

Depression, quality of life, subjective well-being, and psychometric assessments in Brazilian patients with Chagas disease: A literature review

Depressão, qualidade de vida, bem-estar subjetivo e avaliações psicométricas em pacientes brasileiros com doença de Chagas: Uma revisão da literatura

Depresión, calidad de vida, bienestar subjetivo y evaluaciones psicométricas en pacientes brasileños con enfermedad de Chagas: Una revisión de la literatura

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Guilherme Stavale Hasslocher¹

ORCID: <https://orcid.org/0009-0004-1421-869X>

Universidade Federal do Rio de Janeiro, Brazil

Email: guilherme.hasslocher@gmail.com

Gabriel Lourenço Ferreira Carvalho¹

ORCID: <https://orcid.org/0009-0005-7373-1714>

Universidade Federal do Rio de Janeiro, Brazil

Email: gabrielourencofcarvalho@gmail.com

Mathews Rocha Neri da Costa¹

ORCID: <https://orcid.org/0009-0000-1547-1452>

Universidade Federal do Rio de Janeiro, Brazil

Email: mathewsrocha1262@gmail.com

Gabriel Pereira Machado¹

ORCID: <https://orcid.org/0009-0001-6394-5779>

Universidade Federal do Rio de Janeiro, Brazil

Email: gabrielpereiramachado01@gmail.com

Mauro Felipe Felix Mediano²

ORCID: <https://orcid.org/0000-0001-6369-3631>

Instituto Nacional de Infectologia Evandro Chagas, Fundação Oswaldo Cruz, Brazil

Email: mffmediano@gmail.com

Amanda Londero-dos-Santos¹

ORCID: <https://orcid.org/0000-0003-3536-0834>

Universidade Federal do Rio de Janeiro, Brazil

Email: amandalondero@me.com

Alejandro Marcel Hasslocher-Moreno²

ORCID: <https://orcid.org/0000-0002-5430-7222>

Instituto Nacional de Infectologia Evandro Chagas, Fundação Oswaldo Cruz, Brazil

Email: alejandro.hasslocher@gmail.com

Abstract

Chagas Disease (CD) has a significant impact on the health of the Latin American population. It primarily affects low-income individuals, people with low levels of education, and residents of rural areas and poor neighborhoods of large urban centers. One-third of affected individuals may develop symptoms that interfere with their lives, reducing their ability to work and leading to discrimination. This restrictive and adverse reality can generate psycho-affective disorders that manifest in social, family, and work relationships. Studies have shown that patients with CD may exhibit psychological changes, both cognitive and related to the perception of well-being, showing an association with depression, sadness, reduced quality of life, higher stress levels, and lower resilience. The present study aims to conduct a literature review of the psychometric assessment of depression, quality of life, and subjective well-being in Brazilian patients with CD. A literature review was conducted based on a search of databases from 2005 to 2023. A total of 158 articles were identified, of which 26 were eligible for analysis. Among the studies that analyzed the psychosocial nature of CD, the majority focused on socio-anthropological issues, using interviews that emphasized socioeconomic, non-measurable, symbolic, and cultural aspects. Few studies have utilized instruments with robust psychometric properties. Advancing knowledge in the psychosocial context requires the use of rigorously validated psychometric tools for the psychological assessment of patients with CD.

Keywords: Chagas disease; Psychological assessment; Psychometric instruments; Quality of life; Depression; Subjective well-being.

¹ Departamento de Psicometria, Instituto de Psicologia, Universidade Federal do Rio de Janeiro, Rio de Janeiro, RJ, Brasil.

² Instituto Nacional de Infectologia Evandro Chagas, Fundação Oswaldo Cruz, Rio de Janeiro, RJ, Brasil.

Resumo

A Doença de Chagas (DC) tem um impacto significativo na saúde da população da América Latina. Afeta principalmente indivíduos de baixa renda, pessoas com baixo nível de escolaridade e residentes de áreas rurais e bairros pobres de grandes centros urbanos. Um terço das pessoas acometidas pode desenvolver sintomas que interferem em suas vidas, reduzindo sua capacidade laboral e levando à discriminação. Essa realidade restritiva e adversa pode gerar distúrbios psicoafetivos que se manifestam nas relações sociais, familiares e profissionais. Estudos demonstram que pacientes com DC podem apresentar alterações psicológicas, tanto cognitivas quanto relacionadas à percepção de bem-estar, mostrando associação com depressão, tristeza, redução da qualidade de vida, níveis elevados de estresse e menor resiliência. O presente estudo tem como objetivo realizar uma revisão da literatura sobre a avaliação psicométrica da depressão, qualidade de vida e bem-estar subjetivo em pacientes brasileiros com DC. A revisão foi baseada em buscas em bases de dados realizadas entre 2005 e 2023. Foram identificados 158 artigos, dos quais 26 foram considerados elegíveis para análise. Entre os estudos que abordaram a natureza psicossocial da DC, a maioria concentrou-se em questões socioantropológicas, utilizando entrevistas que enfatizam aspectos socioeconômicos, simbólicos, culturais e não mensuráveis. Poucos estudos utilizaram instrumentos com propriedades psicométricas robustas. O avanço do conhecimento no contexto psicossocial requer o uso de ferramentas psicométricas rigorosamente validadas para a avaliação psicológica de pacientes com DC.

Palavras-chave: Doença de Chagas; Avaliação psicológica; Instrumentos psicométricos; Qualidade de vida; Depressão; Bem-estar subjetivo.

