



## ORIGINALES

### Quality of life of patients with Crohn's disease

Qualidade de vida de pacientes com doença de Crohn

Calidad de vida de pacientes con enfermedad de Crohn

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#### ABSTRACT:

**Objective:** To assess the quality of life of Crohn's disease patients treated at the clinic of the University Hospital from Piauí.

**Methods:** Exploratory and cross-sectional study in the University Hospital of Piauí - Brazil, from July to December 2015, with a sample of 52 Crohn's disease patients. A form was applied to characterize the sociodemographic and clinical profile, and the instrument "Inflammatory Bowel Disease Questionnaire" was used to assess the quality of life.

**Results:** Most participants were females, adults, self-declared brown-skinned, married, with family income of two minimum wages, with high school education and non-smokers and alcohol drinkers. Diagnostic time was longer than five years, and patients are partly in remission of the disease. Few patients had marked weight loss, diarrhea and abdominal pain in the last three months. Patients had been hospitalized due to Crohn's disease, a quarter of them had undergone surgical resection of the bowel and had had complications such as fistulas, more often. As drug treatment, association of immunomodulators and aziotioprina was used. Most had performed laboratory tests for control, followed by colonoscopy and they had never abandoned treatment. Patients presented regular quality of life and the response "never" was the most scored in the instrument. Quality of life was regular in the domains of systemic symptoms, emotional and social aspects, and in the intestinal symptoms, it was satisfactory with an average 56.15.

**Conclusion:** Patients with Crohn's disease have a regular quality of life.

**Key words:** Quality of life; Crohn's disease; Nursing

#### RESUMO:

**Objetivo:** Avaliar a qualidade de vida dos pacientes com doença de Crohn atendidos no ambulatório de um Hospital Universitário.

**Método:** Estudo descritivo-exploratório transversal em Hospital Universitário do Piauí- Brasil, de Julho a Dezembro de 2015, e amostra de 52 pacientes com Doença de Crohn. Aplicou-se formulário para caracterização sociodemográfica e clínica, e o instrumento "*Inflammatory Bowel Disease Questionnaire*" para avaliar a qualidade de vida.

**Resultados:** A maioria sexo feminino, adultos, autodeclarados pardos, casados, com renda familiar de dois salários mínimos (392 euros), ensino médio completo e não ingerem bebidas alcoólicas nem fumam. Apresentaram tempo de diagnóstico maior que cinco anos e estão parcialmente em remissão da doença. Não apresentaram acentuada frequência de perda de peso, diarreia e dores abdominais nos últimos três meses. Os pacientes tiveram internação hospitalar devido à doença de Crohn, um quarto deles realizaram ressecção cirúrgica do intestino e como complicações as fístulas tiveram mais presentes. Como tratamento medicamentoso, utilizam associação de imunomoduladores e azatioprina. A maioria realizou exames laboratoriais para controle, seguida de colonoscopia e nunca abandonaram o tratamento. Apresentaram qualidade de vida regular e tiveram a resposta "Nunca" como a mais pontuada no instrumento. Nos domínios dos sintomas sistêmicos, aspectos sociais e emocionais a qualidade de vida foi regular, e nos sintomas intestinais foi satisfatória com média 56,15.

**Conclusão:** Os pacientes com doença de Crohn apresentam qualidade de vida regular.

**Palavras Chaves:** Qualidade de Vida; Doença de Crohn; Enfermagem

## RESUMEN:

**Objetivo:** Evaluar la calidad de vida de los pacientes con enfermedad de Crohn tratados en la clínica de un Hospital Universitario.

**Método:** Estudio transversal, descriptivo, exploratorio en el Hospital Universitario del Piauí- Brasil, de julio a diciembre de 2015, y con una muestra de 52 pacientes con enfermedad de Crohn. Se aplicó un formulario sociodemográfico y clínico, y el instrumento "*Inflammatory Bowel Disease Questionnaire*" para evaluar la calidad de vida.

**Resultados:** La mayoría eran mujeres, adultos, auto-declarados morenos, casados, con un ingreso familiar de dos salarios mínimos (392 euros), escuela secundaria completa y no bebían alcohol ni fumaban. Con más de cinco años de tiempo de diagnóstico y están parcialmente en remisión de la enfermedad. No mostraron frecuentemente pérdida de peso, diarrea y dolor abdominal en los últimos tres meses. Los pacientes fueron hospitalizados debido a la enfermedad de Crohn, una cuarta parte de ellos fueron sometidos a resección quirúrgica del intestino y como complicaciones las fístulas estaban más presentes. Como tratamiento medicamentoso utilizan asociación de inmunomoduladores y azatioprina. La mayoría hacía pruebas de laboratorio como control, seguido por colonoscopia y nunca ha abandonado el tratamiento. Presentaron calidad de vida regular y tuvieron respuesta "nunca" como la más puntuada en el instrumento. En los dominios síntomas sistémicos, aspectos sociales y emocionales la calidad de vida ha sido regular y en los síntomas intestinales fue satisfactoria con un promedio de 56,15 puntos.

**Conclusión:** Los pacientes con enfermedad de Crohn presentaron una calidad de vida regular.

**Palabras clave:** Calidad de vida; enfermedad de Crohn; Enfermería

## INTRODUCTION

Crohn's disease (CD) is one of the most common inflammatory bowel diseases (IBD). It is a systemic inflammatory pathology of transmural origin and unknown etiology that may affect any segment of the gastrointestinal tract. It represents a serious problem of Public Health throughout the world, affecting mainly young people. It is characterized by strong relapses, immunological alterations and extra intestinal manifestations of great magnitude, besides being still incurable <sup>(1)</sup>.

