

RESEARCH ARTICLE

Health-related quality of life in Chagas cardiomyopathy: Development of a theoretical model

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Abstract

Objective: Chagas disease can cause several complications, such as Chagas cardiomyopathy, the most severe clinical form of the disease. Chagas cardiomyopathy is complex and involves biological and psychosocial factors that can compromise health-related quality of life. However, it is necessary to establish interactions that significantly impact the health-related quality of life of this population. Therefore, we aimed to develop and present a theoretical model on the impact of Chagas cardiomyopathy on the health-related quality of life of patients.

Methods: This is a cross-sectional study with a multi-methodology approach. The model's development process relied on the findings of a systematic review of qualitative studies, as well as a qualitative study involving participants from original communities, conventional rural areas and urban centres. Patients diagnosed with Chagas cardiomyopathy were interviewed using a semistructured research script, and the sample size was determined by theoretical saturation. Ultimately, the model underwent evaluation and received approval from three specialists in Chagas cardiomyopathy.

Results: Patients experience many emotional conflicts, manifested by feelings of sadness, existential emptiness and anxiety. They have fears related to the course of the disease, the inability to care for the people they love, their suffering and that of the family caregivers, as well as the fear of invasive treatments and death. The model based on social determinants of health was created and presented three different levels of factors that impact patients' health-related quality of life. At the first and most external level are social, cultural and environmental conditions: absence from work, difficulties in accessing health-care services, limited resources for specialised care and geographical barriers to accessing healthcare services. At a more internally committed level, there are social factors and community networks encompassing social isolation, family conflicts, social stigma, emotional aspects, fears and disabilities. The innermost layer of factors represents personal and behavioural complaints, such as physical ailments and poor sleep quality.

Conclusion: The factors that affect the health-related quality of life of patients with Chagas cardiomyopathy are diverse in their biopsychosocial nature.

KEYWORDS

Chagas disease, health-related quality of life, theoretical model

INTRODUCTION

Chagas disease remains a public health problem in Latin America, even though more than a century has passed since its discovery by the Brazilian scientist Carlos Chagas in 1909 [1]. The disease affects individuals of any age, though it is more prevalent among adults and the elderly due to improvements in vector transmission control [2]. It also affects people with low socioeconomic status in rural areas but has also increased in urban areas and non-endemic countries due to migratory flow [2, 3]. The disease affects between 6 and 8 million people worldwide, causing 12,000 deaths per year [3]. In nonendemic countries such as the USA, Spain, Italy, France, Switzerland and Japan, approximately 3.5% of immigrants have positive serology for the disease [4].

Chagas disease is caused by infection with the protozoan *Trypanosoma cruzi*. It has an acute phase in the first few weeks after contact with the parasite, followed by a chronic phase [3]. During the chronic phase, the individual may present with the indeterminate form of the disease, which is characterised by the absence of clinical manifestations, or with cardiac, digestive, or mixed (both simultaneous impairments) forms of the disease [3]. The cardiac form, namely Chagas cardiomyopathy (ChC), is the most severe clinical form, with the worst prognosis among other cardiopathies, and is responsible for the high morbidity and mortality of the disease [3, 5, 6].

Patients with ChC tend to progress with functional impairment [7], high disability levels [8], medical-labour impacts [9], high rates of depressive symptoms [10] and reduction in health-related quality of life (HRQoL) [11]. Available evidence suggests that HRQoL is reduced in patients with ChC from the early stages and tends to worsen with the progression of heart disease [12, 13]. In addition, it is worse in patients with ChC compared to patients with other heart diseases (ischemic heart disease, heart failure due to undescribed cause, patients with atrial fibrillation) [14, 15] and is associated with several socioeconomic and demographic factors [16]. It suggests that aspects other than the cardiomyopathy negatively impact the HRQoL of patients with ChC.

The HRQoL is a multidimensional construct. It encompasses various facets that constitute the biopsychosocial individual (physical health, psychological well-being, social, cultural and environmental aspects) [17]. One possibility for understanding the HRQoL is the creation of theoretical models, which allow the organisation of characteristics, concepts and propositions, forming a hypothetical-deductive system that represents reality [18]. It is an instrument capable of simplifying a reality so that it becomes more “observable” or “imaginable,” being compared to maps, which are not copies of terrain, but with them, we can guide ourselves on the same. Therefore, it is necessary to create a theoretical model that synthesises the dynamics of HRQoL in individuals with Chagas disease. Once established, the model can be a

valuable tool for improving patients’ lives by providing a solid foundation for enhancing the evaluation process and identifying gaps in both individual interventions and public policies. Furthermore, we reaffirm that the creation of this theoretical model can assist policymakers in identifying areas that require action. It also allows researchers to compare the model’s insights with existing HRQoL assessment questionnaires, potentially contributing to the development of more tailored assessment tools for this population. Thus, this study aimed to create a theoretical model to illustrate the determinants of the HRQoL of patients with ChC.

METHODS

Study design

This is a cross-sectional study with a multi-methodology approach (qualitative techniques, expert opinion and literature reviews), part of a larger project, which aims to create and validate a specific HRQoL questionnaire for individuals with ChC, the Caburé study (<https://doi.org/10.17605/OSF.IO/CVTSF> and <https://osf.io/cvtsf/>). The study was conducted in Brazil, and all the procedures were approved by the institutional ethics committee, as recommended by the Declaration of Helsinki [19].

Three sources were consulted to develop the model: (1) a systematic review of qualitative evidence on the impact on HRQoL of patients with chronic Chagas disease; (2) a qualitative study with patients with ChC; (3) expert’s opinions on ChC.