Resumen

La Enfermedad de Chagas (EC) tiene un impacto significativo en la salud de la población latinoamericana. Afecta principalmente a personas de bajos ingresos, con bajo nivel educativo y residentes en zonas rurales y barrios pobres de los grandes centros urbanos. Un tercio de las personas afectadas puede desarrollar síntomas que interfieren en su vida cotidiana, reduciendo su capacidad laboral y provocando discriminación. Esta realidad restrictiva y adversa puede generar trastornos psicoafectivos que se manifiestan en las relaciones sociales, familiares y laborales. Estudios han demostrado que los pacientes con EC pueden presentar alteraciones psicológicas, tanto cognitivas como relacionadas con la percepción del bienestar, mostrando asociación con depresión, tristeza, disminución de la calidad de vida, mayores niveles de estrés y menor resiliencia. El presente estudio tiene como objetivo realizar una revisión de la literatura sobre la evaluación psicométrica de la depresión, la calidad de vida y el bienestar subjetivo en pacientes brasileños con EC. Se realizó una revisión basada en la búsqueda en bases de datos entre 2005 y 2023. Se identificaron 158 artículos, de los cuales 26 fueron considerados elegibles para el análisis. Entre los estudios que abordaron la naturaleza psicossocial de la EC, la mayoría se centró en cuestiones socioantropológicas, utilizando entrevistas que enfatizan aspectos socioeconómicos, simbólicos, culturales y no mensurables. Pocos estudios utilizaron instrumentos con propiedades psicométricas sólidas. El avance del conocimiento en el contexto psicossocial requiere el uso de herramientas psicométricas rigurosamente validadas para la evaluación psicológica de pacientes con EC.

Palabras clave: Enfermedad de Chagas; Evaluación psicológica; Instrumentos psicométricos; Calidad de vida; Depresión; Bienestar subjetivo.

1. Introduction

Chagas Disease (CD) is an infectious condition classified as a neglected disease according to the World Health Organization (WHO, 2024). CD still represents a serious public health problem in Latin America, with the disease having spread to non-endemic areas of globe (Arsuaga et al., 2024). The disease has both an acute and a chronic phase. The chronic phase occurs after the acute phase has regressed and is characterized by four well-defined clinical forms: the indeterminate form (IF), the cardiac form (CF), the digestive form (DF), and the mixed form (CF plus DF) (Dias et al., 2016). In addition to the impacts on the physical health of patients with CD, depressive symptoms, low quality of life (QoL), and negative psychological health outcomes have also been reported in the literature (Cavalcanti et al., 2019; Hueb & Loureiro, 2005). These findings may be exacerbated by the chronic nature and the stigma associated with the disease, leading to a vicious cycle of psychological suffering. In this context, the comprehensive care of patients with CD should include not only the treatment of physical symptoms but also psychological care to address the emotional impacts of the disease (Lozano Beltrán, 2021).

The main psychological factors to consider are depressive symptoms, quality of life, and well-being. Depressive symptoms have a highly disabling impact, characterized by sadness, empty, or irritable mood, accompanied by somatic and cognitive changes, affecting the individual's functional capacity (American Psychiatric Association, 2014). In Brazil, a study

found that 40.9% of patients with CD had depressive symptoms, and in Switzerland, a study conducted with Latin American patients with CD found a depression prevalence of 28.5% (Ozaki et al., 2011; Jackson et al., 2012). In another study, the majority of patients with CD presented mild depressive symptoms (Marchi & Gurgel, 2011). Moreover, low QoL may be related not only to the physical limitations imposed by the disease but also to the social context and anxiety about the future. Patients with CD have lower levels of health-related QoL, especially those with the cardiac form of the disease (B. G. Oliveira et al., 2011; Sousa et al., 2015; Trindade et al., 2024). This highlights the importance of considering medical and psychosocial factors when addressing the well-being of these patients. Subjective well-being refers to the extent to which a person believes or feels that their life is going well. It involves three components: life satisfaction, positive affect, and negative affect (Snyder et al., 2021). Subjective well-being is higher when life satisfaction is greater, more positive affect are experienced, and fewer negative affect are encountered. Studies have been conducted worldwide to investigate subjective well-being in various contexts and populations, and it is one of the main research topics in the field of positive psychology (Snyder et al., 2021). The subjective assessment of one's well-being allows for an understanding of an individual's experience of happiness, life satisfaction, and positive and negative affect. However, there is a lack of studies investigating subjective well-being in patients with CD.

These psychological variables are assessed using psychological instruments, with standardized tools offering the highest level of rigor. Currently, the Beck Depression Inventory (BDI) (Beck, 1961) is one of the psychological instruments that have been approved by the Brazilian Federal Council of Psychology for the evaluation of depression. Measurement of QoL in patients with CD can be performed using different instruments, such as the WHOQOL-BREF, SF-36, and MLWHFQ, each of which assesses distinct domains of this construct (Fleck et al., 2000; Ciconelli et al., 1999; American Thoracic Society, 2004). These instruments evaluate pre-conceived dimensions identified as important for quality of life, however, they may not capture aspects of life that are personally significant to each individual. The assessment of QoL, happiness, or well-being can be assessed globally and subjectively, meaning they do not depend on specific dimensions or objective events. In this regard, Böckerman *et al.* found that QoL measures based on pre-conceived dimensions do not fully capture the impact on subjective well-being associated with chronic diseases (Böckerman et al., 2011). The authors suggest that instruments measuring QoL and subjective well-being should be used complementarily.

Literature reviews on cognitive and psychosocial functioning in CD have shown that these impairments are associated with the disease. However, existing studies tend to focus narrowly on specific outcomes, particularly quality of life, without integrating other relevant psychological constructs such as depression and subjective well-being. Moreover, although several instruments are available to assess these constructs, there is limited systematization regarding their application to Brazilian patients with CD and the outcomes derived from their use. Given this context, the main objective of the present study is to conduct a literature review on the psychometric assessment of quality of life, depression, and subjective well-being in Brazilian patients with CD. The secondary objectives are to identify the instruments used to assess these constructs and to compile the mean scores of Brazilian patients with CD on these instruments in order to calculate a composite average score.

2. Methodology

A bibliographic review was conducted and of a qualitative and quantitative nature, and of the specific type of systematic literature review (Pereira et al., 2018) using simple descriptive statistics with data classes, values of absolute frequency in quantity and relative frequency in percentage, mean values and standard deviations (Shitsuka et al., 2014), and was conducted through a search in the databases: PubMed, Google Scholar, SciELO, Scopus, and Web of Science, covering the period from 2005 to 2023 and using the search keywords: Chagas disease, psychological evaluation, psychometric

instruments, quality of life, depression, subjective well-being. We excluded literature review articles, those that did not use instruments to measure psychological variables, those without a description of the results of the instruments used to measure psychological variables, or those that did not assess the Brazilian population. These criteria were applied by four independent reviewers who read the article abstracts and, when necessary, the full text. After applying the exclusion criteria, the selected studies were fully read and characterized based on the authors, year of publication, main study objective, sample size, detailed sample description, psychological instruments employed, constructs evaluated, and study results. To enhance the critical understanding of the results presented in the articles, effect sizes were manually calculated and reported when possible, using Cohen's *d* and Cohen's *f* coefficients.

