimates that there are more than 300,000 individuals infected by *Trypanosoma cruzi* in the US, and that there are 30,000 to 40,000 individuals who have not been diagnosed. In non-endemic regions there are many cases of underdiagnosis of this disease; most patients are diagnosed with some type of idiopathic cardiomyopathy. In addition, more than 300 children are born infected by *Trypanosoma cruzi* in the United States [7-10].

European Union countries such as Spain, Italy, and Switzerland have also been identified as non-endemic regions, with Spain having the second highest number of infected immigrants in the world, most coming from Bolivia, Paraguay, Nicaragua, Honduras, El Salvador, and Argentina [11].

Canada, Australia, and Japan, which are located on other continents, are also considered non-endemic regions; regarding individuals infected by the protozoa, it is estimated that there are 1,789 cases in Canada, 1,392 in Australia, and 3,592 in Japan. This shows that the disease, although controlled in some endemic countries, is becoming active in non-endemic countries [11].

The internationalization of Chagas disease in countries considered non-endemic and the exponential increase in the transmittal risk of this disease make qualification of health professionals necessary, especially in nursing. Even though treatment has been available for more than 40 years, there are limitations in effectiveness in the chronic phase, when these patients develop severe cardiac abnormalities resulting in important changes in functional health standards.

Given the increase in the prevalence of Chagas disease in non-endemic regions, it is crucial to update nurses on the care of patients with Chagas cardiomyopathy resulting from Chagas disease in order to establish a nursing process that will achieve positive results.

The aim of this study is Identify relevant aspects of Chagas cardiomyopathy that require nursing care.

# **Methods**

This is an integrative review study of the literature that was developed based on the five stages proposed by Witthmore and Knafl [12, 13]: identify the problem, search in the literature, evaluate the data, analyze the data, and present the findings.

The formulation of the question was guided according to the PICO strategy (Patients: adults; Intervention: nursing; Comparison: non-required, Outcome: Chagas cardiomyopathy), which resulted in the following guiding question: "What information or actions should nurses know about when taking care of adults with Chagas cardiomyopathy?"

The review covered the period from 2005 to 2015 and included articles in Portuguese, Spanish, and English. Included in this review were studies that addressed possible nursing actions for patients with Chagas disease. Articles were initially selected after analysis of titles and summaries. Then the studies were read in full and their contents analyzed according to the technique described by Sampieri [14]. Each study was assessed from a unit

of analysis, which includes the theme, item, character, and time-space. From there, studies were categorized by grouping them according to the data found in each.

Articles related to disease transmission vertically or through breastfeeding were excluded, as well as articles that addressed nursing care of newborns, children suffering from Chagas disease, and articles related to the prevention of the disease.

The following databases were used: International Literature in Health Sciences (MEDLINE), Latin American and the Caribbean Literature in Health Sciences (LILACS), Scientific Electronic Library Online (SciELO), National Center for Biotechnology Information (PubMed/NCBI), and Brazilian Nursing Database (BDENF) using the standard terms: Keywords of Health Sciences (DeCS) / Medical Subjects Headings (MeSH): doença de chagas/enfermedad de chagas/chagas disease and cardiomiopatia chagásica/cardiomiomatía chagásica/chagas cardiomyopathy crossed with the terms enfermagem/enfermeria/nursing using the Boolean rule AND/OR. (Table 1)

The articles identified were initially analyzed by two nurses who characterizing them as to year and language. Then the studies were read and evaluated

**Table 1.** The text below describes the search strategies for each database.

	PubMed	LILACS MEDLINE BDENF		
Chagas Disease and Nursing	("chagas disease"[MeSH Terms] OR ("chagas"[All Fields] and "disease"[All Fields]) OR "chagas disease"[All Fields]) and ("nursing"[Subheading] OR "nursing"[All Fields] OR "nursing"[MeSH Terms] OR "nursing"[All Fields] OR "breast feeding"[MeSH Terms] OR ("breast"[All Fields] and "feeding"[All Fields]) OR "breast feeding"[All Fields]) and ("2005/01/01"[PDat]: "2015/01/12"[PDat])	Chagas Disease and Nursing	tw: (chagas disease and nursing) and (instance: "regional") and ( year_cluster: ("2009" OR "2011"))	
Chagas Cardiomyopathy and Nursing	("chagas cardiomyopathy"[MeSH Terms] OR ("chagas"[All Fields] and "cardiomyopathy"[All Fields]) OR "chagas cardiomyopathy"[All Fields]) and ("nursing"[Subheading] OR "nursing"[All Fields] OR "nursing"[MeSH Terms] OR "nursing"[All Fields] OR "breast feeding"[MeSH Terms] OR ("breast"[All Fields] and "feeding"[All Fields]) OR "breast feeding"[All Fields]) and ("2005/01/01"[PDat]: "2015/01/12"[PDat])	Chagas Cardiomyopathy and Nursing	chagas cardiomyopathy and nursing and (instance: "regional") and ( year_cluster: ("2009" OR "2011"))	

as to quality, objective, methodological approach used, and findings in relation to the guiding question.