Systematic review

A systematic review of qualitative evidence was carried out in accordance with the principles of the Cochrane recommendations [20] and was reported following the Guidelines for Improving Transparency in Reporting the Synthesis of Qualitative Research [21]. Records found in the databases were screened by titles and abstracts, and those deemed potentially eligible had their full texts reviewed to confirm detailed eligibility (primary qualitative studies involving patients of any gender or age, with positive serology for *Trypanosoma cruzi*, conducted in any healthcare setting). For data analysis, we (1) conducted a metatheory analysis (analysing and interpreting different theoretical and philosophical perspectives, sources and assumptions presented in individual studies); (2) defined the characteristics and relationships among them (such as location, sample specificities, data collection methods and disease stage); and (3) performed a resynthesis, where the most frequent information was grouped, and a narrative summary method was used to present the results. Further details of the systematic review can be accessed in the published article [22].

Qualitative study

Theoretical/methodological framework

This is a cross-sectional study that followed the concepts of the interpretivist paradigm and employed phenomenological research strategies, with data collected through individual interviews using a semi-structured script. This set of procedures is previously described [23]. Phenomenological research is suitable for investigating the factors that impact the HRQoL of patients with ChC because, according to the authors, it describes the common meaning of lived experiences among several individuals, aiming to capture the essence of the phenomenon.

This stage was in accordance with the qualitative research method, which investigates the complexity of phenomena, facts and social group processes. The assumptions of social research were followed, trying to understand the social dynamics, concerns and interests of the studied population [24].

Patients registered at the Outpatient Clinic were interviewed between January and June 2023. Patients of both sexes, over 18 years of age, with positive serology for *Trypanosoma cruzi* in at least two available serological tests and electrocardiographic characteristics compatible with ChC [25] were included. Patients with digestive complaints, comorbidities that could influence the HRQoL, and cognitive impairment were excluded. A content analysis was carried out, according to Bardin [26].

The exploration of a phenomenon in phenomenological research is conducted by identifying a group of heterogeneous individuals who are experiencing or have experienced the phenomenon, typically ranging from 3 or 4 to 10 or 15 individuals [23]. In our study, we interviewed a heterogeneous group of patients, including those from indigenous communities, rural areas and urban settings. We employed the theoretical saturation method to determine the sample size, choosing to stop recruitment when the interviews no longer yielded new information, resulting in a sample of 8 patients. The data were analysed using a set of techniques to find qualitative inferential indicators, as recommended by Bardin [26]. Many classification, grouping, coding, or graphic presentation methods were carried out.

The IRAMUTEQ software was used for data management and manipulation, acknowledging the inherent limitations of CAQDAS (Computer-Aided Qualitative Data Analysis Software). It facilitated the creation of graphs and maps to aid in the interpretation of the results [27]. While the software executed the researcher's commands, the analysis itself relied on human expertise. IRAMUTEQ was also integrated with the R environment to perform several lexicographic analyses, which helped in understanding the data. These analyses included: (1) Word Cloud (WC), where words are visually represented, with more frequently mentioned terms appearing larger; (2) Similitude Analysis (SA), which identifies word frequencies and their most common associations with other words, revealing patterns of

connectivity; and (3) Descending Hierarchical Classification, which groups text segments by similar topics while distinguishing those related to different subjects.

Creation of the theoretical model

Two researchers experienced in studies on the HRQoL of patients with Chagas disease and a psychology professional synthesised the evidence constructed and developed the theoretical model of the impact of the disease on the HRQoL of patients. A model was developed to explain the dynamics of HRQoL in patients with Chagas disease based on the Dahlgren and Whitehead model of social determinants of health [28]. This model allows a better understanding of the phenomenon. Features such as a multidimensional approach, layered structure and a holistic view of health provide valuable insights for public health policies, disease prevention, health promotion and addressing inequities [29–31].

The construction was based on the meanings attributed by the authors to the patients' statements and their experience in managing the patients. In the process, the first author (WTS) prepared the first version of the model, which was reviewed and adapted by other authors (HSC and TSA). The final version of the model reached a consensus among the authors. The specialists conducted discussions via digital platforms and email. Figure 1 represents the flowchart of the detailed process.

These experts were professionals involved in the management of patients with Chagas disease. Therefore, the team agreed to minimise the cultural, political, social and ideological influences of their perspectives and voices, prioritising the perspectives and voices of those interviewed whose reports were synthesised. However, it is understood that the process should not be seen as a static method, as the data were collected through interpersonal interactions and were analysed and interpreted based on the meanings the authors attributed to the behaviours, speeches and actions of the individuals, thus actively participating in the research process.

The results are presented in their logical and chronological order of achievement. Initially, the table of main findings carried out by Silva et al. [22] was shown (details in the summary table of results made by the authors in Table 1). Subsequently, the data from the qualitative primary study and the development of the theoretical model were demonstrated.