3. Results

A total of 158 articles were found, of which 26 were selected after applying the exclusion criteria (Figure 1). The articles used the following instruments to measure quality of life: WHO Quality of Life Questionnaire (WHOQOL-BREF) (Fleck et al., 2000), generic SF-36 Quality of Life Questionnaire (SF-36) (Ciconelli et al., 1999), Minnesota Living with Heart Failure Questionnaire (MLWHFQ) (American Thoracic Society, 2004), EuroQol 5 Dimensions, 3 Levels (EQ-5D-3L) (Bagattini et al., 2018), WHO Disability Assessment Schedule (WHODAS-12) (Tavares et al., 2023), and Assessment of Quality of life And RElated events (AQUAREL) (B. G. Oliveira et al., 2006). To measure depression, the instruments used were Beck Depression Inventory (BDI) (Beck, 1961) and Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). No studies were found that measured subjective well-being in patients with CD. To facilitate a clearer understanding of the psychometric quality of the instruments used, Table 1 summarizes the psychometric properties reported in the original adaptation studies cited by the articles included in this review.

3.1 Quality of Life in Patients with Chagas Disease

3.1.1 WHO Quality of Life Questionnaire - WHOQOL-BREF

In the current review, six articles used WHOQOL-BREF. The mean scores for patients with CD for each of the WHOQOL-BREF factors are reported in Table 2.

Hueb *et al.*, in a sample of 80 individuals, including 40 seropositive and 40 seronegative for CD, found no significant differences in means between the two groups for any dimensions of the WHOQOL-BREF using a *t*-test. Effect sizes (Cohen's *d*) were estimated from the available data and found to be approximately .24 (Physical), .29 (Psychological), .09 (Social Relationships), and .03 (Environment), indicating small to negligible effects across dimensions. However, significant differences were found in some criterion questions of the Physical and Psychological dimensions (Hueb & Loureiro, 2006).

Ozaki *et al.* evaluated differences in WHOQOL-BREF dimensions according to the clinical form in a sample of 110 patients with CD. The authors found that, for the mean scores in the physical dimension of quality of life, patients with CD in the indeterminate (I) form had higher scores compared to those in the cardiac (C), digestive (D), and mixed (M) forms. No statistically significant differences were observed among the C, D, and M forms in the physical domain, and effect size estimates (Cohen's *f*) indicated small to negligible differences between these groups (C vs. D: $f = .15$; C vs. M: $f < .01$; D vs. M: $f = .12$). The authors also found that, in the psychological dimension, no significant differences were observed among the clinical forms, and effect size estimates indicated small to negligible differences between the groups: overall $f = .17$; C vs. D: $f = .02$; C vs. I: $f = .15$; C vs. M: $f = .05$; D vs. I: $f = .13$; D vs. M: $f = .06$; I vs. M: $f = .06$. For the social relationships dimension, patients with the I form had higher mean scores than those with the C, D, and M forms. No statistically significant differences were identified among the latter three forms with effect size estimates indicating small to negligible differences

between these groups: C vs. D: $f < .01$; C vs. M: $f = .06$; D vs. M: $f = .06$. In the environment dimension, similar to the psychological dimension, there were no significant differences in mean scores among any of the clinical forms. Effect size estimates were negligible across comparisons: overall $f = 0.02$; C vs. D: $f = 0.01$; C vs. I: $f < .01$; C vs. M: $f < .01$; D vs. I: $f < .01$; D vs. M: $f = .02$; I vs. M: $f = .01$ (Ozaki et al., 2011).

Souza *et al.*, in a sample of 21 patients with CD who had previously experienced a stroke, performed Pearson correlations between the severity of disability caused by the stroke and the WHOQOL-BREF domains. No statistically significant correlation was found between these variables. However, the BDI score was significantly correlated with all dimensions of the WHOQOL-BREF: Psychological: $r = -.73$, $p = .001$; Physical: $r = -.58$, $p = .012$; Environmental: $r = -.71$, $p = .001$; Social Relationships: $r = -.66$, $p = .003$ (Souza et al., 2013).

Santos-Filho *et al.*, in a study involving 361 patients with CD, conducted an exploratory regression analysis using the dimensions of the WHOQOL-BREF as dependent variables and several sociodemographic, clinical, and lifestyle measures as independent variables. The variables that were independently associated with each QoL domains were as follows: Physical Domain- female sex, functional classes II, III, and IV (classified according to the New York Heart Association [NYHA] criteria (New York Heart Association, 1994)), and a sleep duration fewer than seven hours were a predictor of lower QoL scores, while moderate and high levels of physical activity, and >12 years of schooling were predictors of higher QoL scores; Psychological Domain - female sex and functional classes II, III, and IV were predictors of lower QoL scores; Social Relationships Domain - only the cardiac form of the disease without heart failure showed a significant association with lower QoL scores; Environmental Domain - the cardiac-digestive form with heart failure, current smoking, functional classes II, III, and IV, and sleep duration of less than 7 hours were negatively associated with QoL scores, while residents by domicile and per capita income were predictors of higher QoL scores. Finally, in the overall QoL domain, female sex and functional classes II, III, and IV were associated with lower scores (Santos-Filho et al., 2018).

Quintino *et al.* and Oliveira *et al.*, the same study published in two different manuscripts, using the same sample, with one being an update but without new data regarding quality of life, performed a regression analysis in a sample of 625 individuals with CD to evaluate the dimensions of the WHOQOL-BREF as the dependent variables and sociodemographic characteristics as independent variables. The Odds Ratio (OR) and confidence level for each sociodemographic predictor were reported. The results were: age was a predictor for the Physical (OR = .96; $p < .05$) and Environmental (OR = .95; $p < .05$) dimensions; widowed marital status (compared to married) was a predictor for the Physical dimension (OR = .81; $p < .05$); and female gender was a predictor for the Social Relationships dimension (OR = 1.10; $p < .05$). Additionally, differences in the WHOQOL-BREF domains were tested between groups of patients with CD across all clinical forms and patients with non-Chagas cardiomyopathy. No statistically significant differences were found between the groups regarding the mean scores in the WHOQOL-BREF dimensions (Quintino et al., 2020; C. D. L. Oliveira et al., 2021).

