



Implementation of a longitudinal national registry in Iranian IBD patients



Iranian Registry of Crohn's & Colitis

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Background

Recently the quality of life of patients with ulcerative colitis (UC) has been measured with a series of multiple questionnaires. We aimed to assess the quality of life of UC patients who have undergone colectomy compared to a control group of UC patients who have received infliximab.

Methods

An observational cross sectional study was carried out on 140 patients with documented ulcerative colitis referring to an IBD clinic in a teaching hospital. We randomly selected two groups of 70 patients with ulcerative colitis having undergone colectomy or having used infliximab who were in remission for at least a year. Patients were instructed to fill the SF-36 Questionnaire (interviewer-administered) regarding quality of life.

Results

The mean age in the two groups were significantly different, 39.14 ± 11.15 and 32.95 ± 12.18 years, respectively for colectomy and infliximab groups ($P=0.003$). There was a significant difference in general and mental QOL between the two groups ($P=0.041$ and 0.008 , respectively). General and mental QOL had negative linear correlations with number of bowel movements per day. Nocturnal defecation, and stool incontinency did not cause a significant difference in QOL, but anal secretions was shown to significantly decrease physical QOL. Enuresis and urinary hesitancy were seen after colectomy in 13 and 18.6%, respectively. QOL was not statistically related to these adverse effects of colectomy.

Conclusion

We suggest that a disease-specific questionnaire should be designed, making changes in health-related QOL more detectable over time, since it is more sensitive to these changes in IBD patients than a general questionnaire.