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Original Article

Quality of life of patients with inflammatory bowel disease

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A R T I C L E   I N F O

A B S T R A C T

Rationale: Crohn's disease and non-specific ulcerative colitis are part of inflammatory bowel diseases. They have a chronic evolution, leading to important repercussions on patients' quality of life. Measuring this subjective parameter requires an evaluation tool in clinical trials and health programs. The "Inflammatory Bowel Disease Questionnaire" is an American instrument of McMaster University, which had its reproducibility and validity determined in studies in other countries as a measure of the quality of life in IBD.

Objective: To evaluate the quality of life of patients with inflammatory bowel disease through the Inflammatory Bowel Disease Questionnaire, and to correlate the results with sociodemographic data of the patients.

Methods: This is a prospective cross-sectional study carried out with 58 patients; the patients' follow-up was conducted at the outpatient clinic of Coloproctology.

Results: Among the 58 patients evaluated, 70.1% had DC, 62.1% were women, the mean age was 46.08 years, 96.6% were non-smokers, and 24.1% were submitted to surgery for the underlying disease. 43% were in a combination therapy scheme, 44% in monotherapy, and 12% were not using medication. Significant change in quality of life was observed in patients taking prednisone.

Conclusion: The patients with better quality of life are those who were taking prednisone. There was no other correlation with significance in the patients' quality of life.

Qualidade de vida dos pacientes com doença inflamatória intestinal

R E S U M O

Racional: Faz parte das doenças inflamatórias intestinais a doença de Crohn e a Retocolite Ulcerativa Inespecífica Possuem evolução crônica, gerando repercussões importantes na qualidade de vida dos doentes. Medir esse parâmetro subjetivo requer um instrumento de avaliação em ensaios clínicos e de programas de saúde. O "Inflammatory Bowel Disease

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Colite
Qualidade de vida

Questionnaire" é um instrumento norte-americano da McMaster University, que teve sua reprodutibilidade e validade determinada em estudos em outros países, como medida da qualidade de vida em doenças inflamatórias intestinais.

Objetivo: Avaliar a qualidade de vida dos pacientes com doença inflamatória intestinal através do questionário "Inflammatory Bowel Disease Questionnaire", e correlacionar os resultados com dados sociodemográficos dos pacientes.

Método: Estudo prospectivo transversal, realizado com 58 pacientes, acompanhamento no ambulatório de Coloproctologia.

Resultados: Dentre os 58 pacientes avaliados, 70,1% possuíam DC, 62,1% mulheres, idade média de 46,08 anos, 96,6% não tabagistas, 24,1% submetidos à cirurgia pela doença de base. Estavam em uso de terapia combinada 43%, monoterapia 44% e sem uso de medicamento 12%. Foi observada alteração significativa da qualidade de vida nos pacientes em uso de prednisona.

Conclusão: Os pacientes com melhor qualidade de vida são os que estavam em uso de prednisona. Não houve outra correlação com significância na qualidade de vida.

Introduction

Crohn's disease (CD) and idiopathic ulcerative rectocolitis (IUR) are the forms of inflammatory bowel diseases (IBD), being characterized by a chronic inflammation of the intestine. The cause of IBD is still unknown and there is some interaction between genetic, environmental and immune factors.[1,2] These diseases affect young and old people, with no predilection as for race and gender.[3,4]

According to Ordinance No. 483 of April 1, 2014m of the Brazilian Ministry of Health, chronic diseases are those disorders with a gradual onset, with a long or uncertain duration, and which, in general, present multiple causes and whose treatment involves changes of the patient style of life, in a process of continuous care that usually does not lead to one's healing.

The concept of quality of life (QoL) refers to how well people perform their functions in daily life and the personal assessment of their well-being, and the forms of inflammatory bowel disease, both IUR and CD, have important repercussions on the QoL of the carriers.[5]

The measurement of QoL is an important parameter when one assesses the impact of chronic diseases, since the physiological changes, despite providing important information for the clinician, can cause various effects both for patients and their families, as they influence functional capacity and well-being – critical aspects for the patient.[6,7]

In order to evaluate the QoL of patients with inflammatory bowel disease, the "Inflammatory Bowel Disease Questionnaire" questionnaire, already validated in Brazil, was applied and subsequently we correlated the IBDQ data with sociodemographic and morbidity data available.