Its clinical presentation consists of exacerbated periods and the inflammatory process can develop important complications, such as stenoses, abscesses, fistulas, rectal bleeding, obstructions and neoplasias <sup>(2)</sup>. With the advance of biomedical knowledge, its occurrence has found to be associated with genetic and environmental factors, such as the detailing of bacteria and/or increased intestinal permeability, causing gastrointestinal lesions. In this new context, both the environmental, food,

immunological and infectious elements have been overly investigated as possible explanations of CD <sup>(3)</sup>.

Several epidemiological studies have shown a growing incidence and prevalence of CD, with about a 15-fold increase in the last decades, especially in New Zealand and Australia, which totaled 16 cases per 100,000 inhabitants, and in the United States with seven per 100,000. With higher occurrence in urban centers and upper-class population, CD has a prevalence of 50:100,000 in developed countries <sup>(1)</sup>.

In Brazil, published studies on CD prevalence are still few, and one of the first highlighted a growing number of CD in the second half of the 20th century <sup>(4)</sup>. A study carried out in São Paulo estimated 14.8 cases per 100,000 inhabitants, with an equal incidence among women and men <sup>(5)</sup>. In Piauí, there is little published research on this topic, despite the growing interest.

It is now known that CD can cause intestinal signs and symptoms with major repercussions, interfering in the social life of patients. In this context, because this is an aggravating disease, patients deal with numerous complications and exacerbations every day. It is imperative, therefore, to investigate the social, physiological and psychological factors patients face, as these can lead to constant changes with intense experiences considered negative to the well-being, more precisely to the quality of life (QoL).

Studying the QoL in present days is challenging due to the multiplicity and subjectivity that the concept itself carries with it, since there is still no consensus among researchers about its correct definition. The World Health Organization (WHO) has established that QoL represents the perception of an individual about his position in life, in the culture environment and in the value systems in which he lives, and in relation to his goals, viabilities, standards and concerns <sup>(6)</sup>.

QoL is determined by comparing the current to the ideal state, as well as what people consider to be important factors in their lives. This measurement serves as a good parameter for assessing the impact of the disease on individuals' life, considering that both physiological and psychic modifications can have varied effects on these patients and in their whole families, influencing from the functional capacity up to their social well-being <sup>(7)</sup>.

Due to the relevance of this investigation, the following problem was brought into consideration: what are the changes in the QoL of the individuals affected by CD? In view of the importance of the theme, the present study aims to evaluate the QoL of patients with CD assisted at the outpatient clinic of the University Hospital of Piauí (HUPI).

The study of the QoL of people with this incurable pathology is expected to bring great contributions, because the results will help in the inferences, and in the possibility of predict which area needs most care.

## **MATERIAL AND METHOD**

This is a descriptive-exploratory and cross-sectional study with a quantitative approach performed in a sample of 52 patients diagnosed with CD assisted at the HUPI outpatient clinic, a teaching hospital in the municipality of Teresina-PI. Sampling was

non-probabilistic, by convenience. This procedure made it possible to obtain the highest number of CD patients in the sample according to the following inclusion criteria: patients with CD, of both sexes, with confirmed diagnosis, and under outpatient follow-up at the HUPI. Colostomy and/or ileostomy patients were excluded due to the particularity of some items of the instrument used to evaluate the QoL of patients with IBD; hospitalized patients and children (<12 years) were also excluded.

Data were collected using a semi-structured form covering sociodemographic characteristics (sex, age, schooling, family income, number of people living in the house, skin color, smoking and alcohol drinking habits), clinical aspects (diagnosis time, treatment time, associated comorbidities, remission of disease, first symptoms of the disease, more frequent symptoms in the last three months, number of hospitalizations, surgical procedures, examinations, complications and drug treatment). To evaluate the QoL of patients with IBD, we used an instrument *entitled Inflammatory Bowel Disease Questionnaire (IBDQ)*.

This instrument is validated and translated into Portuguese, with good psychometric measures regarding validity and reliability, and Cronbach's index of 0.9. It has 32 questions divided into domains, which are presented in an unordered way to reduce bias in responses <sup>(8)</sup>.

These domains are intestinal symptoms, systemic symptoms, social aspects and emotional aspects. Each domain has multiple choice questions with seven alternatives. The score "one" means worse QoL and "seven", better QoL; the total score is the sum of the scores obtained in each domain.

The scale of points resulting from the sum of each response ranges from 32 to 224 points. The following classification of QoL was used as reference:  $\geq 200$  points corresponds to excellent QoL, 101-150, good QoL, 151-199, regular QoL and  $\leq 100$ , poor QoL <sup>(9)</sup>.

For qualitative evaluation of the sum of each domain of the IBDQ, we used the mathematical method proposed by *Tilio et al* <sup>(10)</sup>. The intervals between the minimum and maximum scores of each domain were divided by three; thus, scores between 24 and 40.99 were considered unsatisfactory; between 41 and 55.99, regular; and from 56 to 70, satisfactory.

