

Manifestations and strategies of coping with Chagas Disease that interfere in the quality of life of the individual: a systematic review

Marília Abrantes Fernandes Cavalcanti (<https://orcid.org/0000-0001-5499-5830>)¹
Ellany Gurgel Cosme do Nascimento (<http://orcid.org/0000-0003-4014-6242>)¹
João Carlos Alchieri (<https://orcid.org/0000-0002-4150-8519>)¹
Cléber de Mesquita Andrade (<https://orcid.org/0000-0002-0264-8842>)¹

Abstract *We aimed to identify the manifestations and coping strategies of Chagas disease that influence the quality of life of the affected subject. This is a literature systematic review carried out in PubMed, SciELO and Lilacs databases, through which six papers were retrieved, in addition to six publications identified with the verification of the bibliographic list and four papers through manual search, which were independently evaluated by two reviewers. The variables addressed were set in the thematic axes manifestations of Chagas disease that interfere in the quality of life of the individual and coping strategies that influence the quality of life of patients affected by Chagas disease, subdivided into three realms, namely, physical, psychological and social. The results seen in all addressed realms evidenced a quality of life compromised by the disease, measures mostly limited to the patient's physical realm and incipient records of studies in the area. We suggest further exploring the proposed theme, believing that knowledge of the patient living with the disease promotes the development of effective health intervention strategies.*

Key words *Chagas disease, Trypanosoma cruzi, Quality of life*

¹ Faculdade de Ciências da Saúde, Universidade do Estado do Rio Grande do Norte. R. Atirador Miguel Antônio da Silva Neto s/n, Aeroporto. 59607-360 Mossoró RN Brasil. marilia_abrantes17@hotmail.com

Introduction

Classified as one of the 17 neglected tropical diseases listed by the World Health Organization (WHO)¹, Chagas disease is transmitted by the protozoan *Trypanosoma cruzi*² and, in Latin America, is the endemic disease with the greatest impact on morbimortality in a group of 21 countries, where it is estimated that it affects 5-6 million people, of whom less than 1% receive treatment and approximately 7,000 cases result into death annually¹.

In the case of the Brazilian setting, it stands out among chronic diseases due to the fact that it affects approximately 1.2 million individuals³ and because it is the fourth cause of death among infectious-parasitic diseases in the age groups over 45 years⁴.

Before this burden, Chagas disease control and treatment became priorities for the World Health Organization⁵, suggesting the development of new disease monitoring strategies in order to promote the improvement of users' quality of life², here addressed broadly, and is illustrated with excellence by the concept elaborated by the World Health Organization (WHO)⁶, for which quality of life is understood as the individuals' perception of own insertion in life, in the context of culture and systems of values in which they live and in relation to their goals, expectations, standards and concerns⁷. It is characterized, therefore, as a complex concept, which aggregates environment, physical and psychological aspects, dependence level, social relationships and personal beliefs of the subject⁸, not limited to the exclusive approach of symptoms and dysfunctions of illnesses, as considered by other definitions portrayed in the literature⁹.

Thus, given the interference of Chagas disease in different aspects of life of individuals and their need to adjust to the condition of chronic disease, we aimed to identify the manifestations and strategies of coping with the disease that influence the quality of life of affected subjects, with the understanding that evaluation of the living conditions of carriers results in the improvement of care supported in the planning and organization of actions¹⁰.

Methods

This is a systematic review of literature. Before the lack of revision protocols that considered the inclusion of several types of studies, the "Meth-

odological Guidelines for Systematic Review and Meta-Analysis of Randomized Clinical Trials" of the Ministry of Health were adopted¹¹ and the protocol was adapted to meet the research proposal. The scientific question guiding the study was the following: "What are the manifestations and strategies of coping with Chagas disease that influence the quality of life of the affected subject?"

The search in the databases occurred between January and September 2016 and considered three databases: PubMed, SciELO and Lilacs, which cover literature referring to regions of epidemiological relevance with regard to Chagas' disease.