3.1.2 Generic SF-36 Quality of Life Questionnaire – SF-36

Eight articles included in this review used SF-36 generic quality of life questionnaire. The mean scores for patients with CD for the reported dimensions of the SF-36 are detailed in Table 3.

Oliveira *et al.*, in a study that included 77 patients with CD and 31 without CD, all of whom had pacemakers, found through a Student's t-test that there were no significant differences in SF-36 scores between the two groups. They found statistically significant differences between the groups in the dimensions of Physical Functioning ($p = .011$) and Limitation Due to Emotional Problems ($p = .02$) on the SF-36. In both dimensions, the scores were higher in the healthy control group (B. G. Oliveira et al., 2008).

Oliveira *et al.* demonstrated that patients with CD compared to those without the condition exhibited worse physical functioning ($p = .011$) and role-emotional ($p = .020$). Additionally, the physical score was lower in the group of patients with CD, although not significant ($p = .078$). Worse physical functioning was also associated with low education levels (OR = 16.82), cardiovascular symptoms (OR = 4.12), and worse functional classification (OR = 8.02). Women presented a worse mental component (OR = 9.43) (B. G. Oliveira et al., 2011).

Pelegrino *et al.* in an observational study with 43 patients with the cardiac form of CD and 59 with non-Chagas cardiomyopathy, found that patients with Chagas cardiomyopathy had lower health-related quality of life compared to the non-CD group in the dimensions of Physical Functioning ($p = .01$) and Physical Limitations ($p = .002$) (Pelegrino et al., 2011).

Cardoso *et al.* (Cardoso et al., 2014), in a study including 56 patients with CD who had pacemakers, identified an average SF-36 score of 63.72 ± 17.97 . Linear regression analyses revealed that a higher body mass index was significantly associated with worse QoL ($\beta = -1.08$; 95% CI: -1.99 a -.18; $p = .019$) (Pelegrino et al., 2011).

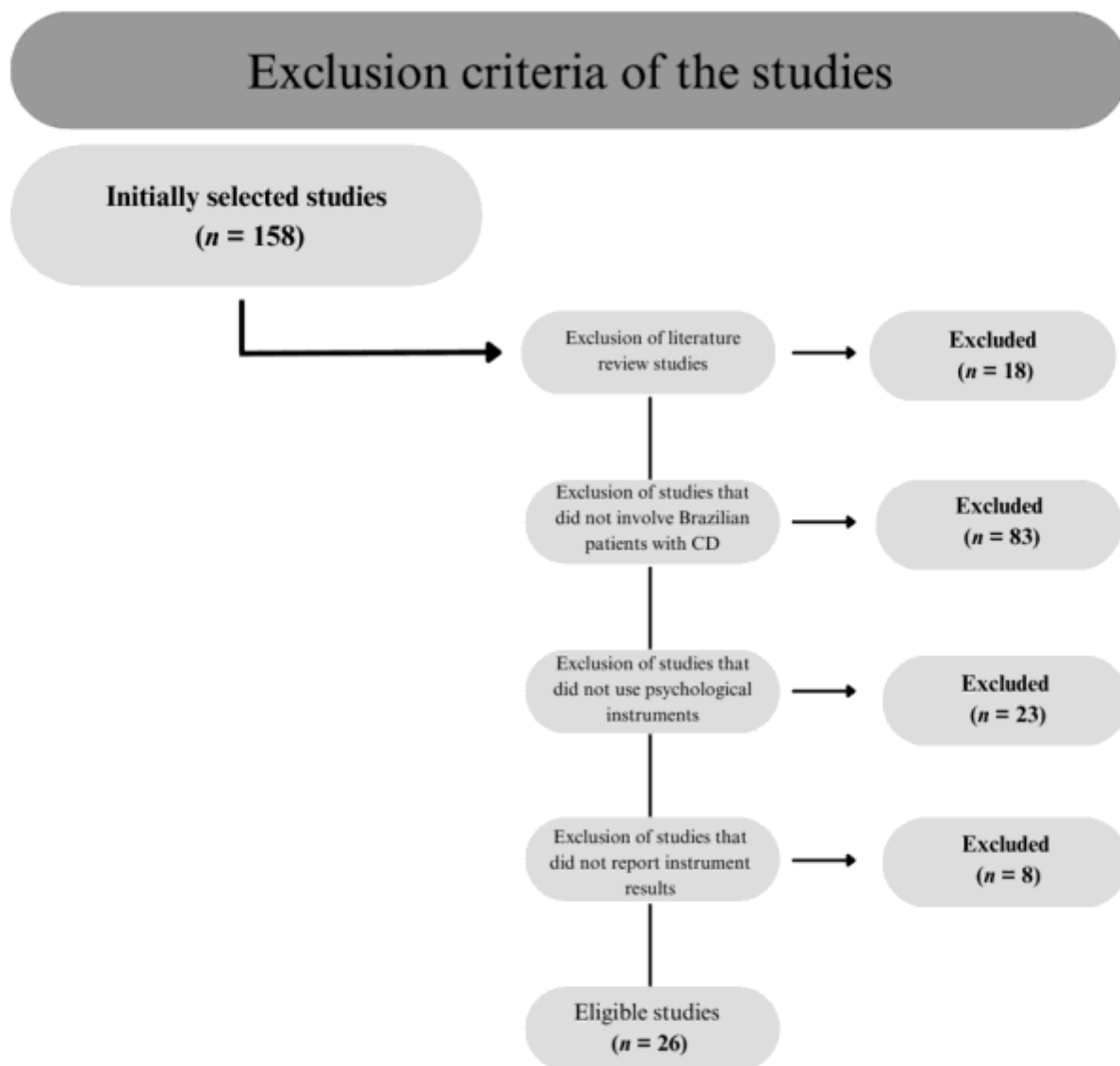
Costa *et al.*, in a longitudinal study with 75 patients with CD, of whom 20 had cardiovascular events, observed that patients with events had lower scores on the SF-36 in the dimensions of General Health ($p = .047$) and Social Functioning ($p = .026$) compared to the group without events (Costa et al., 2019).