As for the systemic symptoms, scores between 6 and 19.99 were considered unsatisfactory; between 16 and 25.99, regular; and from 26 to 35.00, satisfactory. With regard to social aspects, scores between 6 and 19.99 were considered unsatisfactory; between 16 and 25.99, regular; and from 26 to 35.00, satisfactory. In the domain emotional aspects, scores between 19 and 40.99 were unsatisfactory; between 41 and 62.99, regular; and from 63 to 84, satisfactory.

Data collection took place in December 2015. Participants were individually approached at the HUPI gastroenterology outpatient clinic after consultations during immune-modulatory infusions, and monthly at the meeting of the Association of Patients with Crohn's Disease and Ulcerative Colitis in the North and Northeast of Brazil (ACROHNN). The development of the study met the national and international requirements regarding the ethics in research involving human beings, obeying the resolution 422/2012, with number of CAAE 48207115.0.0000.5214.

The data processing and statistical analysis were performed in the *Statistical Package for the Social Science*, version 20.0. Quantitative variables were presented through descriptive statistics (mean, median and standard deviation). The *t-test* was used for comparisons of QoL with sociodemographic and clinical data of patients with CD, and oneway ANOVA was used for variance. The level of significance of  $p < 0.05$  F was considered in the analyses.

## RESULTS

Fifty-two patients of both sexes were evaluated: 55.8% were female, aged 26-36 years, reaching a mean age of 37.04 years; 48.1% self-declared to be brown skinned and 34.6% were married or had common-law-marriage. In relation to the family type, 77.0% are nuclear, with an average of 1 to 5 people living in the same household, 25.0% live with monthly income of two minimum wages and 17.3% with more than five wages, considering the current value of € 191. Regarding schooling, 44.2% of the sample had a high school education, 26.9% were unemployed, 26.9% pensioners, and 63.5% claim to follow the Roman Catholic Apostolic religion.

Regarding habits, 96.2% of the participants declared to be non-smokers and 80.8% stated that they did not drink alcoholic beverages. The characteristics of the study population for the analyzed variables are described in Table 1.

**Table I - Distribution of sociodemographic and economic characteristics of patients with CD (n = 52). Teresina (PI), Brazil, 2015.**

Variables	m±sd	n	%
<b>Age (years)</b>	37.04 ± 13.84		
15 – 25		21	40.4
26 - 36		25	48.1
37 - 47		51	9.6
38 – 58		1	1.9
<b>Sex</b>			
Female		29	55.8
Male		23	44.2
<b>Skin Color</b>			
Brown		34	65.4
White		12	23.0
Black		6	11.6
<b>Schooling</b>			
Illiterate		3	5.8
Primary Education		9	17.3
Secondary Education		23	44.2
Higher Education		16	30.8
Postgraduate Degree		1	1.9
<b>Marital Status</b>			
Married/Common-Law Marriage		18	34.6
Single		12	23.1
Widow/widower		12	23.1
Divorced		10	19.2
<b>Occupation</b>			
Pensioner		14	26.9
Unemployed		14	26.9
Housewife		13	25.0
Retired		8	15.4
Employed		3	5.8
<b>Family type</b>			
Nuclear		40	77.0

Extensive	9	17.3
Unitary	1	1.9
Rebuilt	2	3.8
<b>Lives</b>		
Accompanied	49	94.2
Alone	3	5.8
<b>Number of people living in the house</b>		
1-5	45	86.5
6 - 11 people	7	13.5
<b>Family income *</b>		
Less than 1 (minimum wage)	11	21.2
One (1) Minimum Wage	10	19.2
Two (2) Minimum Wages	13	25.0
Three (3) Minimum Wages	1	1.9
Four (4) Minimum Wages	8	15.4
More than five (5) Minimum Wages	9	17.3
<b>Smoking Habits</b>		
Yes	2	3.6
No	50	96.2
<b>Etilism</b>		
Yes	10	19.2
No	42	80.8
<b>Religion</b>		
Roman Catholic Apostolic	33	63.5
Evangelic	15	28.9
Other	2	3.8
None	2	3.8

\* Value of the minimum wage in € 191. m = mean, sd = standard deviation.

Regarding clinical aspects, the time of diagnosis of CD was more than five years in the case of 36.5% of the sample. Regarding remission, 50.0% answered that they are not active. As for intestinal symptoms in the three months prior to data collection, it was verified that 34.0% did not present weight loss, only 26.9% had abdominal pain and 35.0% of the cases did not have diarrhea.

As for the existing comorbidities, 86.5% reported none. About one in three cases have already been hospitalized during the course of the disease.

Regarding the appearance of complications related to CD, 53.8% stated that they have or already had fistula, 35.5% have already presented rectal bleeding/hemorrhage. A quarter of the interviewees have already undergone surgical resection of the intestine. Regarding the examinations for treatment/control of the disease during the year 2015, 96.1% had performed laboratory tests and 55.7%, colonoscopy.

All participants used infliximab intravenously, and 46.2% use oral aziotioprin, with respect to combined pharmacological therapy used at present. There was no report of abandonment of treatment (Table 2).