All references that met the following criteria were included: a) they showed primary data; b) they were characterized as full-text; c) and had a Portuguese, English or Spanish version. All studies that: a) were not available for free; b) did not classify as scientific paper or course final paper; c) and were not related to the topic of interest, and this should be conditioned by consensus between two evaluators were discarded.

The terms employed for the search were previously selected considering the controlled vocabulary for indexing papers of the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH) system, through which descriptors "Chagas disease" and "Quality of Life" were captured, used in SciELO and Lilacs and "Chagas Disease" and "Quality of Life", corresponding to PubMed. The Boolean operator "AND" was applied to promote the combination between the two chosen terms, so that the association "Chagas Disease AND Quality of Life" was used in SciELO and Lilacs and "Chagas Disease AND Quality of Life" in PubMed.

Initially, 92 papers were published in PubMed, 21 in SciELO and 47 in Lilacs, totaling 160 publications. In PubMed, filters "free text", "human species" and "Portuguese, English and Spanish languages" were selected, which downsized papers to 47, 38 and 38 respectively. In SciELO, restricting the search by adopting the "Portuguese, English and Spanish languages" filters, the number of selected productions fell to 21. Finally, in the Lilacs database, using the "full text available", "human species" and "Portuguese and English languages" filters the total number of productions identified were limited to 28, 24 and 24 in this order. The "year of publication" restriction criterion was not used, since its selection would substantially reduce the number of articles indexed. Thus, the collection of references in the three databases returned 83 papers.

Papers were stored in the reference management software called Endnote Web. Extracting the publications in duplicate, the total number of papers was reduced to 57. In the identification of potential eligible studies, these papers were analyzed independently by two evaluators, namely, a nurse with PhD in Health Sciences and a psychologist with a PhD in Psychology, and disagreements regarding exclusion were resolved by consensus.

When the evaluation was carried out by the approximation between the title and the theme, the number of papers decreased to 38, of which, after applying the criterion of summary analysis and excluding literature reviews, 13 and 12 remained, respectively. Of these productions, confirming the eligibility for the detailed reading of the manuscript and considering the approximation with the guiding question of this study, 6 papers were selected through the mentioned databases, as shown in Figure 1.

We understand that the identification of studies mediated by search in electronic databases is essential and useful. However, if only this is considered as an identification tool, a sensitive proportion of information that can contribute emphatically to the discussion can be disregarded. By modifying the course of the review, other recruitment strategies were used, such as the verification of bibliographic references and manual search (hand searching)¹¹.

In the investigation of the list of bibliographic references of studies captured through databases, 120 publications were initially obtained. After extracting the duplicates found, this number fell to 116. Of these, after analysis of agreement between the title and the theme proposed, 58 were maintained. Considering the free full-text studies available, the number was further reduced to 33. After discarding the publications that did not qualify as scientific papers or course final papers, 21 papers remained, of which, after exclusion by summary, 11 were left out. Excluding literature review studies, papers were reduced to 10, arriving at six papers after a detailed full-text reading, as shown in Figure 2.

We also considered the inclusion of works referring to gray literature, which includes literary productions that have not been formally published in books or journals, but which must also be considered in the process of searching for scientific evidence¹¹, represented here by a dissertation and a theses found during the process of visualizing the list of bibliographic references, which are indexed in the digital repositories of

the State University of Campinas (UNICAMP) and the University of São Paulo (USP), sequentially.

Finally, through manual search (handsearching) carried out on the Google Scholar site, with descriptor “Chagas Disease”, four articles related to the topic under discussion were identified. Therefore, we concluded the selection of relevant papers with 16 publications.

The process of extracting data from papers that were screened was performed independently by two evaluators and was guided by a standard analysis form previously elaborated and used in the evaluation of the studies recruited in all the aforementioned search strategies. Any disagreements in the data collected regarding their inclusion in the study was resolved by consensus between the two reviewers.