RESULTS

Systematic review of qualitative evidence

The electronic search identified 591 studies, of which 338 (57.2%) were excluded due to duplication. After analysing the titles and abstracts, nine studies remained for

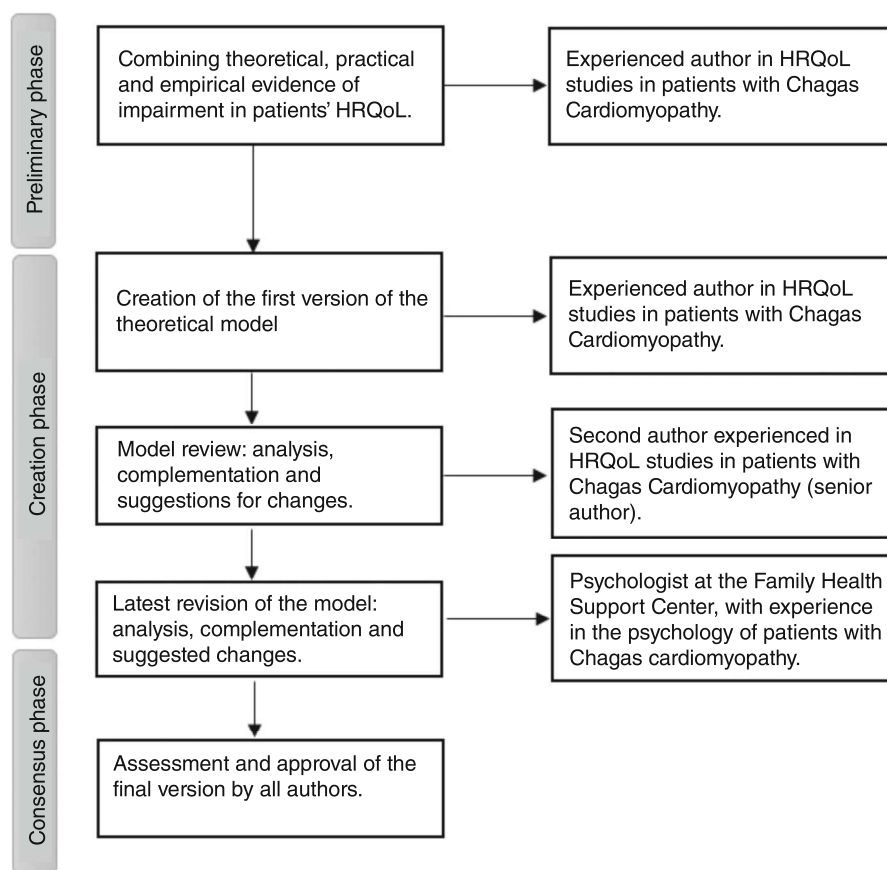


FIGURE 1 Flowchart of theoretical model creation. HRQoL, health-related quality of life; Senior author, head of the research group, with extensive experience in the subject and mentor or advisor to students; Family Health Support Center (NASF), a multidisciplinary team that provides technical and pedagogical support to Family Health Teams.

TABLE 1 Characteristics of patients ($n = 8$) of the primary study.

Variable		Mean (SD) or frequency and percentage (%)
Age		61.63 $\pm$ 13.20
Sex (female)		5 (62.5)
Years of study	Did not study	3 (37.50)
	Up to 8 years	4 (50.00)
	11 years and over	1 (12.50)
LVEF		61.28 $\pm$ 11.16
Functional class	Preserved ($\geq 50\%$)	6 (85.72)
	Systolic dysfunction ($< 50\%$)	1 (14.28)
	NYHA I	6 (75.00)
Housing		2 (25.00)
Housing	NYHA II	2 (25.00)
	Rural	2 (25.00)
	Urban	4 (50.00)
Original community		2 (25.00)

Abbreviations: LVEF, left ventricular ejection fraction; NYHA, New York Heart Association.

full-text review. Of these, only five met the eligibility criteria and were included. The authors found moderate evidence that social stigma, fear of the future, absence from work/

physical complaints and emotional component, and low confidence evidence that fear of treatment affect the HRQoL of patients with chronic Chagas disease (regardless of the clinical form). Details in the original publication [22].

Qualitative primary study

Eight patients with ChC were interviewed, with an average age of 61 years, residents of original communities (situated in the Jequitinhonha Valley, municipality of Chapada do Norte, Minas Gerais, Brazil), common rural communities and urban areas (rural and urban areas of the municipalities of Diamantina, Serro and São Gonçalo do Rio Preto, both in the southeastern region of Brazil).

Word cloud

The word cloud of the interviews is demonstrated in Figure 2. The most frequent words were “God” ($f = 62$), “disease” ($f = 33$), “work” ($f = 30$), “Chagas” ($f = 27$), “die” ($f = 26$), “daughter” ($f = 26$), “house” ($f = 21$) and “live” ($f = 19$). In general, family, housing, religiosity, death and fears were common issues.

Similarity analyses

There was a tendency towards subjects that involved four main subjects. (1) The word “home” has always been linked to family issues, loneliness and work; (2) the word “son” was strongly linked to fear, death, worries, care and help, among others, demonstrating a great fear related to possible

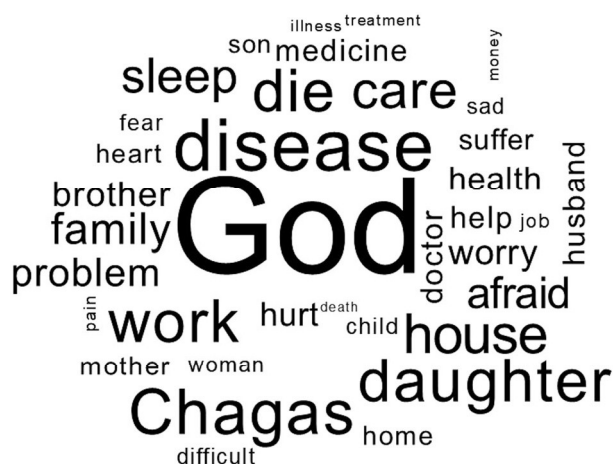


FIGURE 2 Word cloud of the interviews conducted.

death and consequent absence in the children's life; (3) the word “die” was linked to the words God, brother, mother and father, and illness, which can be explained by the religiosity/spirituality that involves the act of dying, the relationship between the illness process and death and the characteristic losses family members of father, mother and siblings of patients with Chagas (many of the patients have already lost family members due to the disease); (4) the terms “disease” and “Chagas” are very close due to their grammatical complementarity, linked to them one can strongly observe the term death, hinder, medicines and exams, demonstrating the association of the disease with death, medical consultations and exams (Figure 3).