**Table II - Characterization of Clinical Aspects of patients with CD (n = 52).  
Teresina (PI), Brazil, 2015.**

<b>Variables</b>	<b>n</b>	<b>m±sd</b>	<b>%</b>
<b>CD Diagnosis Time (years)</b>			
Less than one (1)	3		5.8
One (1)	3		5.8
Two (2)	10		9.6
Three (3)	5		19.2
Four (4)	4		7.7
Five years	8		15.4
Over five (5)	19	6.73±6.06	36.5
<b>Disease Remission</b>			
Yes	26		50.0
<b>CD intestinal symptoms in the last three months</b>			
Abdominal pain	18		34.5
Diarrhea	14		26.9
Weight loss	19		36.5
Others	27		51.9
<b>Admission due to CD</b>			
Yes	19		36.5
<b>Complications due to CD</b>			
Fistulas	28		53.8
Rectal bleeding/hemorrhage	19		36.5
Others	8		15.4
<b>Medications used</b>			
Mezalasine	14		23.1
Azothiothrin	24		46.2
Infliximab	52		100

M = mean, sd = standard deviation.

Source: direct search

The study showed that 32.7% had regular QoL, 30.8% had good QoL, 26.9% had excellent QoL, and 9.6% had a poor QoL

No significant differences were found in the mean values of overall QoL between sexes, both of which were classified as good according to the IBDQ scale. Participants who had presented weight loss, abdominal pain and diarrhea had lower QoL values, that is, worse QoL.

Illiterate CD patients had low average QoL, which differed statistically from those with high school ( $p = 0.021$ ) and higher education ( $p = 0.035$ ), both with a good average QoL. The presence of fistula and hemorrhage, as well as the marital status, did not lead to statistically significant differences in the study population (Table 3).

**Table III - Comparison of means of overall QoL according to IBDQ scale, regarding gender, weight loss, abdominal pain, diarrhea, fistula and hemorrhage, schooling and marital status. Teresina (PI), Brazil, 2015.**

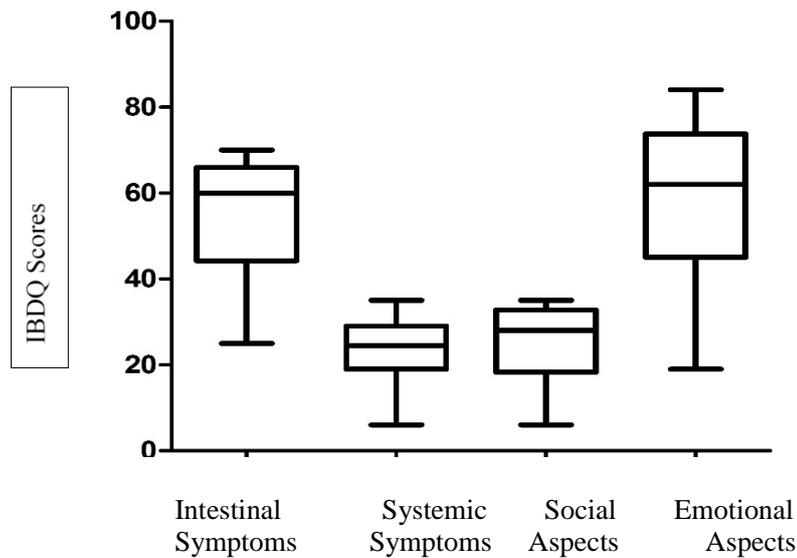
	QoL (n=52) (m±sd)	p-value
<b>Sex</b>		
Male	166.76±46.21	0.311 <sup>a</sup>
Female	154.13±41.43	
<b>Weight Loss</b>		
Yes	141.74±36.07*	0.015 <sup>a**</sup>
No	172.36±45.02	
<b>Abdominal pain</b>		
Yes	132.17±36.25*	0.000 <sup>a**</sup>
No	176.53±40.49	
<b>Diarrhea</b>		
Yes	140.71±32.29*	0.041 <sup>a**</sup>
No	168.71±45.92	
<b>Fistula</b>		
Yes	164.64±43.32	0.546 <sup>a</sup>
No	157.13±45.78	
<b>Hemorrhage</b>		
Yes	153.53±48.10	0.349 <sup>a</sup>
No	165.58±41.90	
<b>Schooling</b>		
Illiterate	92.33±15.01*	0.035 <sup>b**</sup>
Primary Education	155.78±46.26	
Secondary Education	169.09±36.23	
Higher Education	165.47±48.03	
<b>Marital Status</b>		
Single	171.00±43.44	0.314 <sup>b</sup>
Married	167.72±44.21	
Divorced	162.30±35.14	
Widow/widower	140.58±49.97	

<sup>a</sup> = t-test; <sup>b</sup> = One way ANOVA; \* Statistically lower mean values. \*\* Significant p-values at the 95% level.

As for IBDQ domain scores, intestinal symptoms had a standard deviation (SD) of 56.15 ± 12.04 with a median of 60, reaching a maximum value of 70 points; systemic symptoms had 23.35 ± 7.17 SD, median of 24.50, minimum value of 6 and maximum of 35 points; social aspects had 25.71 ± 8.23 SD, median of 28.0, minimum of 6 and maximum of 35; emotional aspects has 58.21 ± 18.81 SD, median of 62, minimum of 19 and maximum of 84.

The overall score of QoL had a standard deviation of 161.17 ± 44.15, with a median of 169, a minimum of 60 and a maximum of 223. This information is shown in figure I.

**Figure 1 - Domains of the IBDQ of CD patients (n = 52). Teresina (PI), Brazil, 2015.**



### Qualitative analysis of IBDQ scores

In the analysis of IBDQ domains, 53.9% of respondents answered that in the last two weeks they did not have diarrhea, 44.3% had no cramps and 19.0% had felt discomfort due to pain in the intestines, and 9.3% had swelling. Regarding the issue of flatulence, 44.2% reported no problems; 76.9% did not present "rectal bleeding" at defecation.