Results

Papers found through databases were reviewed and are shown in Chart 1, in terms of authorship, year of publication, objectives, methodological course and variables studied. We identified papers published between 1997 and 2012, whose studies were carried out in the states of Rio Grande do Sul (1), Minas Gerais (2), Paraná (1), Rio de Janeiro (1) and São Paulo (1).

As to the type of study, three were classified as descriptive, one as ethnographic, one as prospective intervention and one as cross-sectional. The number of participants involved in the research ranged from 10 to 131 individuals. Among papers, three used the qualitative approach as an analysis method. Regarding data collection tools, the open-ended interview was used in three studies, the questionnaire and medical records verification was used in one study, one study performed clinical tests and one combined the use of questionnaire with clinical trials.

The variables evidenced in the studies were listed in two categories of analysis: *manifestations of Chagas disease that interfere in the quality of life of the individual* and *coping strategies that influence the quality of life of patients affected by Chagas' disease*. Three realms emerged from these two categories: physical, psychological and social, as illustrated in Charts 2 and 3.

The physical realm evidenced issues regarding the impact of the clinical condition of the disease on the normal functioning of the organism and on the maintenance of daily activities of the affected individual and therapeutic measures

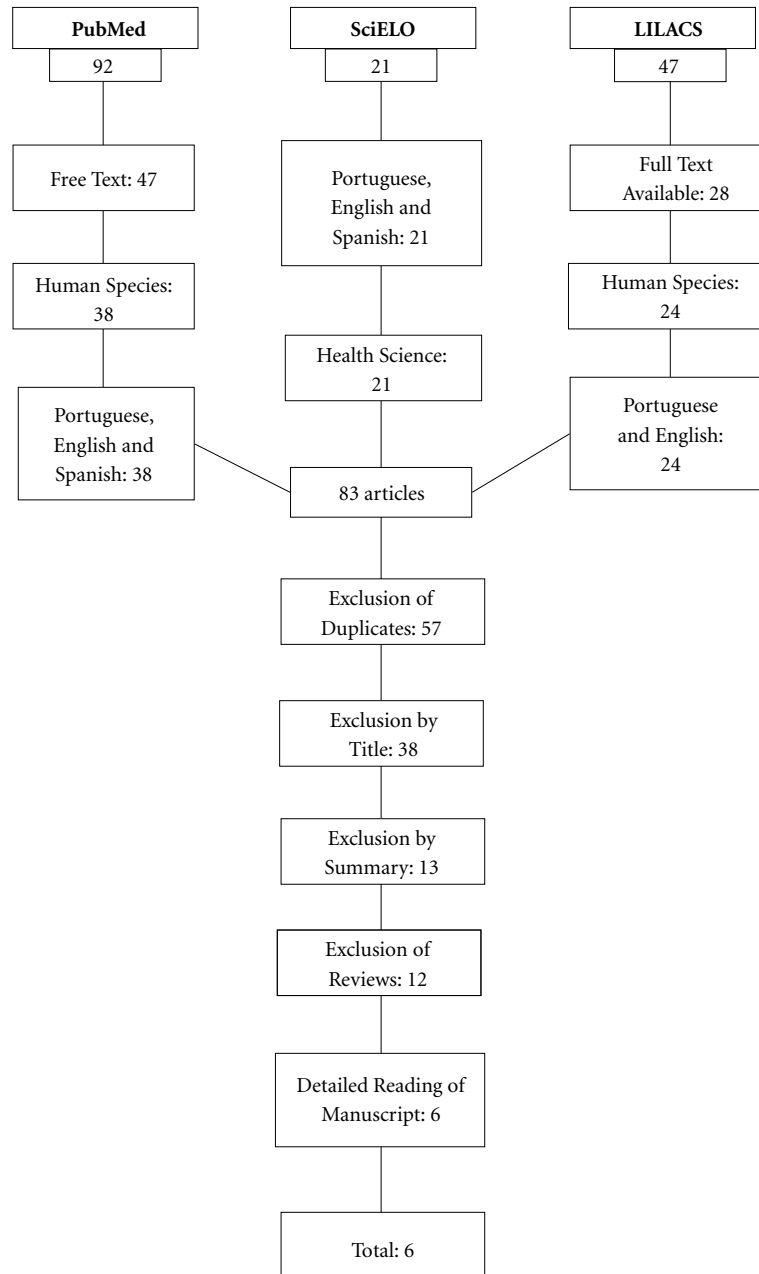


Figure 1. Flowchart to identify studies on the quality of life of individuals with Chagas disease, selected from PubMed, SciELO and Lilacs databases.

that include physical exercises, pharmacological therapy, pacemaker implantation and heart transplantation.