Methods

This is a cross-sectional, prospective study, with no conflict of interest, and costs will be borne by the researchers. The study was conducted from August 2016 to January 2017, and involved patients with IBD registered in the exceptional medicine program of the Health Department of the State of Mato Grosso do Sul (MS), after their evaluation by an auditor physician and with the Ordinance criteria being fulfilled. Patients with an undetermined cause of colitis and patients undergoing diagnostic investigation were excluded.

To evaluate the QoL, the North American form of McMaster University, "Inflammatory Bowel Disease Questionnaire (IBDQ)", a questionnaire translated and validated in Portuguese, was the instrument applied, along with a small form on morbidity and sociodemographic characteristics. The IBDQ consists of 32 items covering four domains: intestinal symptoms, systemic symptoms, social aspects, and emotional aspects, and the response options are presented in the form of multiple choice, with seven alternatives. The scores 1 and 7 mean, respectively, the worse and the better state of QoL.[5,6]

The volunteer patients answered the questionnaires without any external help; once completed, the questionnaires were confidentially deposited in a box.

After the data collection, the IBDQ results were cross-checked with the questionnaire on socio-demographic characteristics, as follows: age, gender, disease, diagnosis time, surgery resulting from the disease, medication in use, smoking, and disease activity. The results of the IBDQ were submitted to statistical treatment with the use of SPSS (version 23) and GraphPad Prism (version 6.01) programs, cluster analysis, and the chi-squared test, with significance established as $p < 0.05$.

Results

Descriptive analysis

Age and gender

The mean age of all patients studied ($n = 58$) was 46.1 ± 15.1 years. The mean age of men ($n = 22$, 37.9% of the total) was
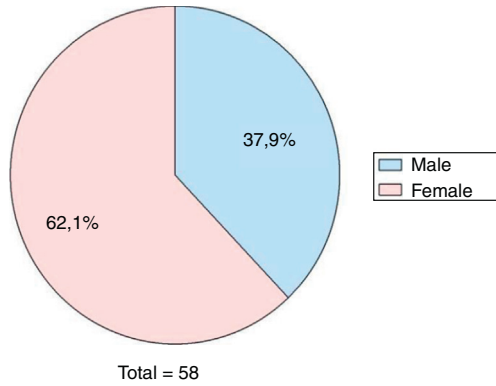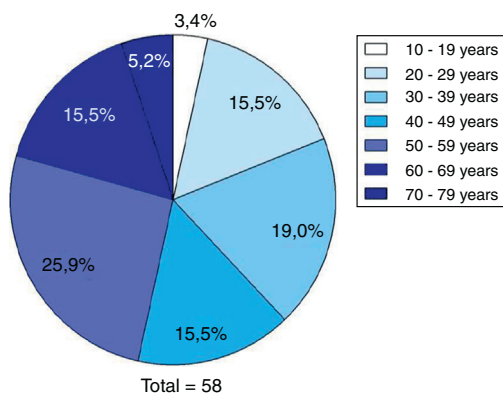
Fig. 1 – Distribution of the patients studied by gender.

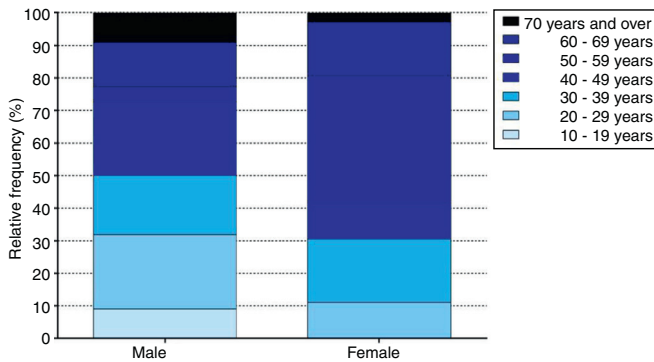**Fig. 2 – Distribution of the patients studied by age group.**

Fig. 3 – Distribution of the patients studied by age group and gender.