As for accidental evacuation in clothes, 78.9% said they never had this problem, and 71.4% did not present difficulty to evacuate, being unable to evacuate despite the effort, and 11.5% had felt nauseous in the last two weeks. In the domain of intestinal symptoms, the QoL of the study participants was satisfactory, with a mean of 56.15.

Regarding the domain of systemic symptoms, when asked about the frequency of feeling tired, fatigued or exhausted in the last two weeks, there was a similarity between "never and rarely" responses, corresponding to 23.1%; as for physical disposition felt, 32.6% showed a moderate amount of energy and 15.4% felt bad.

Regarding the frequency of problems that prevented them from having a good night of sleep or waking up due to intestinal dysfunction, 48.1% said they never had such problem, and 32.6% reported having a problem in maintaining their body weight. The QoL in this domain was regular, with a mean of 23.35.

In the domain of social aspects, 51.9% participants answered that they had not been unable to go to school or work because of the intestinal problem in the last two weeks, while 17.4% responded "always" and "almost always". In relation to canceling or delaying an appointment due to evacuation dysfunction, 5.9% answered that this always happens and 15.3% reported having difficulties to play sports or have fun as much they would like.

Regarding the frequency of avoiding places that do not have easy access to toilets, 55.9% answered that they never had this problem and 11.5% said they always suffer with this impasse. In the aspect of diminished sexual activity because of the intestinal problem, 28.4% of respondents said they had experienced no limitation in the past few weeks. The QoL in this domain was regular, with an average of 25.71.

As for emotional aspects, 27.0% of participants said they rarely feel frustrated, impatient or restless; 51.6% stated that they never wondered about the possibility of having surgery due to the intestinal problem. When asked about the fear felt in not finding a close toilet, 9.6% reported that they felt this fear in the last two weeks. As for feeling depressed and without courage, 17.3% reported that they always have these feelings.

As for the frequency of feeling worried or anxious, due to the concerns that CD itself entails, 36.7% answered never having such feelings, and 11.5% affirmed to feel relaxed and tranquil.

About being embarrassed because of the intestinal problem, 13.7% said they have suffered with this, and 11.5% always felt like crying in the last two weeks, 50.0% did not feel anger because they have IBD. The participants' QoL was regular in this domain, with a mean of 58.21.

It is also worth noting that in relation to feeling angry, 27.0% answered that they had never had this attitude in the last two weeks, just as 34.6% never felt lack of understanding by other people. Regarding satisfaction or thankfulness with their personal lives, 34.6% answered that they feel extremely satisfied and could not be happier or grateful at this time. In this area the participants' QoL was regular, with a mean of 58.21.

There were similarities in the answers "always and very few times" in relation to feeling worried and anxious, but "Never" was the alternative that prevailed.

## DISCUSSION

In this study, there was a greater incidence of CD in the adult age group. Scientific evidence has pointed to a greater development of DC among younger people, as it most commonly begins during adolescence and at the beginning of adult life <sup>(11)</sup>. On the other, some advocate that there is no difference in the clinical course of the disease when the age parameter is considered, and the worst QoL of AD patients is seen in old ages <sup>(12)</sup>.

Prevalence of females, brown skinned people, married/living a common-law-marriage and with complete high school were also noted in the study. These data, in particular regarding sex, is recurrent in most international and Brazilian studies <sup>(8-12)</sup>. However, the authors claim that this is not a general feature, and may depend on geographical location, as well as on gender-related differences in cultural habits and their different inherent risk factors <sup>(13)</sup>.

A study investigating the relationship between clinical and sociodemographic factors and QoL showed that there is no direct relation, and that gender is not a predictive factor. On the other hand, QoL tends to be better among men with IBD compared to women <sup>(14-15)</sup>. This study also reported that the brown or white skin colors were more

prevalent in CD cases, although there is no significant correlation. Similar findings were found in our present research <sup>(16)</sup>.

Highest educational level was significantly related to better QoL. This can be explained by the ability to obtain more information, including greater knowledge of the possible complications of the disease and a lower level of anxiety <sup>(17-12)</sup>. In this sample, the illiterates presented poor QoL. This has also been found in other studies with CD patients that showed inferior results in relation to QoL <sup>(18-19)</sup>.

Notably, most participants live with a family income of two minimum wages, have a nuclear form of family organization, and are unemployed. These information correlate with the social profile of the population in Brazil, in particular of patients who seek Public University Hospitals <sup>(20)</sup>. On the other hand, considering some factors that may influence in certain areas, mainly in the social and psychological scope, being close to family and having their support is crucial and promote satisfactory results in the recovery of patients. A study that evaluated the labor ability of IBD patients, including CD, found high rates of unemployment compared with the regular population <sup>(21, 19, 22)</sup>. The QoL in many dimensions is significant lower among patients who are not actively engaged in work, since the professional situation is viewed as a basic and strongly influent aspect, especially in patients with chronic disease <sup>(23)</sup>. On the other hand, recent research pointed out that although patients were active, this led to no significant changes in the QoL assessment, which is similar data to those found in the present survey <sup>(24)</sup>.