The psychological realm included feelings generated from the discovery, the coping and trend of the disease, the self-perceived quality of

life and the influence of religious beliefs before the chagasic condition.

Finally, issues concerning the social realm were raised, considering the interference of the disease in the affective ties and introduction in the labor market, the repercussion of social se-

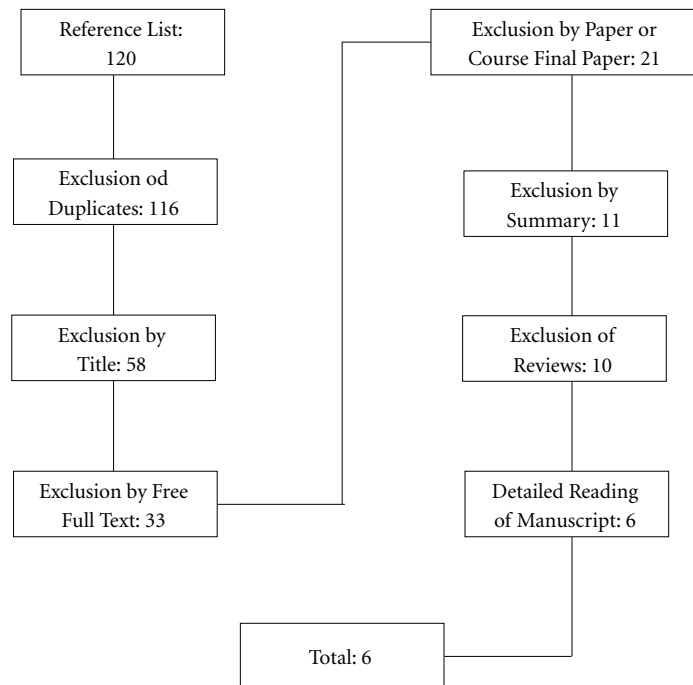


Figure 2. Flowchart for the identification of studies on the quality of life of patients with Chagas' disease collected through verification of the list of bibliographic references.

curity and the access of the affected person to health services.

Discussion

Chagas disease manifestations interfering in the quality of life of the individual

Physical realm

In the differentiation between genders, it was revealed that women show greater risks of low quality of life in the mental, emotional and physical functioning areas¹². Regarding the age groups, increased age was observed as a favoring factor of compromised psychological realm due to the individual's apprehension vis-à-vis the intensified possibility of death over time¹³.

The fact that most patients become aware of their condition belatedly, as a result of the manifestation of symptoms or even random discovery while at a health service^{10,14} promotes a situation in which the disease goes unnoticed through the acute phase, which is an aggravating factor in their quality of life, assuming that a well-directed

treatment initiated in the expected time increases the survival of patients¹⁰.

Coping with physical pain in several segments of the body was found in cardiac, digestive and cardiodigestive forms, both forms of manifestation of the disease, which affects the productivity of individuals and compromises the sense of well-being¹⁰.

Configuring a greater limitation to the Chagas' disease patient, in relation to the development of normal activities, the cardiac form was associated to decreased well-being and commitment in the execution of labor activities and in the achievement of income necessary for survival¹⁰. In contrast, the digestive form, which accompanies significant changes in the digestive tract, impairs esophageal mobility and system morphology¹⁴.