An analysis of the methodological quality of the quantitative studies was carried out as recommended in the Strobe statement [15], based on the number of items existing in each study analyzed; they were considered to be of good quality when the studies fulfilled more than 50% of the items required [16]. No evaluation was applied to literature reviews and qualitative studies.

# Resulst

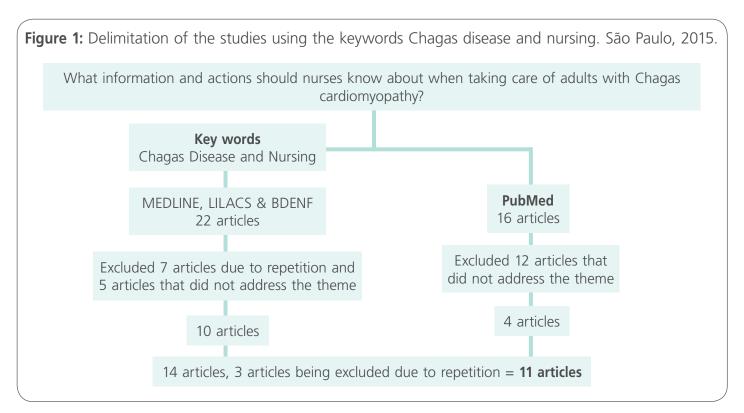
A total of 22 articles were identified in the databases of MEDLINE, LILACS, and BDENF AND 16 articles were identified in the databases of PUBMED. After exclusions due to repetition or not being relevant to this review, 11 articles were included in this review, as shown in **Figures 1**.

After they were read and analyzed, the articles were characterized as to their year of publication and language, as shown in **Table 2**.

**Table 2.** Characteristics of the articles selected according to year of publication, language, and authorship. São Paulo, SP, 2015..

	N=11	%
Year of Publication		
2007	2	18.19
2009	3	27.27
2010	3	27.27
2012	1	9.09
2013	1	9.09
2015	1	9.09
Language		
Portuguese	5	45.45
English	5	45.45
Spanish	1	9.09
Total	11	100

The **Table 3** describes the articles included in the integrative review and their characterization as to title, objective, methodology used, methodological quality, results, and conclusions relevant to the guiding question of this research.



**Table 3.** Summary of the articles included in the integrative review. São Paulo, 2015.

Authors	Title of Article	Year	Objective	Type of Study	Results	Conclusion/ Recommendation	Methodological Quality
Sadala MLA, Stolf NAG, Bicudo MAV	Heart transplant: the experience of individuals with Chagas disease [17]	2009	To investigate the experience of heart transplantation experienced by patients with Chagas disease	Qualitative, Phenomenology	<ul> <li>Nine patients evaluated between the ages of 20 and 60.</li> <li>Notice Chagas disease by falling ill and its physiological limitations.</li> <li>Long hospital stay until heart transplantation.</li> <li>The transplant means a new lease on life and has the idea of being a high-risk and highly complex surgery.</li> <li>They have a desire to get back to their family responsibilities after the heart transplantation.</li> </ul>	<ul> <li>The experiences lived before the transplantation are striking with these patients.</li> <li>The focus should center on patients, encouraging them to take a lead role in their care. Importance of family participation.</li> </ul>	Not evaluated
De Oliveira AP, Gomes LF, Casarin ST, De Siqueira HCH	The life of patients with chronic Chagas disease: possibilities of nurses' actions for healthy living [18]	2010	Getting to know how patients with chronic Chagas disease live in the municipalities of Rio Grande do Sul.	Qualitative, exploratory	<ul> <li>Majority are men between the ages of 51 and 82.</li> <li>There is a predominance of patients with low income living in rural areas and in urban areas.</li> <li>Difficulty doing daily activities such as domestic work or remunerated work.</li> </ul>	<ul> <li>Severe sociopolitical and cultural problem that involves issues of public health.</li> <li>Raise awareness among customers through health education.</li> <li>Health education can help patients in dealing with the disease, protect them from discomfort, improve their lifestyle, and increase their expectations and quality of life.</li> </ul>	Not evaluated
De Oliveira Jr W	All-around care for patients with Chagas disease: a challenge for the XXI century [19]	2009	Addressing comprehensive care (biopsychosocial) of patients with Chagas disease and heart failure	Bibliographic Revision	<ul> <li>Discusses care models: biomedical, biopsychosocial, and psychological factors of Chagas disease.</li> <li>Importance of the multidisciplinary team in caring for patients with CD.</li> <li>Nurses play an important role in the care of these patients due to their frequent contact, control of signs and symptoms and water balance, along with health education for patients and their families.</li> </ul>	<ul> <li>Multidisciplinary care should include actions with the patients, their families, and their environment so that it brings technical expertise together with the ability to deal with human beings.</li> <li>Importance of health education</li> </ul>	Not evaluated

