Health – related quality of life in patients with inflammatory bowel disease: a Tunisian study

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Qualité de vie dans les maladies inflammatoires chroniques de l'intestin : Etude Tunisienne

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RÉSUMÉ

Prérequis : Les maladies inflammatoires chroniques de l'intestin ont un retentissement important sur la vie quotidienne des malades.

But : Décrire la qualité de vie des patients tunisiens ayant une maladie inflammatoire chronique de l'intestin et de la comparer à une population témoin.

Méthodes : La qualité de vie est mesurée par la version tunisienne du questionnaire général SF 36 et du questionnaire spécifique: l'IBDQ-32.

Résultats : Soixante deux patients étaient inclus (23 maladie de Crohn, 39 rectocolite ulcéro-hémorragique). Le groupe contrôle comportait 62 sujets sains. La qualité de vie de malades tunisiens avec une maladie inflammatoire chronique de l'intestin, mesurée par le SF-36, est plus mauvaise que celle de la population témoin sans différence significative. En utilisant l'IBDQ-32, on a trouvé des scores plus bas chez les femmes, les patients avec maladie de Crohn, ayant un niveau socio-économique bas et une maladie active. Les facteurs comme des poussées ou des hospitalisations antérieures, l'ancienneté de la maladie, l'antécédent de résection intestinale, la durée de rémission, le traitement d'entretien, le statut civil et le tabagisme n'avaient pas d'impact significatif sur la qualité de vie de ces malades.

Conclusion : La plupart des patients avec une maladie inflammatoire chronique de l'intestin ont une altération modérée de leur qualité de vie. Cependant, les femmes, les malades ayant une maladie de Crohn active et un niveau socio-économique bas sont les plus affectés. Une meilleure prise en charge clinique et un soutien psychologique de ces malades vulnérables peut améliorer leur qualité de vie.

Mots-clés

Qualité de vie – rectocolite ulcéro-hémorragique- maladie de crohn

SUMMARY

Background : Inflammatory bowel disease (IBD) impairs health-related quality of life (HRQOL).

Aim: To describe HRQOL in Tunisian patients with IBD and to compare it with a reference population.

Methods: HRQOL was assessed with the Tunisian versions of the Medical Outcomes Study Short Form 36 (SF 36) and the Inflammatory Bowel Disease Questionnaire (IBDQ-32).

Results: Sixty two IBD patients were included (23 CD, 39 UC). The control group consisted of 62 healthy subjects. We have shown that HRQOL in Tunisian patients with IBD, measured with the SF-36, is lower than that of a Tunisian reference population without significant differences. Using the IBDQ-32, we found lower scores in women, in patients with CD, with material deprivation, and with active disease. Factors such as the experience of previous relapses or hospitalisations, disease duration, previous resective surgery, remission duration, maintenance therapy, marital status and smoking status do not have a significant impact on HRQOL in these patients.

Conclusion: Most patients with established inflammatory bowel disease showed only minor impairment of their HRQOL. However, women and the patients suffering from active and Crohn's disease as well as the materially deprived patients are most at risk.. Better clinical care and psychological counselling for these more vulnerable groups may improve their quality of life.

Key-words

Quality of life – ulcerative colitis – crohn's disease

Ulcerative colitis (UC) and Crohn's disease (CD) are chronic inflammatory bowel diseases (IBD) that impose a considerable burden on the life of patients. Conventional clinical and morphological indexes based on patients' symptoms and the degree of inflammatory activity may not be enough to estimate the impact of disease on patients' lives and don't assess the important psychosocial repercussions of the disease (1, 2, 3).
The concept of health – related quality of life (HRQOL) encompasses a more complete evaluation of the effects of the disease incorporating physical, emotional and social aspects of health perception, and health functioning (3, 4). Instruments that measure HRQOL can be divided into generic or disease – specific questionnaires.

AIM

To describe, for the first time at our knowledge, HRQOL in Tunisian patients with established IBD and to compare it with a reference population.