Symptoms such as palpitations, precordial pain and dyspnea¹⁰, related to the cardiac form¹⁵, and dysphagia, regurgitation, epigastralgia and dinofagia¹⁰, corresponding to the digestive form¹⁵ are evidenced as manifestations that influence the lifestyle of patients affected by Chagas' disease and individual routine maintenance, where

Chart 1. Studies on the quality of life of the subject affected by Chagas' disease, selected through the PubMed, SciELO and Lilacs databases, described in terms of authorship, year of publication, objectives, method, sample, variables studied and main findings.

Author	Year of study	Title	Study location	Objective	Method	Sample	Variables studied	Main findings
OLIVEIRA; GOMES; CASARIN; SIQUEIRA	2010	Chronic Chagas disease carrier life: possible nursing actions for a healthy life	Two municipalities of Rio Grande do Sul	To know how Chagas' disease patients live and to outline possible nursing actions for a healthier life	A descriptive and exploratory study with a qualitative approach. Participants answered the semi-structured interview.	10 patients with chronic Chagas' disease	Retirement, diagnosis of the disease, clinical form, physical pain, daily activities	Early retirement of individuals affected by Chagas' disease is not enough to defray the cost of the disease. Most patients with the chronic form become aware of their condition belatedly, after the development of symptoms or when seeking, by chance, health services. All subjects reported feeling pain in the various body segments. The individuals affected, with emphasis on the cardiac patients, showed a poor performance of daily activities and at work.
AMATO; AMATO NETO; UIP	1997	Evaluation of the quality of life of patients with Chagas disease submitted to heart transplantation	Heart Institute of the Hospital das Clínicas, Faculty of Medicine, University of São Paulo	To analyze the situation of patients with Chagas' disease submitted to transplantation and who were alive	The interview with the members of the sample was adopted as a collection tool	11 patients affected by Chagas disease undergoing heart transplantation	Heart transplant	Patients with Chagas disease treated with heart transplantation showed improvements in the limitations of activities and life prospects
MAGNANI; OLIVEIRA; GONTIJO	2007	Representations, myths and behaviors of the patient undergoing pacemaker implantation in Chagas disease	Pacemaker Outpatient Clinic of the Hospital das Clínicas of the Federal University of Minas Gerais (UFMG)	To evaluate the incorporation of pacemakers in the life of individuals with Chagas disease	Ethnographic qualitative research, based on an open-ended interview.	15 patients with chronic chagasic heart disease with pacemakers	Social representations about Chagas' disease, use of pacemaker, social support, religious beliefs	Social representations elaborated around the disease trigger psychological damages that establish barriers in the life dynamics of patients. As for social bonds, family and friends are in solidarity with the affected individual, while the labor relationships are weakened. In faith, the subject seeks answers to the disease condition. Faced with the need to use the pacemaker, the initial idea is that one has a fragile heart. Over time, however, it becomes a natural extension of the body and is visualized as the source of life.

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Author	Year of study	Title	Study location	Objective	Method	Sample	Variables studied	Main findings
OLIVEIRA; S. ABREU; G. ABREU; ROCHA; RIBEIRO	2011	Health-related quality of life in Chagas' disease	Hospital das Clínicas of the Federal University of Minas Gerais (UFMG) and the Orestes Diniz (CTR-DIP) and the Center for the Treatment and Reference of Infectious and Parasitic Diseases	To define the quality of life profile of patients infected with Chagas disease	A cross-sectional study was performed in which the patients underwent clinical examination, ECG, Holter, Doppler and echocardiogram monitoring and autonomic function tests, in addition to having answered the Minnesota Living With Heart Failure Questionnaire (MLWHFQ) and Medical Outcomes Study 36-item short-form (SF-36) questionnaires	126 patients with Chagas' disease and 21 in the control group	Gender, tests' abnormalities	Being a woman was characterized as a risk for worse quality of life scores in the physical, mental and emotional realms. Changes in the electrocardiogram were not related to the quality of life deficit. An abnormal Doppler echocardiogram, ventricular arrhythmia and worse functional classification triggered a poorer quality of life.
ARAÚJO; ANDÓ; CASSAROTTI; MOTA; BORGES; GOMES	2000	ACHEI Program: Chagasic Care with Comprehensive Education in the Municipality of Maringá and Northwest Region of Paraná, Brazil	Laboratory of Chagas' disease at the State University of Maringá (UEM)	To report the experience of implanting a psychosocial support group for the care of patients with Chagas' disease and to describe the patients' profile	Questionnaires were carried out and medical records of the participants were examined	131 patients with Chagas Disease	Diagnosis, disinformation, stigma, changes in tests	The shock caused by the diagnosis of the disease is aggravated by misinformation and stigma about the disease. Discrete changes in electrocardiogram and chest radiographs were related to the benignity of the disease