Chambela *et al.* evaluated the impact of pharmaceutical care on the quality of life of patients with heart failure due to CD and compared the results with a control group (without pharmaceutical care) over 12 months of follow-up. Improvements in physical function and vitality were more pronounced in the intervention group than in the control group at six- and 12-months follow-up. Role physical function and social functioning also improved more in the intervention group than in the control group at six and 12 months. Mental health showed a significant improvement in the intervention group compared to the control group at six, nine, and 12 months of follow-up. General health consistently improved in the intervention group at all measurement points. There were no significant differences in the domains of bodily pain and emotional function during the follow-up period (M. D. C. Chambela et al., 2020).

Siva *et al.* in a cross-sectional study evaluated 35 clinically stable patients with Chagas cardiomyopathy and preserved cardiac function to investigate factors associated with depressive symptoms. QoL was assessed using the SF-36 questionnaire. Results showed that patients with depression (37% of the sample) had significantly lower scores in the SF-36 mental health component compared to non-depressed patients (mean mental summary score: 31 vs. 58; $p < .001$). Effect sizes (Cohen's d), estimated from the available data, were approximately 2.19, indicating a large effect size between groups for this SF-36 dimension. In multivariate analysis, only the SF-36 mental component and physical activity level (HAP score) remained independent predictors of depressive symptoms (adjusted $R^2 = .66$). These findings highlight the strong association between impaired mental health-related quality of life and depression in patients with Chagas cardiomyopathy (W. T. Silva et al., 2020).

Avila *et al.* show that patients with systolic dysfunction had lower scores in the physical domains of the SF-36, suggesting a poorer quality of life in terms of physical functioning, physical performance, and general health perception. The physical summary of the SF-36 proved more effective in identifying systolic dysfunction than the mental summary. The AUC = .73, indicating moderate capacity to discriminate patients with systolic dysfunction. The mental summary performed worse (AUC = .62), suggesting that mental health, as assessed by the SF-36, has less impact or a weaker direct relationship with systolic dysfunction compared to physical components. The authors explore cutoff points for the physical and mental summaries of the SF-36, analyzing the best combination of sensitivity and specificity to identify patients with systolic dysfunction. Also, the SF-36 was used not only as a measure of quality of life but also as a screening tool to predict the presence of cardiac dysfunction, highlighting its role beyond a purely subjective assessment (Ávila et al., 2021).

Figure 1 - Flow chart of studies.



Source: Authors.

3.1.3 Minnesota Living with Heart Failure Questionnaire - MLWHFQ

Seven articles used MLWHFQ. The reported Means of MLWHFQ. Total Score is in Table 4.

Villas-Boas *et al.* evaluating the quality of life of patients with CD, demonstrated a significant improvement in the global score in the first month after the stem cell implantation procedure. This improvement was sustained during the two months of follow-up. In addition, functional capacity, as assessed by the six-minute walk test (6MWT), showed a significant increase in the distance walked, with sustained improvement throughout the follow-up period. The NYHA functional class showed a reduction, indicating an improvement in the clinical condition of patients. The left ventricular ejection fraction, which was initially severely depressed, showed a significant recovery after one month, remaining stable in the second month. These results suggest that the procedure contributed to the improvement in quality of life, Physical Functioning and ventricular function, despite the severity of the clinical condition of patients (Vilas-Boas *et al.*, 2006).

Oliveira *et al.*, in a study with 125 patients with CD and 21 without CD, found that patients with CD had significantly

higher scores on the MLWHFQ, indicating poorer quality of life compared to the patients without CD. These results suggest that the presence of CD is associated with a negative impact on the quality of life perceived by patients, as assessed by this specific instrument (B. G. Oliveira et al., 2011).

Ritt *et al.*, in a study with 55 patients with CD and heart failure, observed significant correlations between better quality of life and higher peak oxygen consumption (VO₂) values during the cardiopulmonary exercise test ($r = -.301$, $p = .02$) and greater distance covered in the 6MWT ($r = -.375$, $p = .007$). However, the only variable independently associated with a better MLWHFQ score was the greater distance covered in the 6MWT. This suggests that among patients with heart failure due to CD, Physical Functioning measured by the 6MWT test may be an important predictor of perceived quality of life (Ritt et al., 2013).

Paz *et al.*, analyzing 101 patients with heart failure, 23 with CD, identified moderate quality of life (QoL) (34.3 ± 21.6) in this group. Elderly patients (>60 years) reported worse QoL (27.0 ± 20.4) compared to younger patients (42.3 ± 20.2 ; $p < .001$). Economically active patients demonstrated better physical and total scores ($p = .01$). QoL was worse in patients with functional class (FC) III (57.0 ± 17.4) compared to FC I (18.6 ± 14.2 ; $p < .001$). Participants with Chagas heart failure showed significantly lower mean scores in emotional perceptions ($p = .015$) and overall quality of life ($p = .021$), with corresponding Cohen's d effect sizes of .12 and .51, respectively, calculated using the data available in the article (Paz et al., 2019).

Spadaro *et al.*, in a prospective study, evaluated the safety and feasibility of renal denervation in patients with advanced Chagas cardiomyopathy. The sample consisted of 17 patients with left ventricular ejection fraction (LVEF) <40%, randomized into two groups: 11 in the renal denervation group and six in the conservative control group. The intervention was performed by ablation of renal arteries, and the follow-up was nine months. The results indicated that, after the follow-up period, using the MLWHFQ questionnaire, there was no significant difference between the renal denervation group (nine patients) and the control group (four patients), suggesting that the intervention had no relevant impact on the patients' QoL, however, using the data available in the article to calculate Cohen's d yielded a value of .59, indicating a moderate effect size and higher scores in the control treatment group (Spadaro et al., 2019).

Chambela *et al.*, in a study with 40 patients with CD and heart failure, found a negative correlation ($r = -.54$; $p = .002$) between MLHFQ scores and the 6MWT. This indicates that a greater ability to perform the 6MWT test was associated with a lower perception of impairment in cardiovascular health-related quality of life (M. C. Chambela et al., 2017).