METHODS

Between February and April 2008, we enrolled 62 ex-patients suffering from IBD (39 with UC and 23 with CD) seen consecutively at the outpatient unit of the gastroenterology department of Sfax Hospital. Diagnosis was based on conventional clinical, endoscopic, and histologic criteria. As controls, we recruited 62 healthy subjects among the accompanists of patients and the nurses. Control subjects were not matched for age and sex with IBD patients. The mean age in the IBD group was 44,32 years (range, 17 – 79 yr) versus 43,24 years (range, 22 – 79 yr) in the reference population. Sex distribution was 34 men and 28 women in IBD patients versus 32 men and 30 women in control group.
Patient's demographic data and disease – related characteristics are summarized in table 1. Patient HRQOL was assessed using 2 questionnaires. First, the short form 36 (SF-36) is a generic HRQOL questionnaire designed to assess functional status, well being and general perception of health. The questionnaire consists of 8 subscales: physical functioning, bodily pain, vitality level, social functioning, mental health, general health perception, role limitations due to physical health problems and role limitations due to emotional problems. It has been translated into Arabic and validated but not yet published (Allouche C. l'indice SF36 de la qualité de vie: traduction en langue arabe et étude des qualités métrologiques. Doctoral dissertation in medicine. Sfax 2007. Number 2553). Scores varied from 0 to 100 and have a positive correlation with the quality of life. Second, the IBD questionnaire (IBDQ-32) published by Guyatt et al (5) is a self – administered questionnaire that has been translated into Arabic and hasn't been validated yet. It consists of 32 questions that can be grouped into 5 dimensions: emotional function, bowel function I (bowel movements and use of facilities), social function, bowel function II (general bowel symptoms) and systemic function (fatigue, lack of energy, feeling unwell and sleep disturbance). Responses are scored on a 7 – point Likert scale in which 7 corresponded to the highest level of functioning. The instrument produces 5 dimension scores and an overall IBDQ score ranging from 1 to 7. The higher the score is, the better the HRQOL.

Table 1 : Socio-demographic and clinical characteristics of patients

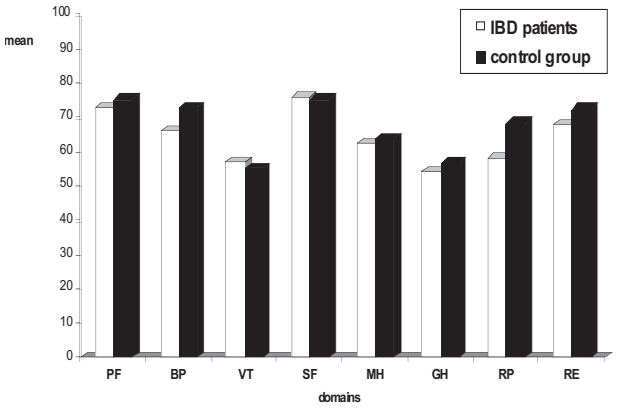
	N (%)
Smoking	20 (32.3)
Married	44 (71)
Material deprivation	16 (25.8)
Patients in remission	58 (93.5)
Remission ≥ 6 months	45 (77.5)
Duration of disease ≥ 5years	32 (51.6)
Maintenance therapy (IS/5ASA)	19 / 41 (30.6 / 66.1)
Previous resective surgery	3 (4.8)
Previous relapses >1	27 (43.5)
Previous hospitalisations >1	19 (30.6)

Statistical analysis was performed with SPSS version 11.0 for windows. HRQOL values were expressed as means. T- Student test was used to compare HRQOL scores between different groups. Two – sided probability values were always computed, and an effect was considered statistically significant at a value of p = 0, 05.

RESULTS

HRQOL in Tunisian patients with IBD, as measured with the generic questionnaire SF-36, was lower than that of a Tunisian reference population. The score differences were most obvious for role – physical and bodily pain but no significant differences were found (figure 1).

Figure 1 : Comparison between SF-36 dimensional scores in IBD patients and control group



PF : physical functioning (p=0.5) ; BP : bodily pain (p=0.1) ; VT : vitality (p=0.5) ; SF : social functioning (p=0.6) ; MH : mental health (p=0.7) ; GH : general health (p=0.4) ; RP : role-physical (0.1); RE: role-emotional (05)

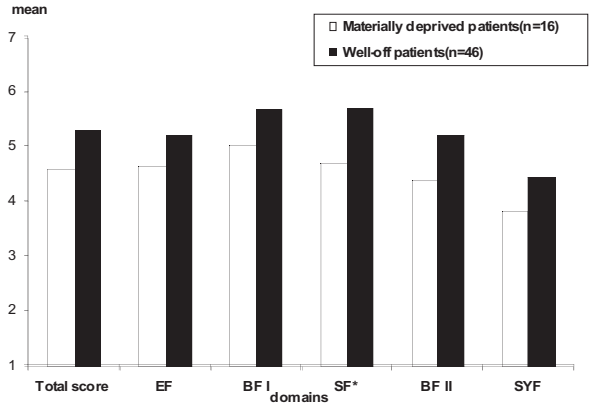
Using the disease – specific questionnaire IBDQ-32, we found that patients younger than 30 years had scores similar to that of the elderly patients. The quality of life was worse in women compared with men. The differences were statistically significant in all dimensions (table2).