Authors	Title of Article	Year	Objective	Type of Study	Results	Conclusion/ Recommendation	Methodological Quality
De Oliveira DAD, Lisboa TB.	Self-care of patients with Chagas Disease: an educational approach [20]	2009	Describe the conduct of nursing in self-care for patients with Chagas Disease. Establish the nursing diagnoses in these patients	Bibliographic research	<ul> <li>The need for health education actions.</li> <li>Self-care approach.</li> <li>Providing information on how to deal with the changes occurring in the patient's body.</li> <li>Key nursing diagnoses: anxiety, fear, risk of constipation, hyperthermia, ineffective nutrition (less than body requirements), risk of impaired skin integrity, knowledge deficit, and impaired adaptation.</li> </ul>	<ul> <li>Patients should be advised to actively participate in actions for self-care.</li> <li>Important educational role of the nurse.</li> </ul>	Not evaluated
Colosio RC, Falavigna- Guilherme AL, Gomes ML, Marques DSO, Lala ERP, Araujo SM	Knowledge and attitudes about Chagas disease among Paraná health professionals [21]	2007	Check the knowledge of and attitudes about Chagas disease among public health professionals from two cities in the state of Paraná	Quantitative, exploratory, and transversal	<ul> <li>Included 75 physicians (cardiologists, general practitioners, and physicians working in the Family Health Program), 75 nurses, 150 nursing assistants, and 187 community health workers.</li> <li>High frequency of ordering exams not recommended for CD.</li> <li>Most doctors are unaware of the treatment of the acute phase of CD.</li> <li>Nursing professionals are not aware about its form of transmission.</li> </ul>	- There is lack of knowledge on the part of professionals from all classes working with primary care, especially with regard to diagnosis and treatment of the acute stage of the disease.	Good (54%)
Ilches MJJ, Coronas JS, Guitiérrez MI, Metz D, Sanchez JS, Sanchez FG.	Knowledge about Chagas disease by health professionals from three hospitals in the province of Almería [22]	2013	Evaluate the knowledge of professionals on various aspects of CD	Quantitative, exploratory, and transversal	<ul> <li>Evaluated 278 basic health care professionals.</li> <li>Low level of knowledge on the part of primary care professionals.</li> </ul>	- Need to provide tools for professionals on the various aspects of CD.	Good (83%)

Authors	Title of Article	Year	Objective	Type of Study	Results	Conclusion/ Recommendation	Methodological Quality
Lennox HA, Karcz DA, Tales H, Masri ME.	Chagas disease: clinical overview and implications for nursing [23]	2007	Familiarize health professionals with Chagas disease and the implications for nursing	A literature review study.	<ul> <li>Increase in the cases of people infected by Chagas disease in the United States and Canada.</li> <li>Nurses should be given tools for recognizing the clinical manifestations and complications of this disease.</li> <li>Attention to the clinical signs of chest pain, palpitations, and syncope.</li> </ul>	<ul> <li>Nurses should be familiar with Chagas disease because of the increase in cases in non-endemic regions.</li> <li>Attention to the clinical aspects of the disease.</li> <li>Surveillance for other forms of transmission (blood transfusion).</li> </ul>	Not evaluated
Snow M.	Checking up on Chagas Disease [24]	2012	Update on the Chagas disease	Review article	- The increase in the rate of infection by Chagas disease was emphasized, along with its signs and symptoms, laboratory testing, and recommended treatment.	<ul> <li>The importance of health education for these patients, since once the chronic phase of the disease begins, drug treatment is no longer effective.</li> <li>Individuals must be advised about the endemic areas and the precautions to be taken, not to donate organs and blood, and maternity issues.</li> </ul>	Not evaluated

# **Discussion**

In the analysis of the articles we noted that most studies addressed literature reviews about the pathophysiological aspects of Chagas disease and its treatment. The categories that most often emerged in this review were: quality of life, clinical aspects of the disease, , health education for patients, and knowledge of health professionals.