Silva *et al.*, in a longitudinal study, followed 108 patients with heart failure (HF) over four assessments, with the aim of analyzing health-related quality of life (HRQoL). Participants had a mean age of 66.62 years, with a predominance of Chagas heart disease and comorbidities such as hypertension and arrhythmias. The results showed improvement in QoL over time, especially between assessments T2 and T3. Statistical analysis indicated that the mean score was 38.2 at T1, 33.6 at T2, 27.8 at T3, and 22.5 at T4, with a significant reduction in HRQoL scores ($p < .01$). The Physical Functioning of patients improved with follow-up, especially for those in the most severe functional classes (NYHA III and IV), with a significant association between functional class and HRQoL results ($p < .05$). These findings suggest that continued monitoring may lead to improvements in quality of life for patients with heart failure, especially for those in more severe conditions (P. C. Silva et al., 2021).

Table 1 - Summary of Psychometric Properties Reported in Adaptation Studies of Psychological and Health-Related Instruments.

Instruments	Reliability coefficients	Evidence based on				Study sample size
		Internal structure	Test content	Relations to other variables		
				Test-criterion relationships	Convergent evidence	
WHOQOL-BREEF	X			X	X	300
SF-36	X			X	X	50
MLHQF	X			X		40
EQ-5D-3L	X					9148
WHODAS-12	X	X				695
AQUAREL	X					139
BDI	X	X	X	X	X	4395
HADS	X				X	78

Source: Authors.

3.1.4 EuroQol 5 Dimensions, 3 Levels - EQ-5D-3L

Two articles used EQ-5D-3L.

Almeida Lins *et al.* evaluated health-related quality of life (HRQoL) and revealed that the domains with the highest frequency of reported problems were "pain/discomfort" and "anxiety/depression," both at 31.7%. The analysis of the relationship between physical performance and HRQoL showed that most patients with moderate and high performance in the 30-Second Chair Stand Test (30sCST) and Timed Up and Go Test (TUGT) tests did not report problems in the domains of "mobility," "usual activities," and "pain/discomfort." The EQ-5D-3L utility index and Visual Analog Scale (VAS) score improved with higher performance levels ($p = .001$ and $p = .023$ for 30sCST; $p < .001$ and $p = .032$ for TUGT). The study was conducted with 63 consecutive adult patients with CD seen at an outpatient clinic, and clinical data were obtained through medical records and interviews (Almeida Lins *et al.*, 2021).

Pavão *et al.* evaluated 68 symptomatic patients with Chagas cardiomyopathy before and after treatment with aspirin and verapamil. The results showed a significant improvement in EQ-5D scores, which increased from .63 to .77 ($p < .001$). Additionally, the EuroQol Visual Analog Scale also improved by 28.6% ($p < .001$). These improvements indicate a positive

impact of the treatment on the health-related quality of life of patients with CD (Pavão et al., 2021).

Table 2 - Mean Scores for Dimensions and Global Score of the WHOQOL-BREF.

Author (year)	<i>N</i>	Physical (<i>SD</i>)	Psychological (<i>SD</i>)	Social Relationships (<i>SD</i>)	Environment (<i>SD</i>)
Hueb (2006)	40	61.00 (18.19)	58.94 (15.38)	67.75 (19.75)	57.69 (13.12)
Ozaki (2011)**	56	60.08 (14.16)	60.08 (14.49)	65.63 (12.72)	53.35 (9.46)
Ozaki (2011)**	54	57.87 (14.92)	61.19 (13.78)	63.27 (14.07)	53.13 (14.07)
Souza (2013)	21	58.99 (14.51)	61.25 (14.08)	64.47 (13.39)	53.24 (10.52)
Santos-Filho (2018)	361	59.5 (17.2)	66.5 (15.4)	68.9 (14.8)	57.2 (13.6)
Quintino (2020)* Oliveira (2021)*	625	57.84 (15.32)	65.98 (12.85)	73.17 (13.99)	57.66 (12.26)
Combined Mean	1157	58.60 (15.98)	65.30 (14.09)	70.67 (14.73)	57.02 (12.74)

Source: Authors.

3.1.5 WHO Disability Assessment Schedule 2.0 - WHODAS-12

One article used WHODAS-12. Tavares *et al.*, in a cross-cultural adaptation of their test for the specific population of patients with CD, reported the following means: Mobility, Activities of Daily Living, Participation, and Cognition Factor: 5.20 (SD = 5.37); Interpersonal Relationships and Cognition Factor: 2.05 (SD = 2.49); Self-Care Ability Factor: 0.44 (SD = 1.19); Total Score: 16.05 (SD = 16.47) (Tavares et al., 2023).

3.1.6 Assessment of Quality of life And RELated events - AQUAREL

One article used AQUAREL. Oliveira *et al.* studied 139 patients with a mean age of 59 ± 14 years (60% women). The majority were illiterate (33%) and retired (71%). CD was diagnosed in 72% of the patients. The AQUAREL revealed lower QoL scores in patients with CD in the domains of chest discomfort and arrhythmia, which were not detected by the SF-

36. Multivariate analyses indicated that functional class was the main determinant of QoL in almost all AQUAREL domains. Female patients and those without a partner had lower scores in the arrhythmia domain (B. G. Oliveira et al., 2008).

Table 3 - Reported values of the generic SF-36 dimensions quality of life questionnaire

Author (year)	N	Physical functioning	Role physical	Bodily pain	General health	Vitality	Social functioning	Role emotional	Mental Health	Physical Components	Mental Components	Total Average
Oliveira (2008)	77	=	=	=	=	=	=	=	=	45 (34-52)	45 (34-52)	=
Oliveira (2011)	125	85 (65-95)	100 (50-100)	62 (42-96)	67 (50-82)	75 (55-85)	88 (63-100)	100 (33-100)	76 (60-88)	48 (38-54)	53 (43-58)	-
Pelegrino (2011)	43	50.1 (25.7)	23.2 (36.7)	58.6 (30.2)	55.2 (19.8)	57.7 (24.0)	64.8 (25.0)	37.2 (43.1)	64.7 (23.2)	=	=	=
Cardoso (2014)	56	-	-	-	-	-	-	-	-	-	-	63.72 (17.97)
Costa (2019)	75	75 (60-90)	75 (50-100)	62 (51-100)	55 (43-72)	65 (50-75)	87 (62-100)	100 (33-100)	64 (48-82)	47 (41-53)	44 (31-56)	=
Silva (2020)	35	=	=	=	=	=	=	=	=	48 (10.19)	48 (18.92)	=
Chambela (2020)	81	46.9 (27.5)	45.9 (44.1)	63.8 (34.0)	56.8 (25.1)	55.6 (26.8)	75.9 (29.2)	63.0 (45.0)	65.1 (24.7)	=	=	=
Avila (2021)	75	72 (67-77)	58 (51-65)	67 (61-65)	57 (53-62)	63 (59-68)	76 (70-82)	68 (60-77)	64 (59-70)	46 (44-49)	42 (38-46)	=

Source: Authors.