Table 1 – Drugs in use by patients suffering IBD.

Drug in use	Number of patients (%)
None	7 (12.06%)
Salicylate, oral	13 (22.41%)
Salicylate, suppository/enema	6 (10.34%)
Methotrexate	1 (1.7%)
Prednisone	12 (20.68%)
Azathioprine	24 (41.37%)
Anti TNF	22 (37.93%)

Table 2 – Diagnosis time and number of patients.

Diagnosis time	Number of patients (%)
Less than 1 year	10 (17.2%)
1–2 years	7 (12%)
2–3 years	13 (22.4%)
More than 5 years	28 (48.2%)

Table 3 – Distribution of disease frequencies according to gender.

	Gender		Total
	Male	Female	
Crohn's disease	16 (27.6%)	25 (43.1%)	41 (70.7%)
Ulcerative rectocolitis	6 (10.3%)	11 (19.0%)	17 (29.3%)
Total	22 (37.9%)	36 (62.1%)	58 (100.0%)

therapy, and 26 (44.08%) were on monotherapy. Table 1 lists the drugs in use.

When asked about disease activity, 31 patients thought the disease was active, 13 believed that the disease was not active, and 14 did not know about it. Table 2 lists the diagnosis times.

Disease

Table 3 shows the frequency distribution of diseases, according to gender, while Table 4 shows the same distribution according to age group.

QoL

The sum of the scores of each domain was divided by the number of questions that composed the domain, and the same procedure was done for the total score. These values are presented in Tables 5–7, with respect to gender, age group, and disease, respectively.

Inferential analysis of the dependent variable "QoL".

QoL versus gender. The D'Agostino and Pearson normality test, applied to the total values of QoL, revealed that we were faced with a parametric sampling distribution, which authorized us to use the Student's *t* test to try to find significant differences between the groups.

The "t" test revealed no significant differences between the groups tested ($p = 0.2374$), indicating that the gender did not influence the QoL of the patient. Fig. 4 illustrates this finding.

QoL versus age group. The D'Agostino and Pearson's normality test, applied to the total values of QoL, revealed that we were faced with a parametric sampling distribution, which allowed us the use of the analysis of variance to try to find significant differences between the groups.

42.5 ± 17.3 years; for women ($n = 36$, 62.1% of the total) the mean age was 48.3 ± 13.4 years.

Fig. 1 illustrates the distribution between genders, while Figs. 2 and 3 list the age groups of the participants.

Only two (3.4%) patients were smokers (one with CD and one with URC) and 56 (96.6%) did not smoke. Only 14 (24.1%) patients underwent surgery due to an inflammatory disease; of these patients, 13 had a diagnosis of CD and only one patient had URC.

Regarding treatment, seven patients (12.06%) were not on medication, 25 (43.01%) were being treated with combination

Table 4 – Distribution of disease frequencies according to age group.

	Age group (years)							Total
	10–19	20–29	30–39	40–49	50–59	60–69	70–79	
Crohn's disease	2 (4.9%)	9 (15.5%)	8 (13.8%)	5 (8.6%)	8 (13.8%)	7 (12.1%)	2 (3.4%)	41 (70.7%)
Ulcerative rectocolitis	0 (0.0%)	0 (0.0%)	3 (5.2%)	4 (6.9%)	7 (12.1%)	2 (3.4%)	1 (1.7%)	17 (29.3%)
Total	2 (3.4%)	9 (15.5%)	11 (19.0%)	9 (15.5%)	15 (25.9%)	9 (15.5%)	3 (5.2%)	58 (100.0%)

Table 5 – Mean and standard deviation of corrected scores, according to domains and gender.