Descending hierarchical classification

To facilitate the handling of the interview texts, we conducted a descending hierarchical classification to find the macro categories of subjects. All textual segments were read and analysed by the authors who conducted content analysis. Four broad categories were found: (1) impacts related to health conditions (33.6%), (2) impacts related to social support (11.7%), (3) impacts related to economic conditions (27.5%) and (4) impacts related to family issues (17.7%).

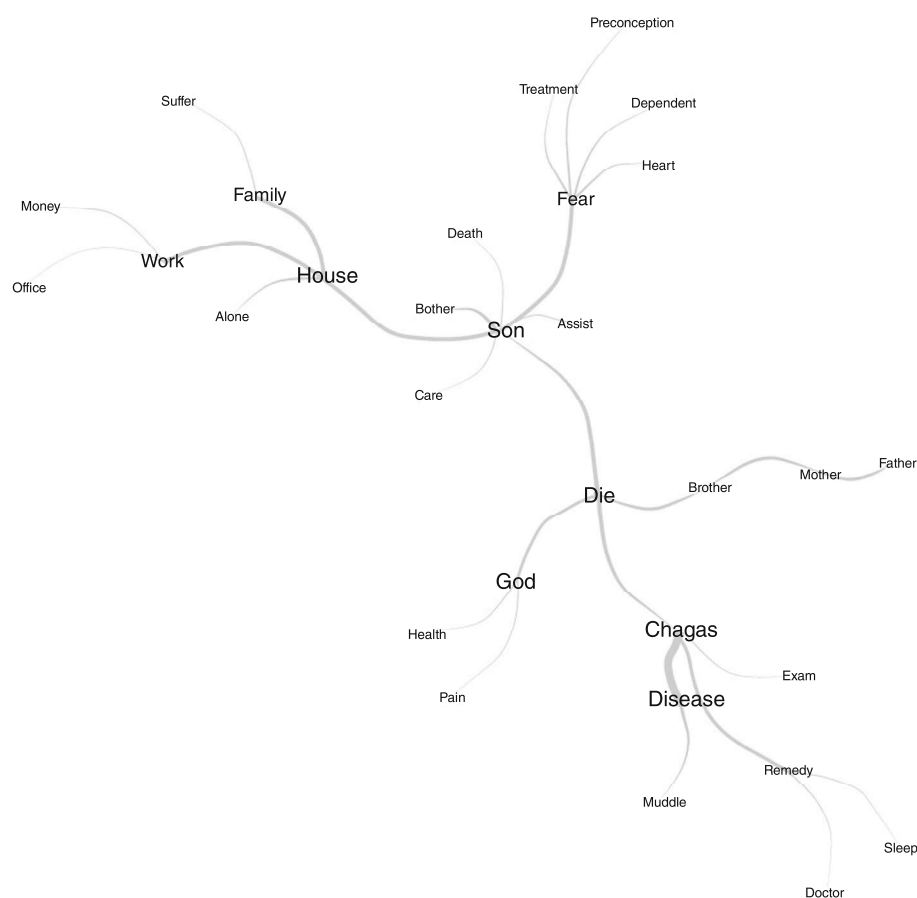


FIGURE 3 Graphical representation of the similarity analysis.

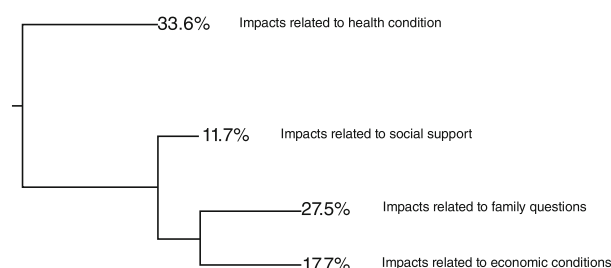


FIGURE 4 Categorization of textual segments.

The textual use of the software was 93.03%. Figure 4 presents the dendrogram with categorization details.

Content analysis: Reading and contextualised reflection on the participants' statements

A manual analysis of the content was conducted through reading and contextualised reflection on the participants' statements. We observed statements that suggest living with fear, which may be related to the progression of the disease (such as fear of increased heart damage), invasive and prolonged treatments, the suffering caused by the disease and to family members, the inability to carry out daily or labour activities and care for loved ones, as well as the fear of dying.

This fear of the future is present in countless reports and is linked to the biopsychosocial aspects of individuals. This analysis is supported by statements such as [...] it bothers me that I'm afraid of the aneurysm (mentioning the apical aneurysm) growing... especially when I start to feel... we feel a lot of things, I don't know if it's what it is [...] or other patients, who reported [...] I'm afraid of having a heart attack and not being able to work, preventing me from working. That's what I'm afraid of [...].

The fear of disease progression and treatment are also present in some statements, such as Ind_01 [...] I'm afraid of falling into a bed... becoming dependent [...] or in the report of patient Ind_02 [...] Fear is like that, staying like this in a coma, right? [...] and Ind_03 "I'm afraid of maybe suffering too much; it's a disease that we suffer a lot. Prolonged treatment!" Ind_02 "I'm afraid of developing it and affecting the heart, things like that? I don't think so yet, but I need to put it in, right? (referring to the pacemaker)."