3.2 Quality of Life in Patients with Chagas Disease

3.2.1 Beck Depression Inventory - BDI

Four studies that used the BDI were identified in this review. Total Score is in Table 5.

Ozaki *et al.*, in a sample of 110 patients with CD, analyzes differences in BDI scores based on gender and clinical forms of the disease. For gender differences, men (n = 54; BDI: M = 12.15, SD = 9.66) and women (n = 56; BDI: M = 11.61, SD = 7.79) were compared using the Mann-Whitney test, which showed no statistical difference (p = .8601). For clinical forms of CD, a rank variance analysis revealed significantly higher scores in the digestive form (n = 14; BDI: M = 17.5, SD = 12.31) compared to the indeterminate form (n = 29; BDI: M = 8.07, SD = 5.04, p = .0219). The cardiac (n = 54; BDI: M = 12.5, SD = 8.92) and mixed forms (n = 13; BDI: M = 11.69, SD = 6.50) did not show any significant differences when compared to each other or to the other clinical forms. The authors, using Pearson correlation coefficients, revealed significant correlations between BDI scores and the dimensions of the WHOQOL-BREF: physical domain: (r = -.55, p < .01), psychological domain (-.70, p < .001), social relations domain (r = -.051, p < .01) and environment domain (r = -.32, p < .01) (Ozaki et al., 2011).

Souza *et al.*, in a sample of 21 patients with CD and a history of stroke, the average BDI score was 11.61 (SD = 7.79). Significant correlations were found between BDI scores and WHOQOL-BREF dimensions: physical Domain (r = -.73, p <

.01), psychological Domain (-0.58 , $p < .01$), social relationships domain ($r = -0.65$, $p < .03$) and environment domain ($r = -0.71$, $p < .01$) (Souza et al., 2013).

Cirelli *et al.* reported depression levels with a mean of 10.87 ± 8.75 (range: 0 to 44). Additionally, the authors found a significant positive correlation between BDI scores and stress ($r = .49$) as well as anxiety ($r = .63$). No significant difference was found in depression levels between women ($M = 11.85$) and men ($M = 10.28$, $p = .324$). Concerning ethnicity, individuals of African descent ($M = 11.03$) and mixed-race individuals ($M = 10.97$) had higher depression levels compared to white individuals ($M = 10.91$) and others ($M = 8.55$). Addressing religious aspects, Evangelicals ($M = 11.79$) and individuals of other religions ($M = 11.50$) showed higher depression levels than Catholics (10.33) and Spiritists (9.87). Regarding housing, individuals living in borrowed housing ($M = 14.67$) or rented homes ($M = 12.80$) exhibited higher depression levels than those living in their own homes ($M = 9.74$). Additionally, those with an income below one minimum wage had higher depression levels ($M = 13.80$) compared to those earning 1 to 3 minimum wages or more ($M = 11.58$). Evaluating the association with functional class, individuals in Functional Class II had significantly higher depression levels ($M = 12.67$) compared to Functional Class I ($M = 9.47$). Individuals with CD had higher mean depression levels ($M = 13.91$) compared to those without the disease ($M = 10.36$), while patients with Chagas cardiomyopathy ($M = 13.82$) exhibited higher depression levels than those with other forms of cardiomyopathy (Cirelli et al., 2018).

Siva *et al.* study investigated depressive symptoms in 35 clinically stable patients with Chagas cardiomyopathy and preserved cardiac function. Depressive symptoms were assessed using the Beck Depression Inventory (BDI), with a mean score of 9 (95% CI: 6–12), and a prevalence of depression observed in 37% of participants. Among these, 62% had mild-to-moderate and 38% had moderate-to-severe depression. In univariate analysis, several variables were associated with BDI scores, but in the multivariate model, only physical activity level (HAP score) and mental health (SF-36 mental component) remained independent predictors (adjusted $R^2=0.66$). These findings suggest that both reduced mental health-related quality of life and lower physical activity are strongly associated with depressive symptom severity in patients with Chagas cardiomyopathy (W. T. Silva et al., 2020).

3.2.2 Hospital Anxiety and Depression Scale - HADS

One article used HADS.

Dessotte *et al.*, in a sample of 104 patients with CD and 140 without CD, all with pacemakers or defibrillators, found that the mean scores on the anxiety and depression subscales for patients with CD were 6.3 ($SD = 4.1$) and 5.6 ($SD = 3.7$), respectively. Using the Student's t-test to calculate the mean differences between the groups, no statistically significant differences were found in the HADS subscales between the two groups. Using the data available in the article, Cohen's d effect sizes were also calculated and yielded $d = .05$ for the anxiety subscale and $d = .10$ for the depression subscale, indicating small to negligible effect sizes in both dimensions (Dessotte et al., 2022).

Table 4 - Reported Means of Minnesota Living with Heart Failure Questionnaire (MLWHFQ) Total Score.

Author (year)	<i>N</i>	Total Score (SD)
Villas-Boas (2006)*	28	50.9 (11.7)
Oliveira (2011)	125	5 (0 – 14)
Ritt (2013)	55	38 (18)
Paz (2019)	101	34.3 (21.6)
Spadaro** (2019)	9	37.4 (17.4)
Spadaro** (2019)	4	49.3 (22.1)
Chambela (2020)	81	32.1 (21.3)
Silva (2021)	122	50.98 (15.52)

Source: Authors.

Table 5 - Reported Values of Beck Depression Inventory (BDI).