Moreover, another factor of great interest is the smoking habit among CD patients, because this represents a consistent risk factor to occurrence and evolution of CD associated with other factors. Evidence shows that patients who are active smokers have about 2- to 4-fold higher risk of having the disease than ex-smokers and non-smokers <sup>(25)</sup>.

On the other hand, studies with a sample of 32 CD patients found no greater risk to the emergence of CD among smokers, although among ex-smokers, 72.7% developed the IBD after quitting the habit. In this study, there was a low prevalence of smokers among patients, probably due to the low sample size. In turn, the relationship of influence between tobacco and QoL with both types of IBD still required studies for confirmation <sup>(26,18)</sup>.

Despite signs of abdominal pain, diarrhea and weight loss are common and significant among CD patients, major occurrences in the past three months were not observed in this study. However, it is pertinent to clarify that these signs are more incident during the active phase of the disease, with a significant decrease in the remission phase. This can be explained by the fact that all participants adhere to adequate drug treatment through the various degrees of intensity. On the other hand, these symptoms led to lower values of QoL, a fact also noted in other studies <sup>(27)</sup>.

In this way, it is clear that CD intestinal symptoms negatively influence the QoL of patients. The symptoms presented by IBD patients may generate high-impact changes, be it in the early or late stages. In this investigation, it was found that a significant number of patients experienced associated symptoms of weight loss, followed by abdominal pain and diarrhea, more intensely at the early diagnosis of the disease, because abdominal pain is quite common in the active phase of the disease <sup>(15)</sup>.

It was shown that the time of diagnosis, be it late or early, is not a variable directly related to QoL of CD patients. The difference can be linked to several other aspects<sup>(18)</sup>. On the other hand, evidence confirmed that patients who found disease more recently tend to be more anxious, which considerably influences the QoL although such significance has not been demonstrated, the longer the duration, the better the QoL<sup>(28)</sup>.

Another feature that leads to worst QoL is the occurrence of hospitalizations, as lower IBDQ scores have been found in other research studies. From the point of view of the clinic, high numbers of hospitalizations and complications are determining factors of QoL. As for the presence of fistula, data found in this study and other research has showed lower indices of QoL in these patients<sup>(29)</sup>.

These results are similar to population-based findings on CD patients, in which a cumulative risk of development of fistula of 33 and 50% was found after 10 and 20 years of diagnosis. Thus, it is interesting to emphasize that these patients have higher risk of needing surgical procedures, another variable that has strong influence on QoL<sup>(30)</sup>.

The QoL aims at improvement of wanting to live harmoniously as well, to display new health conditions<sup>(7)</sup>. The qualitative analysis of IBDQ demonstrated regular QoL. This sample achieved results above the expected, in that the alternative "never" (better QoL) was the main response and that participants feel extremely satisfied, thankful and happy. It is worth noting that there was a predominance of regular QoL in the systemic, social and emotional domains. This is to a study developed with the focus of assessing the QoL among IBD patients<sup>(31)</sup>.

These results show that CD patients have had a regular QoL in the last two weeks. However different factors, such as, the situation of the patient at that moment and his view of his own QoL are fundamental factors that should be considered to the clinical outcome.

On the other hand, data on the intestinal domain obtained the highest mean, and classified as satisfactory QoL<sup>(31)</sup>. This fact can be explained by the fact that the majority of patients are in the remission of the disease, responding well to drug therapy. This component refers to the physical aspects of the disease itself.

It is worth noting that the scores obtained are similar to those found in IBD patients in other countries such as United Kingdom and United States, in particular to the components of intestinal symptoms and emotional aspects<sup>(8)</sup>.

In contrast, another study using the IBDQ found 73.33% of individuals with good to excellent and QoL, and only 26.66% with regular or bad QoL. Discrepancies in these results can have a direct relation with the varied methodologies. However, major significance of IBDQ was not found when extended for a period exceeding 60 days, instead of 15 days<sup>(18)</sup>. A factor to be considered at this moment is fact that these patients are affected by a disease of chronic nature, who in addition to phases of remission and exacerbation, causes a negative impact<sup>(31,32)</sup>.

It is interesting, in this context, to emphasize that QoL in general is linked to the influence and activity of the disease at the present moment, as well as the individual

characteristics of each patient. Thus comparative studies are necessary to better understand the results indicative of regular QoL, although the majority of participants declared to be satisfied.

Finally, the use of Infliximab every two months in CD patients was shown to be effective to induce and maintain the remission in active patients with insufficient response to conventional therapy. This statement confirms the randomized, multicenter study in which 573 patients from 45 centers were divided into three distinct groups separated by differences in the administration of the dose at intervals of 0, 2, and 4 months. After evaluation of 54 weeks, highest remission was seen in the control group that used the Infliximab every eight weeks <sup>(33,34)</sup>.

In order to evaluate the treatment response to factors associated with anti-tumor necrosis factor anti-TNF (Infliximab or adalimumab) in CD patients, a study found that there was better response in patients who used the anti-TNF in combination with azathioprine, especially in women, and that the improvement in QoL was also constant over this same period <sup>(35,36)</sup>. The same research clarifies that a single dose of Infliximab increased significantly the QoL of the group that responded to the IBDQ.

Another variable that deserves clarification is the presence of concomitant comorbidities to CD, which predicts a worse QoL. In this study there was no a marked presence of comorbidities. This may explain the regular QoL, although these comorbidities have been a negative predictive factor found in all domains of the IBDQ, in other studies <sup>(20)</sup>.