Fears related to family issues seem to be divided between the fear of becoming incapable of taking care of loved ones, as mentioned by patient Ind_07 [...] just like I told you, my fear is that I will get sick and not be able to take care of her, you know (her daughter)? That's my big fear. I've seen this happen, like this, even in my family, right? [...]. It is also common to find reports of fear of causing suffering to family members, as said by Ind_08 "[...] I am afraid of suffering, my family suffers with me, but if God gave me the luck of dying suddenly, I would be better. Because the person suffers and the caregiver suffers, right? [...]."

In addition to issues related to health conditions, the family context once again becomes a determining factor in patients' HRQoL. There are frequent reports of family conflicts, as well as family abandonment (emptying the house). Lines like those from participant Ind_04 [...] my niece... is in the wrong world... I see my brother suffering... [...] because she stole my brother's shack [...]. This suffering in family dynamics also occurs due to changes in children, seen by participants as a form of abandonment, as mentioned by participant Ind_01 [...] when my husband passed away, and we still had a cousin who lived with us too, right? She helped, took care... As soon as my husband died, my daughter fell into brachiarria (a term used to say that the daughter left). And after 8 months, I lost my husband, my daughter got married, my cousin also found a boyfriend [...] in general, it's painful, you know? There comes a time in your life when abandonment is worse than illness. You feel abandoned, you know? [...].

Regarding the compromises to HRQoL caused by the health condition itself, labour impacts and limitations in activity stand out, which are closely related to economic concerns. The labour impact of the ChC becomes evident when analysing excerpts such as the statements of patient Ind_06 "[...] the doctor said that I was at risk of death. So, I started saying, I can't work [...]," and from Ind_08 "But this Chagas disease is dangerous, right? They don't like that I work..." This withdrawal from activities due to the disease occurs on the recommendation of third parties, as seen in the reports above, or due to physical manifestations of the disease, as mentioned by Ind_07 "And also when I go to work, I believe that Chagas disease got in the way... yeah. that I feel, like, very tired, right?", [...] before I could do it like that, go to the fields, weed, nowadays I can't, right? I can't walk very fast, I get tired [...].

Two other factors that affect patients' HRQoL arise: financial difficulties and lack of access to health services. The statements of the patients demonstrate that they need to adapt their healthcare costs and daily expenses to the minimum wage they receive as a "sickness benefit." Excerpts from participants' statements highlight this fact, as said by patient Ind_05 [...] no, being able to pay a lot is not possible, right (about consultations and treatments)? There's no way because we only have a minimum wage, right? [...]. According to Ind_01, there are times when it is necessary to choose between treatment and food, showing that it is unfeasible to do both [...] it is very complicated. And my medicines, like, none of them cost less than a hundred reais... None of them, you know? So, I live like this, I have to worry about buying medicine, paying rent, and eating. I said it like this, we have to choose, right? Eating or taking medicine, you can't do both [...]. In small urban centres, patients face financial limitations for the treatment used in collaboration with third parties, as said by Ind_07 [...] just like the medicine where we live, we can buy it on credit. We buy for 30 days.

Financial difficulties are associated with the absence of the state as a promoter of the right to access healthcare,

compromising patients' HRQoL in several aspects. These statements can be seen explicitly in the participants' reports, such as Ind_01 [...] lacking... I didn't have a cardiologist... I didn't have one... Endocrine... So, I started paying. I started paying for everything... Like this... The things I needed... [...]. The patient still reports having to adapt to lower-cost treatment options [...] like medicine. People talk to me, and we have medicine for the entire social class, for those who can pay more, for those who can pay less, like this. So, you have to adapt, right? [...].

The totality of fears, conflicts, and existential difficulties seem to strongly compromise the emotional component and, consequently, the patient's HRQoL. Interviewees present different ways of dealing with emotions, but in addition to fear, anxiety and sadness are frequent in the reports. Sadness is a typical human feeling and condition; however, it can become disabling and cause suffering when associated with other factors. Experiences of sadness, sometimes disabling, are observed in reports such as Ind_04 [...] I live this. I see worse things happen. I've changed a lot, I'm not like I was before. I smile very little. I live like this. I'm not the Ind_04 from before [...]. A similar report was also made by patient Ind_08 [...] I don't really want to go out and have fun for a while now because I liked it [...]. There were moments when attempts were made to avoid talking about their feelings, like Ind_04 [...] I can't say why. There are so many that I'm going to stop and talk about [...]. Sentences that appeared as predecessors of speeches about existential emptiness, such as [...] I can't solve anything... punching the tip of a knife [...].

Still in the emotional aspects, the reports suggest the presence of anxiety. Anxiety is a natural human feeling that allows us to anticipate risky situations and prepare for daily challenges. However, when this emotion becomes very intense, with disproportionate and continuous worries, it causes symptoms that can seriously harm people's HRQoL. These manifestations were expressed in statements like Ind_03 [...] the only thing that happens is that on a day when I'm very thoughtful, that night, if I think about a lot of things, then I don't sleep [...]. This can also be observed in Ind_04's speech [...] when I get really nervous, and something... I'm starting to have, I don't know if it's a fainting spell, it's... I'm fainting, paralysed, stiff... I don't know if it's.