Author (year)	<i>N</i>	BDI Score (<i>SD</i>)
Ozaki (2011)	110	11.88 (8.72)
Souza (2013)	21	11.61 (7.79)
Cirelli (2018)	309	10.87 (8.75)
Silva (2020)	35	9.00 (8.74)
Combined Mean	440	11.16 (8.71)

Source: Authors.

4. Discussion

This study aimed to review the literature on the psychometric assessment of quality of life, depression, and subjective well-being in Brazilian individuals with CD. It also sought to identify the measurement instruments used and to summarize the mean scores reported, with the goal of estimating composite averages. A systematic search was conducted across PubMed, Google Scholar, SciELO, Scopus, and Web of Science for studies published between 2005 and 2023. Tables were developed to compile the reported mean scores and standard deviations for each construct. Out of 158 articles identified, 26 met the inclusion criteria. Quality of life was most commonly assessed using instruments such as WHOQOL-BREF, SF-36, MLWHFQ, EQ-5D-3L, WHODAS-12, and AQUAREL. Depression was evaluated using the BDI and HADS. No studies assessing subjective well-being in CD patients were identified.

This broader overview of the psychometric properties of the instruments used reveals several critical insights. Most studies reported internal consistency, typically via reliability coefficients such as Cronbach's alpha. However, fewer provided evidence of validity based on internal structure, content, or relationships with other variables, key elements for supporting the interpretability of test scores. Among the instruments reviewed, the BDI and WHOQOL-BREF stood out for demonstrating more robust psychometric evidence, including multiple forms of validity and relatively large sample sizes. In contrast, instruments such as the EQ-5D-3L and AQUAREL exhibited limited reporting of psychometric properties in the adaptation studies analyzed.

Notably, the WHODAS-12 was the only instrument identified as having undergone formal adaptation specifically with individuals diagnosed with CD. This finding highlights a significant gap in the literature, given the continued use of these instruments to assess QoL and other psychological constructs in this population. Moreover, the lack of evidence based on internal structure across most studies is particularly concerning, as it is one of the most fundamental procedures for assessing the internal structure of a scale (Brown, 2015). The overreliance on reliability coefficients, while important, may reflect an incomplete evaluation of measurement quality, as precision alone does not confirm that the instrument is measuring the intended construct. Additionally, content validity, often assessed through expert judgment and back-translation during cross-cultural adaptation, was largely underreported, despite being a critical step in ensuring conceptual equivalence between source and target versions (Borsa et al., 2012). Finally, sample sizes in most studies were relatively small, limiting the generalizability and representativeness of findings.

This analysis highlights the importance of assessing QoL in patients with CD. The use of these instruments reveals limited evidence to definitively establish differences in QoL between CD patients and healthy individuals. However, comparisons among different clinical forms of the disease show higher levels of depression and poorer QoL in patients with cardiac and digestive forms (Ozaki et al., 2011; Souza et al., 2013; Pelegrino et al., 2011). Additionally, low QoL in CD patients has been identified as a predictor of negative health outcomes (Costa et al., 2019). However, due to the lack of studies investigating the psychometric properties of these instruments in patients with CD, the observed differences may not reflect true differences in the constructs being assessed. In the absence of validation studies in this population, there is no evidence to support the interpretation of test scores among patients with CD.

It is also important to note that the comparisons made between clinical and control groups in the included studies were primarily based on p-values, without reporting effect size measures. This represents a potential bias, as statistical significance is strongly influenced by sample size. Large samples tend to produce small p-values, regardless of the magnitude of the effect (Nuzzo, 2014). To address this limitation, effect sizes were manually calculated using the means, standard deviations, and sample sizes reported in the studies. Notably, there were cases where no statistically significant differences were found, the

calculated effect sizes indicated considerable effects (Hueb & Loureiro, 2006; Spadaro et al., 2019), suggesting that relevant differences between groups may have been overlooked due to the sole reliance on p-values.

Moreover, for assessing depression, the BDI is highly recommended due to its robust validity evidence and the greater number of studies utilizing it compared to the HADS. This makes the BDI a more reliable normative tool for patients with CD. However, it's important to note that the studies reviewed in this analysis used an older version of the BDI, as the review includes articles published up to 2005. The BDI-II, with its more recent validity and standardization data, is now a more current and recommended option (Beck et al., 2011).

There is a notable lack of tools for measuring subjective well-being in patients with CD. This gap in the literature highlights a significant area for further research and raises the need for studies in this field. In Positive Psychology, a branch of psychology focusing on individual strengths and positive traits rather than solely on negative emotions and suffering, the concept of subjective well-being is crucial (Giacomoni, 2004). The absence of subjective well-being measures in the quantitative analysis of QoL in the reviewed studies underscores an important gap. Measuring subjective well-being would not only provide essential insights into the psychological QoL of patients but also utilize instruments that demonstrate exceptional psychometric properties (Hutz et al., 2011; Zanon & Hutz, 2011).

It is also crucial to consider adaptations in the administration of instruments, not only in self-report formats but also through structured interviews. This consideration is necessary due to the low educational level observed in patients with CD (Hasslocher-Moreno et al., 2021). Although many studies do not explicitly address this, there are clear limitations in data collection because many instruments were initially designed for self-administration. While assisted reading of patients can mitigate this issue, the absence of adequate research on response variability raises concerns about the validity of this approach. Therefore, it is essential to conduct more in-depth investigations into the relationships between psychological variables and physical health in patients with CD, as these insights could significantly enhance our understanding of the disease and its impact on patient well-being.

5. Conclusion

This study is pivotal for advancing the understanding of QoL assessment and other psychological aspects in patients with CD, as it emphasizes not only the outcomes reported in the literature but also the psychometric evidence supporting the instruments used. It would be unwise to interpret such data without first stepping back to question whether the tools used to collect these data are adequately calibrated for this population. The widespread neglect of psychometric properties in many frequently used instruments is concerning. Unlike broader reviews that focus on reinterpreting findings, this review prioritizes the how over the what, placing methodological rigor at the forefront. Additionally, the compilation and organization of mean scores and standard deviations from the scales used across studies has resulted in the creation of a reference database for clinical comparisons. Given that the validation studies of these instruments rarely include CD populations, such normative references are fundamental. They offer a more appropriate benchmark for future analyses involving CD patients than relying on the original normative data from clinical or general populations unrelated to this specific context.

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