Gender	Domains				
	Bowel	Systemic	Social	Emotional	Total
Male	4.90 ± 1.66	4.45 ± 1.55	5.10 ± 1.83	4.32 ± 1.91	153 ± 50
Female	4.54 ± 1.49	3.96 ± 1.67	4.58 ± 1.75	4.33 ± 1.55	137 ± 46
Total	4.68 ± 1.55	4.14 ± 1.63	4.78 ± 1.78	4.33 ± 1.68	143.3 ± 47.7

Table 6 – Mean and standard deviation of corrected scores, according to domains and age group.

Age group	Domains				Total
	Bowel	Systemic	Social	Emotional	
10–19 years	4.90 ± 1.98	4.20 ± 1.98	4.70 ± 1.56	4.50 ± 1.65	145 ± 47
20–29 years	5.68 ± 0.90	4.84 ± 1.04	6.22 ± 1.25	5.15 ± 0.77	175 ± 23
30–39 years	4.12 ± 1.71	3.84 ± 1.51	4.31 ± 1.88	4.39 ± 1.51	130 ± 53
40–49 years	4.04 ± 1.58	3.18 ± 1.53	3.53 ± 1.87	2.81 ± 1.65	114 ± 52
50–59 years	4.35 ± 1.51	4.01 ± 1.97	4.55 ± 1.67	4.29 ± 1.60	141 ± 46
60–69 years	5.08 ± 1.56	4.53 ± 1.56	5.29 ± 1.60	4.78 ± 2.09	149 ± 49
70–79 years	5.87 ± 1.27	5.47 ± 1.10	5.60 ± 1.25	4.89 ± 2.01	179 ± 35
Total	4.68 ± 1.55	4.14 ± 1.63	4.78 ± 1.78	4.33 ± 1.68	143.3 ± 47.7

Table 7 – Mean and standard deviation of corrected scores, according to domains and disease.

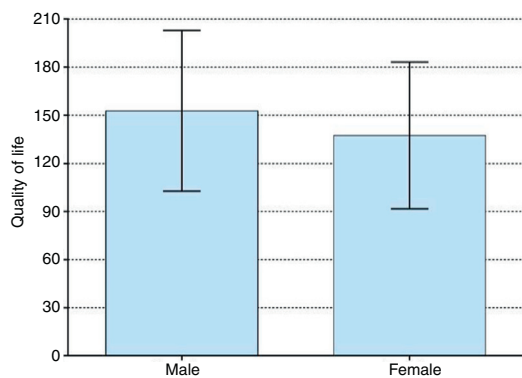| Disease	Domains				
	Bowel	Systemic	Social	Emotional	Total
Crohn's disease	4.77 ± 1.53	4.22 ± 1.66	4.91 ± 1.77	4.28 ± 1.70	145 ± 48
Ulcerative rectocolitis	4.45 ± 1.63	3.95 ± 1.57	4.47 ± 1.82	4.43 ± 1.67	138 ± 48
Total	4.68 ± 1.55	4.14 ± 1.63	4.78 ± 1.78	4.33 ± 1.68	143.3 ± 47.7

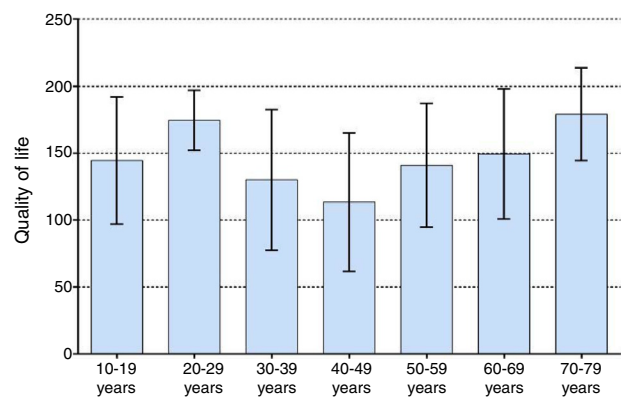**Fig. 4 – Quality of life according to gender.**

Fig. 5 – Quality of life according to age group.