Theoretical model on HRQoL impairment

Understanding the health and the disease process, not as an object of a mechanistic study but as a complex variable that involves several layers related to the subject's biopsychosocial individuality, the model demonstrated in Figure 4 was based on the social determinants model of Dahlgreen and Whitehead [30, 31]. Thus, our model points to 4 macro groups of factors that impact participants' HRQoL, which include political, environmental (social and geographic), functional and individual inequities (Figure 5).

Figure 6 presents the items that impact patients' HRQoL at their major levels of determinants. The figure starts with the most individual factors and moves on to the more

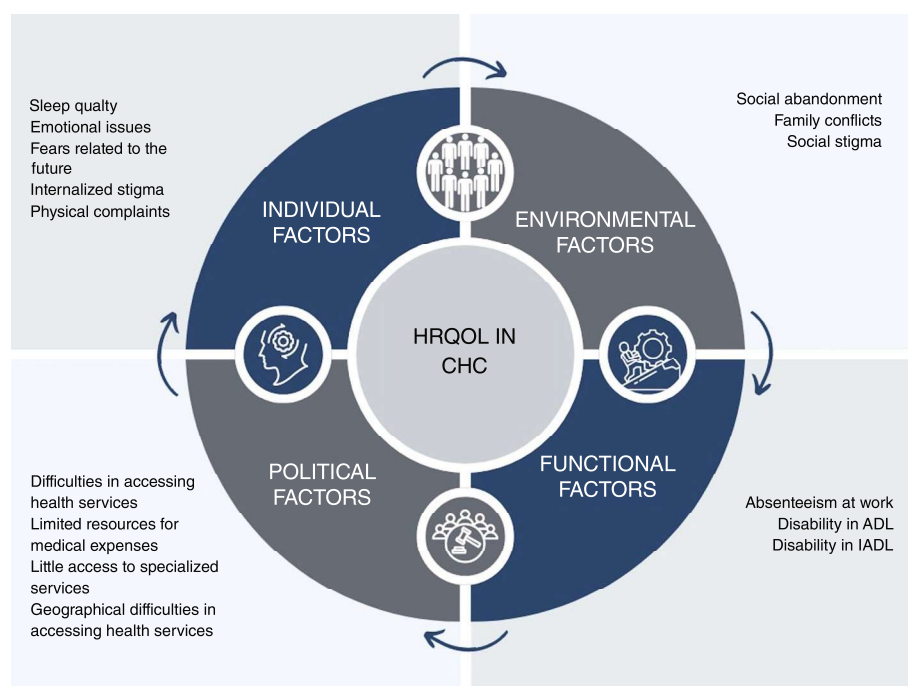


FIGURE 5 Theoretical model of the impact on HRQoL of patients with ChC. ADL, activity of daily living; ChC, Chagas cardiomyopathy; HRQoL, health-related quality of life; IADL, instrumental activities of daily living.

complex factors. Despite being schematized in layers, the elements are not independent, that is, there is a relationship of belonging to the outermost layers. Figure 7 illustrates some of the possible interactions between factors that can lead to compromised HRQoL in people with Chagas disease.

DISCUSSION

This study aimed to develop a theoretical model to illustrate the determinants of the HRQoL in patients with ChC. Our main results are (1) patients experience many emotional conflicts, manifested by feelings of sadness, existential

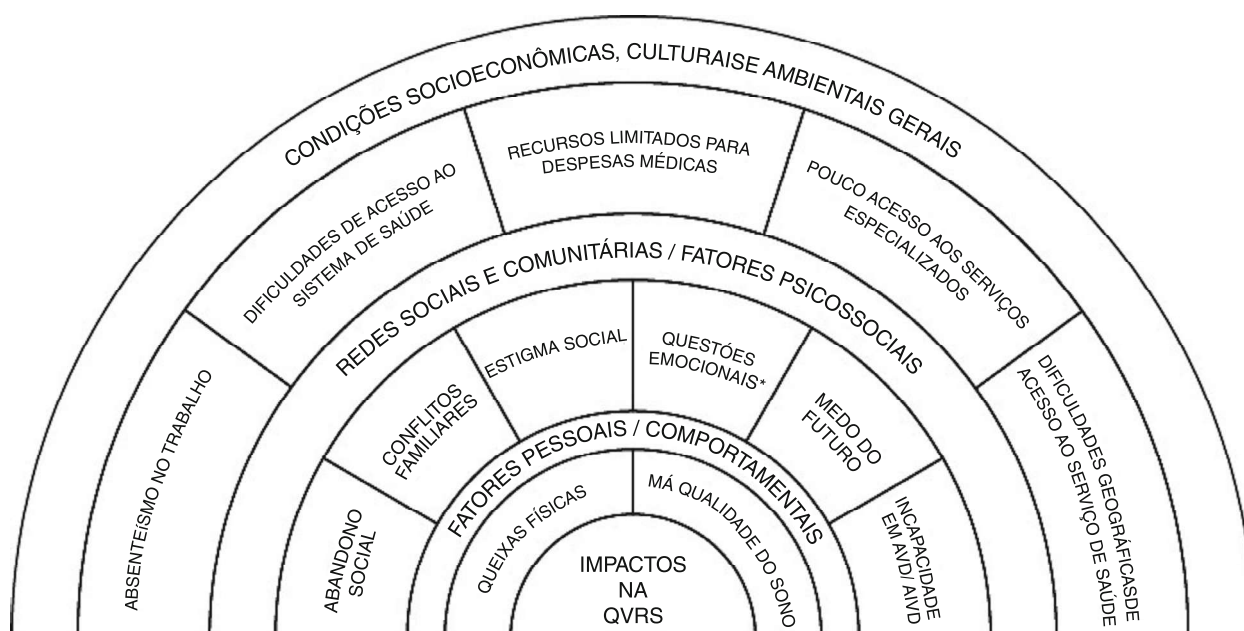


FIGURE 6 Items that impact each level of determinants. (*) Symptoms of anxiety and depression. HRQoL, health-related quality of life.