# **Quality of life**

Patients with Chagas disease show greater expressiveness and clinical deterioration, appearing more often in functional classes III and IV of the New York Heart Association classification of cardiac disease. This reflects worsening quality of life, especially with regard to the physical and social domains [15-17].

Because it is a disease of a biological nature with large psychosocial implications, the management of Chagas disease should be based on the biopsychosocial model with a more humanized vision. Multi-disciplinarity is recognized as the best form of care for patients with Chagas disease, particularly those with Chagas cardiomyopathy. Nurses should work closely with patients and their families, since they are part of the process [19, 20, 24, 25].

A review study of quality of life in patients with Chagas disease found that impairment in functional capacity and low therapeutic intervention for the disease are the highest predictors of worsening of quality of life in these patients. However, it is worth noting that Chagas disease is a neglected disease with greater prevalence in people in copromised so-

cioeconomic and cultural conditions. These patients probably already have poor quality of life that is worsened by onset of the disease.

## **Knowledge of Professionals**

Because of the worldwide increase in the incidence of Chagas disease and worsening clinical impairment of these individuals, causing repeated cardiac decompensation with subsequent progression of the disease toward terminal stages from heart failure, educating health professionals in relation to aspects of Chagas disease is indispensable for professional practice based on patient safety [17].

Three studies were identified in this review that showed a low level of knowledge among health professionals (doctors, nurses, and community health workers), especially with regard to transmission, diagnostic methods, and treatment [21, 22, 26, 27].

The findings of these studies were reinforced by the results of a survey that showed a significant deficit in the knowledge of physicians in relation to Chagas disease, especially among women's health specialists. This confirms the need to train doctors and other professionals in prevention, detection, and monitoring of patients.

### Clinical aspects of the disease

Articles that addressed conceptual aspects of Chagas disease indicated that the incubation period is 5 to 14 days for vector transmission, 5 days for oral transmission and 11 to 30 days for blood transfusion.

Chagas disease occurs in three phases (acute, indeterminate, and chronic) [28]. The acute phase occurs in less than 1% of patients and can be caused by acute transmission of the disease or by reactivation of the chronic form secondary to immunosuppression. The main manifestations include fever, generalized lymphadenopathy, edema, hepatosplenomegaly, acute myocarditis, pericardial effusion, and meningoencephalitis in severe cases.

This phase has been drastically reduced, mainly by preventive measures and by serologic measures that are most effective in blood transfusion [29-32].

The indeterminate phase is characterized by asymptomatic patients with normal electrocardiograms and normal X-rays without cardiac, esophageal, or colon alterations. Although these patients seem to be asymptomatic, they demonstrate positive serology reactions for Chagas disease. About 30% to 40% of these patients will enter the chronic phase of the disease 20 to 40 years after the initial infection, and will present cardiac manifestations 30 to 40 years after the initial infection; other patients will remain asymptomatic throughout their entire life in a condition as hosts [33]. The clinical presentation of the chronic phase is characterized by specific involvement of the organs, particularly the heart, esophagus, and colon characterized in three forms: the digestive form, the cardiac form, and the cardiac-digestive form [34].

Cardiac disorders secondary to Chagas disease are the result of inflammation processes, necrosis, and fibrosis of the cardiac electrical system in the myocardium and in the intramural nervous system due to the presence of the disease, causing electrical manifestations, ventricular failures, and thromboembolic events. The cardiac manifestations of Chagas disease are characterized by the appearance of arrhythmias that mainly include atrioventricular blocks, blocks of the right branch, left anterior fascicular blocks, and appearance of ventricular ectopic beats. These electrical changes are caused by an inflammatory, degenerative, and fibrotic process of the electric conduction system. The appearance of these electrocardiographic changes marks the beginning of the chronic phase, and some articles reviewed indicate that patients with Chagas disease have a higher rate of use of cardiac pacing devices [33-35].

Sudden death is the leading cause of mortalities and is secondary to the onset of severe ventricular rhythms; it is related to various areas of fibro-

tic processes in the myocardium. Other symptoms, such as tiredness, fatigue, and activity intolerance, can occur even in patients without ventricular dysfunction. This is due to chronotropic incompetence secondary to degeneration in the cardiac electrical system [34-36].