## CONCLUSIONS

It is considered that assessing the QoL of CD patients is of paramount importance for enabling reflections and actions, both of patients themselves and of health professionals who assist them, in order to preserve the health and qualify the assistance.

The results of this research allow to affirm that the QoL of the sample studied was regular and there was interference in the lives of individuals surveyed in a negative way, based on the most committed dimensions of the IBDQ instrument. These were the systemic, social and emotional dimensions, and clinical aspects. Weight loss, abdominal pain and diarrhea led to the lowest values of QoL.

The results of this research calls for a reflection on the importance of nursing to know CD patients, in order to facilitate the planning of humanized and personalized assistance.

In the case of implications in clinical practice, the need for permanent evaluation of the QoL of patients through predictive scales in order to become was evidenced as necessary to become a qualifier instrument of assistance. This is important because these patients need to be permanently evaluated in health institutions, including reference hospitals.

The results obtained in this research can be equally important to instigate and encourage researchers and students to carry out further investigation on the theme. The assessment of QoL in this class is something that deserves further research, for

being a disease that encompasses various physiological, social and psychological aspects that interfere with the QoL.

## REFERENCES

- 1.Ministério da Saúde. Secretaria de Assistência a Saúde. Protocolo clínico e diretrizes terapêuticas – Doença de Crohn. Brasília: Ministério da saúde, 2014. Portaria n.966, de 02 de Novembro de 2004. DOU Brasília, DF, n.214, seção I, p. 77-85, 5 de Nov. 2014.
- 2.Freeman HJ. Long-term natural history of Crohn's disease. *World J Gastroenterol.* 2009; 15(11):1315-18. 1315-1318.
- 3.World Gastroenterology Organization Practice Guidelines. Doença Inflamatória Intestinal: uma perspectiva global. 2009.1(1)
- 4.Gaburri PD, Chebli JM, Castro LE, Ferreira JO, Lopes MH, Ribeiro AM et al. Epidemiology, clinical features and clinical course of Crohn's disease: a study of 60 cases. *Arq Gastroenterol.* 1998; 35 (4): 240-6
- 5.Victoria CR., Sassak LV, Nunes HR. Incidence and prevalence rates of inflammatory bowel diseases, in Midwestern of São Paulo State, Brazil. *Arq Gastroenterol.*2009; 46 (1):20-5.
6. World Health Organization (who). The World Health Organization Quality of Life Assesment (WHOQOL): position paper from the World Health Organization. *Soc. Sci. Med.*1998.1995
- 7.Almeida MAB. Qualidade de vida: definição, conceitos e interfaces com outras áreas de pesquisa / São Paul: Escola de Artes, Ciências e Humanidades. EACH/USP.2012.142.
- 8.Pontes RMA, Miszputen SJ, Ferreira-Filho OF, Miranda CFMB. Qualidade de vida em pacientes portadores de doença inflamatória intestinal: tradução para o português e validação do questionário "Inflammatory Bowel Disease Questionnaire" (IBDQ). *Arq. Gastroenterol.* 2004; 41(2): 137-143.
- 9.Meyer ALM. Qualidade de vida no seguimento tardio de doentes portadores de Retocolite ulcerativa submetidos a proctocolectomia com conservação esfinteriana há mais de dez anos. São Paulo. Dissertação. (Mestrado). Universidade Federal de São Paulo. 2009.
- 10.Tilio MSG, Ariasb L, Camargob GM, Oliveira PSP, Panzettib N V, Ayrizonob M L S et al. Quality of life in patients with ileal pouch for ulcerative colitis. *J coloproctol.* 2013; 33(3):113–117
- 11.Graff LA, Walker JR, Bernstein CN. Depression and anxiety in inflammatory bowel disease: a review of comorbidity and management. *Inflamm Bowel Dis* 2009; 15(7):1105-18.
- 12.Michael JR, MD, MSCI, Ashish D MBBS, MSPH, Shehzad A. Saeed, MD. Inflammatory bowel disease in children and adolescents. *JAMA Pediatr.* 2015; 169(11): 1053-1060.
- 13.Moradkhani A, Beckman LJ, Tabibian JH. Health-related quality of life in inflammatory bowel disease: psychosocial, clinical, socioeconomic, and demographic predictors. *J Crohns Colitis.*2013;7 (1):467-73.
- 14.Gandhi S, Jedel S, Hood M M, Mutlu E, Swanson G, Keshavaezian A. The relationship between coping, health competence and patient participation among patients with inactive inflammatory bowel disease. *J. Crohn's Colitis.* 2014; 8 (5):401-408.
- 15.Magalhães JD, Francisca DC, Pedro BC, João FM, Silvia L, Maria JM, José C. Disability in inflammatory bowel disease: translation to portuguese and validation of