it continues

Chart 1. Studies on the quality of life of the subject affected by Chagas' disease, selected through the PubMed, SciELO and Lilacs databases, described in terms of authorship, year of publication, objectives, method, sample, variables studied and main findings.

Author	Year of study	Title	Study location	Objective	Method	Sample	Variables studied	Main findings
FIALHO; TURA; SOUSA; C. R. OLIVEIRA; SOARES; G. R. OLIVEIRA et al.	2012	Effects of a program of exercises on the functional capacity of patients with chronic chagasic heart disease assessed by cardiopulmonary test	Evandro Chagas Clinical Research Institute and the National Institute of Cardiology (INC)	To evaluate the potential effect of an exercise program on the functional capacity of patients with chronic chagasic infection	A prospective intervention study in which patients with chronic chagasic heart disease participated in an exercise program in cardiac rehabilitation. Subsequently, the functional capacity of the participants was evaluated.	18 patients with chronic Chagas' heart disease	Performing physical exercises	There was no improvement or worsening of cardiac symptoms by performing the physical exercise program

a deficit was recorded in daily activities, domestic work and work itself¹⁰. In situations in which individuals did not complain of decreased functional capacity, the preserved possibility of maintaining regular routine was conditioned to the appropriation of medication to minimize discomfort caused by symptoms of the disease in its cardiac and digestive forms¹⁰.

When considering the findings of routine exams, it was observed that more minimal changes in the electrocardiogram^{12,16} and chest radiographs¹⁶ may be related to the greater benignity of the disease^{12,16}. In contrast, abnormal Doppler echocardiography with ventricular dysfunction, the evidence of 24-hours Holter ventricular tachycardia and of heart failure syndrome, especially New York Heart Association functional class III and IV, were considered as depressing quality of life factors¹².

Psychological realm

The disease was characterized as a precursor to high depression levels, possibly related to the uncertainty about possible sudden death related to the cardiac form¹⁷ and facing a megaesophagus surgery related to the digestive form¹⁸.

The moment of disease discovery was characterized as an event that causes shock, apprehension and despair¹³, aggravated by the scarce information and the stigma surrounding the disease¹⁶ acting as a predisposing factor for the development of stress¹⁹.

Literature also portrays the perpetuation of feelings of sadness and fear of death^{13,19-21}, so that this possibility becomes the only perception about the disease, to the detriment of other clinical findings. Chagas' disease becomes a type of condemnation²¹, the disease "that kills suddenly", and this outcome draws from the patient the unique depiction of this disease²².

When taking self-assessments of infected patients, we also observed that Chagas disease causes dissatisfaction with the quality of life, general health and performance of daily activities¹⁷, as well as a lower resilience capacity¹⁹, so that the awareness of vulnerability caused by the disease transforms the individual's relationship with his own life and changes own perception of himself, his resources and his capacities¹³.

In this context, patients who reported symptoms evidenced greater dissatisfaction with the quality of life and had higher stress indexes, even higher than physical symptoms¹⁹. Studies have revealed that even the diagnosis itself triggers negative feelings^{13,19} on a moderate or high scale,

Chart 2. Manifestations of Chagas' disease that interfere in the quality of life of the individual classified according to physical, psychological and social realm.