In addition to the electrical manifestations that are classified as the cardiac form without ventricular dysfunction, some patients have heart failure, which is characterized by a progressive process. Electrocardiographic abnormalities precede the signs and symptoms of heart failure and demonstrate the evolutionary process of the disease. The type of ventricular dysfunction secondary to Chagas disease is classified as dilated cardiomyopathy and affects patients in the later phase of Chagas heart disease, which is characterized by chronic myocarditis involving all heart chambers and the electric conduction system. This process is secondary to parasite persistence in the cardiac tissue, continuous low levels of parasitaemia, and immune-mediated myocardial injury, which is why this type of cardiomyopathy has the worst prognosis [28].

Heart damage secondary to Chagas disease is classified as stage A (patients without symptoms of heart failure and without structural changes of the heart), B1 (asymptomatic with electrocardiographic changes, moderate contractile abnormalities with normal overall ventricular function), B2 (patients with a decrease in the ventricular ejection fraction, without signs and symptoms of heart failure), C (patients with ventricular dysfunction and new or recurrent symptoms of heart failure), and D (patients with symptoms of heart failure at rest, refractory to maximized drug therapy and requiring intensive and specialized interventions) [28].

Initially there is a regional deficit in the myocardium such as occurs in ischemic cardiomyopathy, but the progression of the disease causes swelling and generalized hypokinesia. The most common clinical presentation is of the biventricular type with a higher prevalence of clinical signs related to ventricle deficit (jugular stasis, positive hepatojugular reflex, hepatomegaly, ascites, and lower extremity edema). The hemodynamic condition of dilated cardiomyopathy is secondary to Chagas disease, with greater expressiveness in relation to clinical signs in patients with other forms of cardiomyopathies.

In addition to complaints related to the deficit of right ventricle patients may complain of weakness, probably because this type of heart disease leads to lower blood pressure, especially when associated with right ventricular dysfunction and atypical angina from the inflammation process of coronary microcirculation [28].

Due to structural cardiac abnormalities, especially dilatation of the heart chambers, formation of tip aneurysms in the ventricles, and appearance of atrial arrhythmias in more advanced stages, thromboembolic events can occur. Encephalon vascular accidents are the most common in this type of cardiomyopathy when compared to other etiologies.

#### **Health Education**

The health education process is hard work and requires that professionals remain up-to-date and committed to their work. The perception of the disease, the illness process, and its physiological limitations should be mediated by psychoeducational strategies. This will allow patients to cope with the disease better and be more able to carry out daily activities [17-20].

The health education process should cover everything from prevention to the rehabilitation process. Regarding prevention, some studies have shown that in places where the disease was nonexistent, after news in the media about Chagas disease, the population expressed an interest in learning about the disease, but the information was conveyed in a confused and incomplete manner. This leads us to reflect that the educational process for the population should be structured pedagogically and clearly, including practical prevention activities.

Educational strategies related to early recognition of worsening signs and symptoms, and adherence to pharmacological and non-pharmacological recommendations such as salt and water restriction and weight control, should be reinforced [17-20, 37].

One strategy for treatment of patients with Chagas disease is heart transplantation, which often involves long hospital stays waiting for organs. This may further worsen the disease, causing even greater physical and social limitations for these individuals, which requires well-designed intra-hospital educational strategies [17].

The heart transplantation process involves a lot of feelings (fear, anxiety, guilt, grief, joy, gratitude for receiving the organ) and pathophysiological peculiarities with possible reactivation of the disease due to the permanence of *Trypanosoma*. It is important to work with an educational focus on both patients and their families in order to empower these individuals and help them become accustomed to new health care related to heart transplantation and identify warning signs of reactivation of the disease [17].

# Conclusion

Based on analysis of the studies included in this review, we concluded that there is a need for further studies that address patients with Chagas disease, since most of the studies presented here identified as their methodological approach a review of the literature.

Four broad categories of Chagas disease were identified that can support nursing care: clinical aspects of the disease, quality of life, health education, and knowledge of professionals.

The literature review showed that Chagas disease patients have worse clinical symptoms with more cardiac electrical disorders, with greater use of cardiac pacing devices, longer hospital stays, and worse quality of life as a result of major cardiac impairment.

Another common aspect identified was the importance of the health education process for these patients, emphasizing improvement in adherence to pharmacological and non-pharmacological treatment and self-management of care, including recognition of worsening of clinical signs.

It was observed that there is a knowledge deficit among health professionals, especially in countries that are not recognized as endemic for Chagas disease. This deficit includes everything from preventive measures, diagnostics, therapeutic management, all the way to terminality.

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