The analysis of variance revealed no significant differences between the groups tested ($p = 0.1122$), indicating that the age group did not exert influence in the life of the patient. Fig. 5 illustrates this finding.

QoL versus domain. The D'Agostino and Pearson's normality test, applied to the corrected values of the different domains, revealed that we were faced with a nonparametric sampling distribution, a fact that led us to attempt to transform the results. The procedure of square root transformation of the data yielded a sample universe of Gaussian nature, which allowed us the use of analysis of variance.
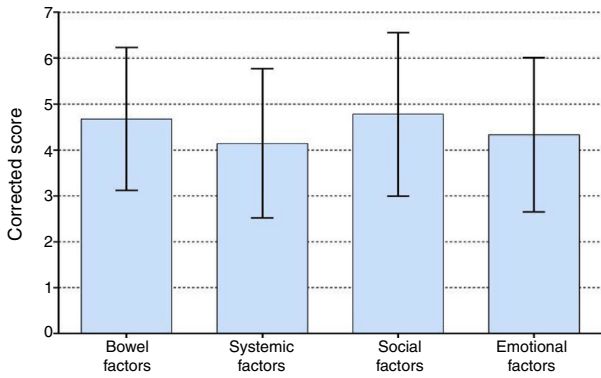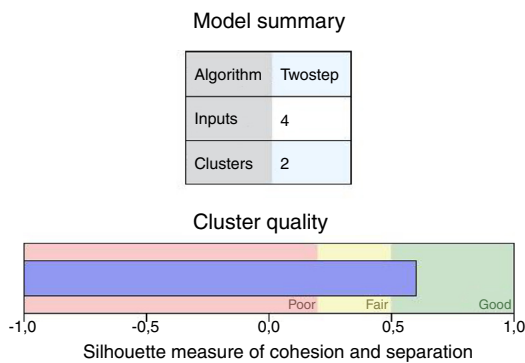
Fig. 6 – Quality of life according to domain.

Model summary

Algorithm	Twostep
Inputs	4
Clusters	2

Cluster quality

Fig. 7 – Cluster analysis applied to study domains. Silhouette index = 0.6.

Clusters

Input (Predictor) Importance

Cluster	1	2
Label	Higher quality of life	Lower quality of life
Description		
Size	51,7% (30)	48,3% (28)
Inputs	Systemic factors 2,85	Systemic factors 5,53
	Social factors 3,40	Social factors 6,26
	Bowel factors 3,50	Bowel factors 5,94
	Emotional factors 3,19	Emotional factors 5,55

Fig. 8 – The importance of each domain in the prediction of quality of life.

Discussion

IBDs can permanently alter the QoL of patients' lives, especially when the disorder goes through a period of exacerbation. The symptoms presented by patients with IBD can generate changes that have a great impact on attitudes, behaviors, and productivity, as well as in physical, emotional, and social aspects.

In this study, we can observe the occurrence of a peak incidence of IBD between 50 and 59 years of age. The predominance of CD in women and the bimodal presentation (20 and 50 years) is compatible with findings in the literature. However, contrary to what has been observed in some studies, IUGR was predominantly in women, not in men.[6]

Smoking did not influence this study since the number of patients ($n = 2$) was not relevant.

When scores taking into account the diagnoses were assessed separately, no statistically significant difference was observed for CD versus IUGR, and this result was similar to that found in a study conducted in Spain.[8] Also, no statistical relevance was observed when the IBDQ score was correlated with sociodemographic data.

According to the cluster analysis, 51.7% of the patients in this sample have a better QoL; and among the domains of IBDQ, the domain of systemic symptoms is the best predictor and the one that has a greater weight for QoL, being followed by the social domain.