Variables		
Physical realm	Psychological realm	Social realm
Female gender	Depression	Social representations
Advanced age	Reaction on discovery of disease	Job loss
Late diagnosis	Sadness	Early retirement
Physical pain	Fear of death	Change in social relationships
Clinical form	Dissatisfaction with the quality of life	Change in social dynamics
Compromised daily activities	Lower resilience capacity	Dissatisfaction with sexual life
	Stressing events	

Source: Own elaboration.

Chart 3. Coping strategies that influence the quality of life of patients with Chagas' disease

Variables		
Psychological realm	Social realm	Social realm
Performing physical exercises	Religious beliefs	Schooling level
Drug therapy		Access to health services
Pacemaker implantation		Social security
Heart transplantation		Preservation of social relationships

Source: Own elaboration.

regardless of the manifestation of symptoms¹⁹, that is, the stressor does not have to be there to develop stress¹³. Anticipatory suffering stands out as a stress promoter, with the proliferation of negative thoughts about one's own life condition, causing, consequently, the complication of the established condition¹⁹.

Social realm

Faced with the social representations elaborated around the disease, we concluded that myths, cultural meanings and negative values that characterize the disease under the popular perception trigger psychological damages that set barriers in the life dynamics of carriers²².

In the labor context, it was observed that decreased physical vigor drives job's loss²¹. Because they are included in unfavorable socioeconomic conditions, workers expand occupation of the informal sector, in which they perform manual or part-time labor activities and are subjected to the long working hours, which assure them only the minimum to survive, without the prospect of a more promising future²³, and they are also confronted by obstacles that involve social repercussions and cultural prejudices surrounding the disease²². The retirement process also has reper-

cussions and is accelerated by the progression of late complications of the disease, which require continuous treatment and special care¹⁰.

As for the maintenance of social ties, we find two different situations, since, controversial to the feeling of solidarity emanated by family or friends, that is, by the most intimate social group, the subject faces the process of weakening relationships at work, in which marginalization of infected individuals by the others occurs, highlighting the discrimination directed to the pathology²².

The social impact was also illustrated in the statements of patients with Chagas' disease, in which they said that they did not enjoy life properly and had higher rates of dissatisfaction with sexual activities when compared to seronegative groups¹⁷.

Coping strategies that influence the quality of life of patients affected by Chagas disease

Physical realm

Regarding the direct benefits of physical exercise for patients with Chagas' disease, scientific evidence is still incipient and controversial.

While results suggest that regular physical activity is beneficial for physical conditioning and functional capacity, no improvement or worsening of cardiac symptoms through exercise programs²⁴ was detected. However, possibly, only movements of an individual with a chronic disease and was still at rest provides a bonus on the quality of life, with the understanding that individuals who used to perform little physical activity and included it in their routine contributed to decreased general mortality rate, when compared to those who adopted a sedentary lifestyle²⁵.

Regarding drug use, such as beta-blockers, when applied to major and more severe manifestations of heart disease related to Chagas' disease can attenuate symptoms and produce benefits in physical and mental mood, ability to perform activities, psychological satisfaction and social involvement, leading to an improved quality of life and extended life in a large number of patients²⁶.

Psychological realm

As to the psychological confrontation of the disease, it was observed that, in order to justify own Chagasic condition, patients anchor their beliefs in religious notions, so that answers they need are sheltered in the divine will, and, thus, medical science gaps are filled by religion through effective explanations for "life's drama". In this context, two distinct currents arise: on the one hand, the unshakeable belief in divine providence, which provides strength to individuals so that they may receive and face the daily disease-related difficulties and fears and, on the other, the accountability of the divine for the current situation and the resignation of the affected individual²².

Social realm

The association between the higher formal educational level and a better quality of life of the individual, regarding whether physical, psychological, social or environmental aspects¹⁷ was evidenced. In this context, the low level of schooling was characterized as one of the triggering elements of feelings of hopelessness and emotional conflicts, which represent low resilience capacity¹⁹.