Table 2 : Comparison between mean values of the total and the dimensional IBDQ -32 scores according to the sex

	H (N=34) (Standard deviation)	F (N=28) (Standard deviation)	p
Emotional function	5,4 (0,9)	4,5 (1,2)	0,002
Bowel function I	5,9 (1,1)	4,9 (1,4)	0,003
Social function	5,7 (1,1)	5,0 (1,2)	0,02
Bowel function II	5,3 (1,4)	4,5 (1,6)	0,03
Systemic function	4,8 (1,3)	3,5 (1,4)	0,001
Total score	5,5 (0,9)	4,6 (1,1)	0,001

The quality of life was lower in patients with material deprivation compared with well-off patients. The difference was significant only in social domain (figure 2).

Figure 2 : Comparison between mean values of the total and the dimensional IBDQ -32 scores according to the material level



EF: Emotional function (p=0,1); BFI: bowel function I (p=0.1); SF: social function (* p=0.02); BFII: bowel function II (p=0.1); SYF: systemic function (p=0.2); total score (p=0.08)

UC patients reported better HRQOL than CD patients in all domains. The largest impact appeared to be on the bowel function II and the systemic domains with significant differences (table3). We found a significant negative correlation between the clinical activity and the IBDQ total score. The differences for bowel function I and social function were statistically significant, whereas those for the 3 other dimensions were not significantly different (table 4). As shown in table 5, factors such as the experience of previous relapses or hospitalisations, disease duration, previous resective surgery, remission duration, maintenance therapy, marital status and smoking status do not have a significant impact on HRQOL in these patients.

Table 3 : Comparison between mean values of the total and the dimensional IBDQ -32 scores in UC and CD patients

	UC (N=39) (Standard deviation)	CD (N=23) (Standard deviation)	p
Emotional function	5,2 (1,2)	4,8 (1,1)	0,2
Bowel function I	5,5 (1,4)	5,3 (1,2)	0,4
Social function	5,5 (1,3)	5,2 (1,1)	0,3
Bowel function II	5,3 (1,5)	4,3 (1,6)	0,01
Systemic function	4,6 (1,4)	3,6 (1,4)	0,01
Total score	5,2 (1,2)	4,8 (1,0)	0,1

Table 4 : Comparison between mean values of the total and the dimensional IBDQ -32 scores according to the clinical activity

	Remission (N=58) (Standard deviation)	Relapse (N=4) (Standard deviation)	p
Emotional function	5,1 (1,1)	4,1 (1,3)	0,1
Bowel function I	5,6 (1,2)	3,6 (1,4)	0,003
Social function	5,5 (1,2)	4,2 (1,6)	0,03
Bowel function II	5,0 (1,6)	4,0 (1,1)	0,1
Systemic function	4,3 (1,5)	3,1 (0,9)	0,1
Total score	5,2 (1,1)	3,8 (1,1)	0,02

Table 5 : Comparison between mean values of the total IBDQ - 32 score according to socio-demographic and clinical characteristics

		mean score (Standard deviation)	p
Age	≤ 30 years (N=14)	5,0 (1,1)	0,7
	> 30 years (N=48)	5,1 (1,1)	
Smoking status	smoker (N=20)	5,3 (1,0)	0,08
	Nonsmoker (N=42)	5,0 (1,1)	
Marital status	married (N=44)	5,1 (1,1)	0,7
	not married (N=18)	5,0 (1,2)	
Disease duration	< 5 years (N=30)	5,1 (1,1)	0,7
	≥ 5 years (N=32)	5,0 (1,1)	
Remission duration	< 6 months (N=13)	5,4 (0,8)	0,2
	≥ 6 months (N=45)	5,1 (1,1)	
Previous relapses	≤ 1(N=35)	5,2 (1,0)	0,2
	> 1(N=27)	4,9 (1,2)	
Previous hospitalisations	≤ 1(N=43)	5,1 (1,1)	0,6
	> 1(N=19)	5,0 (1,2)	
Previous resective surgery	yes (N=3)	4,6 (1,1)	0,4
	no(N=59)	5,1 (1,1)	
Maintenance therapy	IS(N=19)	5,2 (0,9)	0,6
	5ASA(N=41)	5,1 (1,2)	

DISCUSSION

IBD patients had a reduced HRQOL, as measured with SF-36, compared to the Tunisian background population. We did not find significant differences, which may be explained by the fact that the majority of the patients' sample was in remission. Elsewhere, we did not compare patients with relapsing disease to control group because of their small number.

Bernklev et al (6) found that HRQOL in a Norwegian population – based cohort of patients with IBD, as measured with SF-36, is lower than that of a Norwegian reference population. However, they reported that patients in remission had a scoring profile similar to that of the reference population. Also, Hjortswang et al (7) reported that UC patients in remission had SF-36 scores similar to a Swedish reference population, whereas patients with a relapsing disease had lower scores for almost all dimensions.