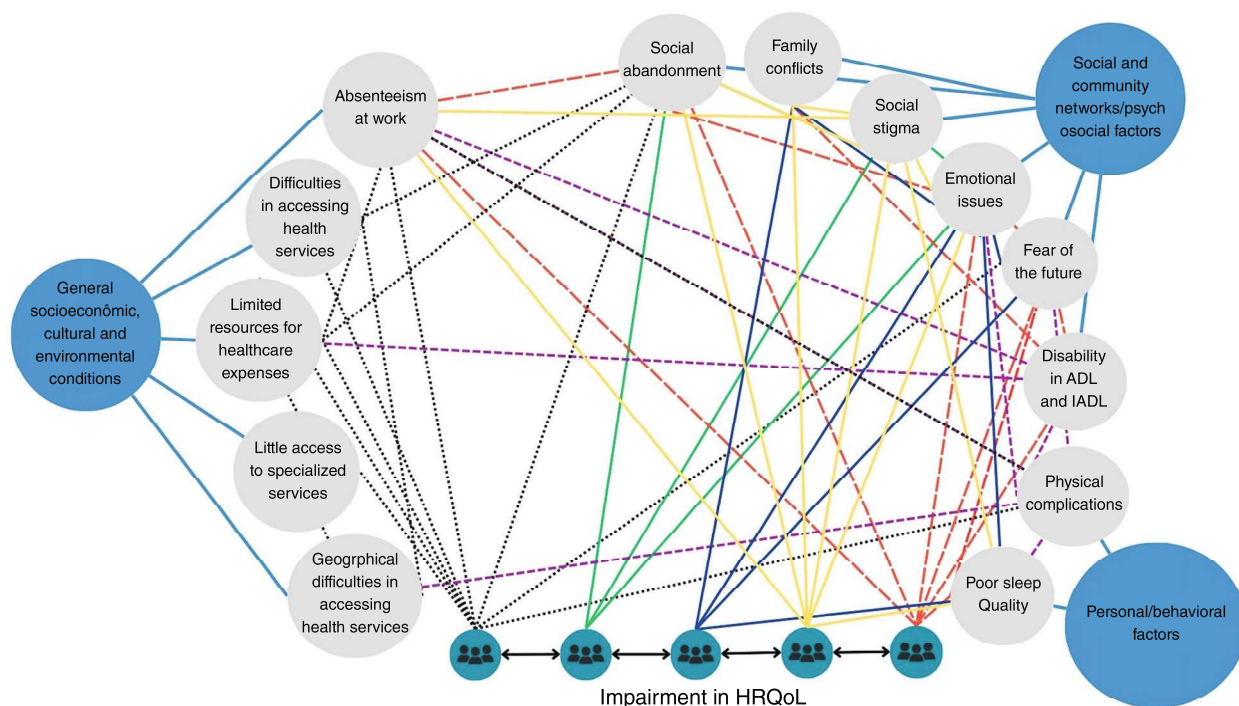


FIGURE 7 Potential interactions among factors contributing to compromised health-related quality of life (HRQoL) in individuals with Chagas cardiomyopathy. ADL, activities of daily living; HRQoL, health-related quality of life; IADL, instrumental activities of daily living.

emptiness and anxiety; (2) patients have fears related to the clinical course of the disease, the inability to care for the people they love, their suffering and that of family caregivers, as well as the fear of prolonged and invasive treatments and their death; (3) patients live in a context of lack, including lack of access to the health system, and finances; (4) the disease has a major medical, labour and activity impact; (5) social stigma impacts patients' HRQoL, and (6) the theoretical model that best explains the impact on patients' HRQoL has four macro constructs, in which the facets of social determinants that impact patients' lives are encompassed according to their characteristics, with the macro components being formed by individual, environmental, functional and political aspects.

The theoretical model of the determinants of the HRQoL in patients with ChC corroborates the perception that the process of health, disease and injury involves a complex network of biopsychosocial factors [32]. These determinants can be understood as the conditions in which people are born, grow, work, live and age, and inequities in these factors can lead to undesirable health outcomes, such as illness and health problems [32]. This finding can be observed in the literature and through the analysis of the content found in our interviews, demonstrating that, in addition to biological illness, individuals with ChC have their HRQoL compromised by several contextual factors.

The impacts of Chagas disease can be understood as a biopsychosocial construction since childhood, as they generally occur in socioeconomically disadvantaged regions [33], and growing up in conditions of social vulnerability, characterised by difficult access to schools, food insecurity, malnutrition and lack of basic sanitation, exposing them to others parasites [34]. When they reach adulthood, these patients may experience both pathophysiological manifestations of the disease and the lack of assistance [35], stigmatisation, financial difficulties, fears and emotional conflicts, which combined can lead to significant individual complaints, such as worsening quality of sleep, which in turn, starts to act as a cause and consequence of emotional complaints. These factors negatively influence the HRQoL [36]. At advanced ages, patients experience new impactful factors, such as social abandonment [37, 38], financial difficulties, the coexistence of other diseases, increased disability and fear of the future.