In the evaluation of access to health services, it was found that scarce health resources compromise the quality of life, since individuals affected report the need for routine medical follow-up¹⁷. According to this rationale, if access to health care is difficult, stressful or of poor quality, the disease tends to progress and compromises the

way of life of the individual. On the other hand, the possible contact with an adequate and accessible health system triggers improved physical health and minimizes associated psychological and social conflicts, promoting the acceptance of the disease, the sense of well-being, social belonging and patient safety, which implies a better quality of life of the affected groups²⁴.

The process of accelerating retirement has also been mentioned, however, the financial value offered by social security also does not exceed the expenses with the treatment and the minimum for the individual's livelihood, which disrupts the psychological and social plan, since it stands adrift from the normal development of society¹⁰.

Regarding the preservation of social relationships, this has been described as facilitating access to information regarding health care, disease monitoring, support in times of crisis and participation in social events¹⁸.

Coping strategies for individuals with severe chagasic heart disease

Due to the constitution of the analysis categories, the need to highlight Chagas disease patients with severe heart disease emerged, which includes the following cases: a) quickly developing severe acute heart diseases, with important limitations of the individual's work activities; b) chronic heart diseases in a situation of limitation of the patient's physical and functional capacity, despite the indicated clinical and/or surgical treatment; c) chronic or acute heart diseases with total pharmacological or mechanical inotropic support dependence; d) terminal heart disease, which reduces life expectancy and does not respond to the stimuli of maximal pharmacological therapy or to external hemodynamic support²⁷.

In this perspective, the studies also demonstrated coping strategies for two situations related to severe chagasic heart disease: patients who underwent implantation of implantable devices (pacemaker and/or cardiodesfibrillator) and individuals who required heart transplantation.

In the specific case of patients undergoing pacemaker implantation, it was observed that the experience assumes divergent values throughout the process. The initial idea is that one has a fragile heart, of such intensity that it requires surgical intervention that will convert all the normal functioning of the organism to an unknown apparatus, instigating dread. In the long run, the pacemaker becomes a natural extension of the organism and is seen as a keystone of the bearer's existence, as a tool that rescues life from the

moment it was being lost. It thus takes on an unquestionable responsibility: it replaces the heart with what it is no longer able to do, becoming a source of life²².

Regarding the appropriation of the heart transplantation strategy, the literature revealed that patients with Chagas' disease who underwent this therapy, while not achieving an optimal stage of quality of life, obtained positive results in at least some markers, such as with regard to limited actions and life perspective²⁸.

Final considerations

Results in all realms addressed showed a quality of life compromised by the disease, in addition to coping strategies mostly limited to the physical realm of the patient, suggesting the need to strengthen the individual in the physical, psychological and social fields, so that interventions may encompass the preservation or recovery of the individual's functional capacity, through the acceptance and empowerment of the subject in the daily coping with the disease, through the provision of accessible and effective health services and the reintegration of the individual into the family and social core.

The limitations of the study build on the lack of a universal concept of quality of life, as well as a standard tool for the evaluation of this concept, in relation to the individual affected by Chagas' disease. The search for studies that address this subject showed scarce records, privileging aspects that go back to the physical realm of the individual, to the detriment of psychological and social elements, which also absorb a dizzying impact of the illness situation faced by the subject and, thus, require measures that meet the corresponding needs.

Moreover, the damage caused to the quality of life originating from the chagasic condition is not very detailed as to the stratification of the disease, since in most findings, individuals are treated only as Chagas' disease carriers, without specifying the clinical form, except severe Chagas' heart disease cases.

We recommended the elaboration of specific tools for the analysis of the impact of Chagas' disease on the experience of the affected subject, in addition to the exploration of the highlighted area, starting from the premise that knowledge about the life of the individual affected by Chagas disease in its different clinical forms may guide the design of more effective health strategies, highlighting the need for studies that promote space for the manifestation of the individual's perception of own health-disease process.

Collaborations

MAF Cavalcanti, EGC Nascimento, JC Alchieri and CM Andrade worked on the design, outline, analysis and interpretation of data, writing, critical review and approval of the version to be published.

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