Using the IBDQ-32, we found impairment of the health – related quality of life mainly in women, those with Crohn's disease, a relapsing disease and with material deprivation. We found that women's scores were lower than those of men in all dimensions. This sex effect has previously been reported by other authors (2, 6, 8). Psychologic factors may play a greater role in some women than in men (9, 10); women often have a more serious disease – related to worries and concerns - than men (10, 11).

In patients with CD, the scores for bowel function II and systemic function domains were significantly lower than those for patients with UC, indicating that patients with CD have more general bowel symptoms that interfere with their well-being. Some controversy has arisen as to whether HRQOL is more impaired in CD or in UC. A review of the published literature on HRQOL in CD suggests that when generic questionnaires are used, patient's score with CD is similar to, or worse than, that of the patients with UC in almost all areas, and when specific questionnaires are used, the general differences become less apparent (12).

We also found that active disease impairs patient's perceptions of health. The scores for bowel function I and social function were significantly lower in patients with relapsing disease than those of patients in remission, suggesting that bowel movements disturbance interferes with their social life. These data support previous reports of the influence of disease activity on HRQOL (1, 2, 4, 6, 13).

We found that patients with material deprivation had a lower HRQOL. This finding is in accordance with study on United Kingdom patients (8). Our study included patients most of them were in remission, and got them from a single Hospital source, which might bias results.

CONCLUSION

This transversal study using a generic and a specific – disease questionnaires shows that Tunisian patients with IBD experience only minor impairment of their quality of life compared with that of reference population. Patients with Crohn's disease, active disease, material deprivation, and women with either type of inflammatory bowel disease are more likely to show greater impairment of the perception of health. Clinicians responsible for the care of patients with inflammatory bowel disease should be aware of these more vulnerable groups.

Références

1. Zahn A, Hinz U, Karner M, Ehehalt R,Stremmel W. Health-related quality of life correlates with clinical and endoscopic activity indexes but not with demographic features in patients with ulcerative colitis. Inflamm Bowel Dis. 2006; 12: 1058 - 67.
2. Casellas F, Arenas JI, Baudet JS, 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.
3. Oliveira S, Zaltman C, Elia C, et al. Quality-of-life measurement in patients with inflammatory bowel disease receiving social support. Inflamm Bowel Dis. 2007; 13: 470 - 74.
4. Larsson K, Lööf L, Rönnblom A, Nordin K. Quality of life for patients with exacerbation in inflammatory bowel disease and how they cope with disease activity. J Psychosom Res. 2008; 64: 139 - 48.
5. Guyatt G, Mitchell A, Irvine EJ, et al. A new measure of health status for clinical trials in inflammatory bowel disease. Gastroenterology. 1989; 96:804-10.
6. Bernklev T, Jahnsen J, Lygren I, Henriksen M, Vatn M, Moum B. Health-related quality of life in patients with inflammatory bowel disease measured with the short form-36: psychometric assessments and a comparison with general population norms. Inflamm Bowel Dis. 2005; 11: 909 - 18.
7. Hjortswang H, Jarnerot G, Curman B, et al. The influence of demographic and disease-related factors on health-related quality of life in patients with ulcerative colitis. Eur J Gastroenterol Hepatol. 2003; 15: 1011 - 20.
8. Rubin GP, Hungin APS, Chinn DJ, Dwarakanath D. Quality of life in patients with established inflammatory bowel disease: a UK general practice survey. Aliment Pharmacol Ther. 2004; 19: 529 – 35.
9. Drossman DA, Patrick DL, Mitchell CM, Zagami EA, Appelbaum MI. Health – related quality of life in inflammatory bowel disease. Functional status and patient worries and concerns. Dig Dis Sci. 1989; 34: 1379 – 86.
10. Blondel-Kucharski F, Chircop C, Marquis P, et al. Health-related quality of life in crohn's disease: a prospective longitudinal study in 231 patients. Am J Gastroenterol.2001; 96:2915-20.
11. Moser G, Tillinger W, Sachs G, et al. Disease-related worries and concerns: a study on out-patients with inflammatory bowel disease. Eur J Gastroenterol Hepatol. 1995; 7: 853 – 8.
12. Cohen RD. The quality of life in patients with crohn's disease. Aliment Pharmacol Ther. 2002; 16: 1603- 09.
13. Hjortswang H, Ström M, Almeida RT, Almer S. Evaluation of the RFIPC, a disease-specific health-related quality of life questionnaire, in Swedish patients with ulcerative colitis. Scand J Gastroenterol. 1997; 32: 1235-40.