Table 8 – Contingence table for quality of life according to prednisone use.			
Use of prednisone	Better quality of life	Poorer quality of life	Total
No	19 (32.7%)	27 (46.6%)	46 (79.3%)
Yes	11 (19.0%)	1 (1.7%)	12 (20.7%)
Total	30 (51.7%)	28 (48.3%)	58 (100.0%)

The one-way ANOVA test revealed no significant differences among the values of the domains tested ($p = 0.157$), indicating that none of the domains have a greater importance in the QoL of the patient. Fig. 6 illustrates this finding.

Domains versus medication. The cluster analysis applied to the domains by the TwoStep algorithm reveals the presence of two distinct groups, as shown in Figs. 7 and 8.

Based on this distribution of patients in two distinct groups, analyses were performed based on chi-squared tests, in order to determine significant correlations between QoL and the various sociodemographic factors, among them the medication used by the patients in the sample.

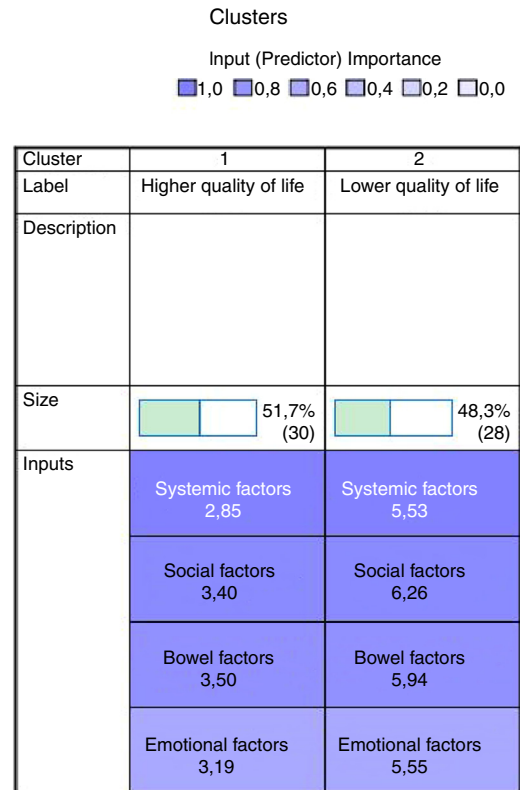It was found that the use of prednisone significantly increases patients' QoL ($p = 0.0026$), as shown in Table 8.

Conclusion

There was no statistical significance of the QoL of patients with IBD when compared with sociodemographic variables. On the other hand, the cluster analysis demonstrated that the systemic domain of IBDQ can be considered a good predictor of QoL and that, in addition, patients who were taking prednisone had better scores for QoL.

Conflicts of interest

The authors declare no conflicts of interest.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.jcol.2017.06.009.

REFERENCES

1. Silva AF, Schieferdecker MEM, Amarante HMBS. Ingestão alimentar em pacientes com doença inflamatória intestinal. ABCD Arq Bras Cir Dig. 2011;24:204–9.

2. Kleinubing-Junior H, Pinho MSL, Ferreira LC, Bachtold GA, Merki A. Perfil dos pacientes ambulatoriais com doenças inflamatórias intestinais. ABCD Arq Bras Cir Dig. 2011;24:200–3.

3. Braunwald E, Fauci AS, Hauser SL, Longo DL, Kasper DL, Jameson JL. Medicina interna, vol. II, secção 289, 17 ed. Rio de Janeiro: McGraw-hill; 2010.

4. Ware JE. Standards for validating health measures: definition and content. J Crohnic Dis. 1987;40:473–80.

5. Pontes RMA. 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;41:137–43.

6. Souza MM, Barbosa DA, Espinosa MM, Belasco AGS. Qualidade de vida de pacientes portadores de doença inflamatória intestinal. Acta Paul Enferm. 2011;24:479–84.

7. De Boer AG, Bennebroek Evertsz' F, Stokkers PC, Bockting CL, Sanderman R, Hommes DW, et al. Employment status, difficulties at work and quality of life in inflammatory bowel disease patients. Eur J Gastroenterol Hepatol. 2016;28:1130–6.

8. 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;11:488–96.