- the Inflammatory Bowel Disease – Disability Score. *GE Port. J. Gastroenterol.* 2015; 22 (1): 4-14.
16. Zelinkova Z, Der Woude CJ, Gender and. Inflammatory Bowel Disease. *J. Clín. Cell Immunol.* 2014; 5(4): 245.
17. Faria LC, Ferrari MLA, Cunha AS. Aspectos clínicos da doença de Crohn em um centro de referência para doenças intestinais. *GED Gastroenterol Endosc Dig.* 2004 ; 23(4):151-64.
18. Casellas F, Arenas JI, Baudet JS, Fábregas S, García N, Gelabert J, et al. Impairment of health-related quality of life in patients with inflammatory bowel disease: a Spanish multicenter study. *Inflamm Bowel Dis.* 2005; 11(5): 488-96.
19. Coelho MID. Qualidade de Vida e Doença Inflamatória Intestinal. Covilhã. Dissertação (Mestrado Integrado em Medicina). Universidade da Beira Interior - Faculdade ciências da Saúde. 2010.
20. Taft TH, Keefer L, Artz C, Bratten J, Jones MP. Perceptions of illness stigma in patients with inflammatory bowel disease and irritable bowel syndrome. *Qual. Life Res.* 2011; 20 (9): 1391-1399.
21. Peruzzi EP, Soares HF, Barros GG, Rego RGG, Zaltman CEC, Siqueira EC. Análise descritiva dos perfis social, clínico, laboratorial e antropométrico de pacientes com doenças inflamatórias intestinais, internados no Hospital Universitário Clementino Fraga Filho, Rio de Janeiro. *Arq. Gastroenterol.* 2007; 2(4):332-339.
22. Feagan BG, Bala M, Yan S, Olson, Hanauer S. Unemployment and disability in patients with moderately to severely active Crohn's disease. *J. Clin. Gastroenterol.* 2005; 39(3):390-500.
23. Israeli, E, Graff AL, Clara I, Walker R J, Mix L M, Targownik LE, Beenstein C N. Low prevalence of disability among patients with inflammatory bowel diseases a decade after diagnosis. *Clín. Gastroenterol. Hepatol.* 2014; 12(8): 1330-1337.
24. Leowardi C, Hinz U, Tariverdian M, Kienle P, Herfarth C, Ulrich A, Kadmon M. Long-term outcome 10 years or more after restorative proctocolectomy and ileal pouch-anal anastomosis in patients with ulcerative colitis. *Langenbecks Arch Surg.* 2010; 395 (1):49-56.
25. Hahnloser D, Pemberton JH, Wolff BG, Larson DR, Crownhart BS, Dozois RR. Results at up to 20 years after ileal pouch-anal anastomosis for chronic ulcerative colitis. *Br J Surg.* 2007; 94 (3):333-40.
26. Campos MOB, Cavalcante TB. Smoking: etiologic factor for Crohn's disease. *Rev Enferm UFPI.* 2012; 1(3):201-204.
27. Martins Jr EV, Araújo IS, Atallah AN, Miszputen SJ. Tabagismo e doença inflamatória intestinal: estudo epidemiológico caso-controle. *Arq Gastroenterol.* 1996; 33(2): 654-657.
28. Bielefeldt K, Davis B, Binion DG. Pain and inflammatory bowel disease. *Inflamm Bowel Dis.* 2009; 15(5): 778-88. Review.
29. Kuriyama M, Kato J, Kuwaki K et al. Clinical factors that impair health-related quality of life in ulcerative colitis patients vary with the disease duration. *Eur J Gastroenterol Hepatol.* July 2008; 20(7): 634-41.
30. Burisch J, Weimers P, Pedersen N, Cukovic-Cavka S, Vucelic B, Kaimakliotis I, et al. Health-related quality of life improves during one year of medical or surgical treatment in a European population-based inception cohort of patients with inflammatory bowel disease--an ECCO- Epi Com study. *J Crohns Colitis.* 2014; 8 (9):1030-42
31. McDermott E, Keegan D, Byrne K, Doherty GA, Mulcahy HE. The Short Health Scale: A valid and reliable measure of health related quality of life in English speaking inflammatory bowel disease patients. *J Crohns Colitis.* 2012; 21 (4):123-32.

32. Tilio M S G. Análise da qualidade de vida pós-operatória em pacientes com reservatório ileal por retocolite ulcerativa. Campinas-SP. Dissertação [Mestrado] Universidade Estadual de Campinas. 2013. [acesso em 04 dezembro 2015]. Disponível em <http://www.bibliotecadigital.unicamp.br/document/?code=000906635>
33. Almeida, MG; Kiss, DR; Teixeira, MG, Habr - Gama, Angelita. Quality of life of long follow-up patients submitted to proctocolectomy with ileal pouch. Rev Bras coloproctol. 2000;20(3):145-52.
34. Schnitzler F, Fidler H, Ferrante M. Mucosal healing predicts long-term outcome for maintenance therapy with infliximab in Crohn's disease. Inflamm Bowel Dis. 2009; 15(9) 1295–301.
35. Hanauer SB, Feagan BG, Lichtenstein GR, Mayer LF, Schenreiber S, Colombel et al. Maintenance infliximab for Crohn's disease: the ACCENT I randomised trial. Lancet. 2002; 359: 1541-1549.
36. Silva, ICL. Qualidade de vida relacionada à saúde em pacientes acometidos por doença inflamatória intestinal tratados com terapia biológica. Dissertação [Mestrado] Universidade Estadual Paulista Júlio de Mesquita Filho, Faculdade de Medicina de Botucatu, 2015. [Acesso em 01 dezembro 2015]. Disponível em: <http://repositorio.unesp.br/handle/11449/128144>.
37. Santos CH M. Comparison between infliximab and adalimumab in the treatment of perianal fistulas in Crohn's disease. J. Coloproctol. 2014;34(3): 154-158.

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