The model has a structure that starts from more individual factors to more complex ones, and the classes are dependent, that is, the most internal groups have dependencies on the most external groups [39]. Although presented graphically separately to facilitate understanding, it is important to recognise the interdependence between the aspects that contribute to the impairment of HRQoL. This perspective is supported by important theorists of human development. Luria, for example, emphasises in his studies how the social and cultural context influences cognitive development, arguing that psychological issues are shaped by social and cultural interactions [40, 41]. On the other hand, Wallon highlights the importance of emotions and interpersonal

interactions in the psychological formation of the individual, emphasising how these dimensions affect psychological development [42]. Thus, the interaction of factors, from the most external level to the subject's most internal level, can be crucial for how they feel and think about themselves and the world.

The interview findings reveal that sadness, anxiety and fear are prominent emotions in the psychological experiences of patients, significantly affecting their health-related quality of life (HRQoL). Sadness, often linked to feelings of loss or limitations, can trigger avoidance behaviours and make it difficult to process these emotions, potentially leading to depressive symptoms and psychological distress [43, 44]. Anxiety, as reported by participants, appears to stem from uncertainty about the disease's progression and the impact of physical limitations on daily activities. It can manifest both physically and in sleep disturbances [45]. Fear, particularly related to death or becoming dependent on others, was frequently mentioned and may be intensified by sociocultural factors, such as concerns about being unable to care for one's family [46]. These emotional challenges create a cycle of emotional and functional impairment, leading to reduced autonomy, behavioural changes, feelings of dependence, and ultimately, a diminished HRQoL [17].

Considering what was mentioned above, we reaffirm that actions focusing on social determinants of health have important effects on global health [47]. However, the biopsychosocial practice must not be fragmented because the discourse has been "biomedicalized" [48], fragmented and reductionist, limiting the psychosocial factors to behaviour and cognition [49]. Therefore, greater attention is needed to biopsychosocial factors, understanding the environment and personal factors not only as contextual factors (barriers or facilitators) [50].

Understanding the subject as a whole must consider biopsychosocial factors in their entirety. Environmental and personal factors should not be seen as facilitators or barriers but as determinants of health outcomes and part of the subject [51, 52]. When analysing the theoretical model of the determinants of the HRQoL in patients with ChC, it can be concluded that prevention, control and clinical management actions for the condition require interventions on socioeconomic, cultural, general environmental conditions, social networks and personal factors. Additionally, these actions should be carried out through coordinated and simultaneous policies, aiming at changes from broader to individual factors in the short, medium and long term. Public policies should be decentralised and tailored to individuals with Chagas disease, taking into account the specific economic, social and cultural characteristics of each region.

Policies could include the establishment of multidisciplinary teams that facilitate comprehensive discussions on the relationship between prejudice, discrimination and healthcare [53]. These teams should be deployed in communities and aim to reduce both physical and psychological suffering among affected individuals. Additionally, they

should collaborate with policymakers to overcome economic and geographic barriers through public welfare programs, ensuring access to fundamental human rights, such as quality housing and nutritious food [54]. These public policies may have an impact beyond Chagas disease, influencing the overall health and disease process. By addressing the social determinants of this process, they are expected to improve the living conditions, health and well-being of both individuals with and without Chagas disease.

It is also crucial for the state to maintain a presence in underserved communities, providing accessible healthcare, particularly for those who face geographical and financial constraints in accessing specialised facilities [55]. This requires deploying trained teams to remote areas working in collaboration with primary healthcare services. Mobile healthcare units (MHUs) can play a pivotal role in this effort, offering diagnostic services such as electrocardiograms, echocardiograms and digestive exams [56]. These units should visit communities regularly, providing essential support to local healthcare teams [56].

This study has some limitations. The interviews were carried out only in Brazil, and the participants belonged to functional class I or II, which compromises the external validity of the study. On the other hand, although our sample was relatively small (eight individuals), the interviews were carried out face-to-face and we obtained reports from patients living in original communities, rural and urban areas, exploiting different environments. Future research in other endemic countries and with immigrants or descendants of immigrants in non-endemic countries should be conducted to verify the factors that impact the HRQoL of people with Chagas disease, as they may supplement the findings described here. In addition, it is desirable to expand the sample size and have international collaboration to better understand the aspects that impact the lives of people with Chagas disease. As strengths, we highlight that this study has patients living in original communities, rural communities and urban centres, covering a wide geographic distribution range of patients.

CONCLUSION

The determinants of the HRQoL of patients with ChC are heterogeneous in their biopsychosocial features. They should be seen in a holistic nature, not reduced to biological, behavioural or functional aspects, but rather as a complexity that encompasses social aspects and their general political, cultural and environmental components. We believe that the study has the potential to better guide the management of patients with ChC, reinforcing that it is more than a heart disease, there are strong psychosocial features. This study also demonstrates that policymakers need to commit to confronting inequities and that health professionals must decentralise attention, covering not only biological and functional aspects. The main factors impacting HRQoL include emotional conflicts, such as feelings of sadness, existential

emptiness and anxiety. These also encompass fears related to the progression of the disease, the inability to care for loved ones, personal suffering, the suffering of family caregivers, and concerns about invasive treatments and death. Managers and policymakers must dedicate efforts to establishing multidisciplinary teams for comprehensive patient care. In addition, they should focus on addressing economic and geographic barriers, ensuring access to quality housing and nutritious food and developing mobile health units to provide diagnostic services within communities. New studies in other countries with larger sample sizes should be conducted to further expand knowledge about the impact on HRQoL of people with Chagas disease.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Data are available upon reasonable request. The datasets generated and analysed during the current study are available through contact with the corresponding authors: henriquesilveira@yahoo.com.br.

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