Quality of Life in Patients with Inflammatory Bowel Diseases within the CCFA Partners Cohort

Millie D. Long MD, MPH, Michael D. Kappelman MD, MPH, Christopher F. Martin MSPH, James D. Lewis MD, MSCE, Patricia M. Kinneer, Robert S. Sandler MD, MPH

Background and Aims: Quality of life (QoL) in patients with inflammatory bowel diseases (IBD) may change in association with changes in disease activity. A validated instrument, the short IBD questionnaire (SIBDQ), is able to quantify and detect meaningful changes in health related QoL. We aimed to determine baseline QoL in patients with Crohn's disease (CD) and ulcerative colitis (UC) in a national Internet cohort of patients with self-reported IBD (CCFA Partners). We then aimed to determine if QoL changed with disease activity or with duration of IBD. We finally aimed to compare QoL in patients with active UC to QoL in patients status post colectomy with pouch formation.

Methods: We developed an Internet cohort (CCFA Partners) of patients with IBD. Invitations to join the cohort were sent via email to individuals listed on CCFA rosters. Respondents completed a baseline survey that included modules on disease course, disease activity (short CD activity index (CDAI) and simple clinical colitis activity index (SCCAI)), and quality of life (SIBDQ). Only adults (age>17) with IBD were eligible for inclusion. Descriptive statistics were used to compare QoL by CD or UC and also by levels of disease activity. Bivariate analyses and linear regression were to evaluate the effects of disease duration on QoL.

Results: A total of 7819 individuals with self-reported IBD joined CCFA Partners. In the overall population, the median SIBDQ score was 50 (IQR 41-58), CD 50 (IQR 40-58), UC 52 (42-59), p<0.01. The SIBDQ ranges from 10 (poor) to 70 (optimum). See tables below for SIBDQ by disease activity and disease duration.

	Quartiles of disease activity				p value*
	Low CD: SCDAI <73 UC: SCCAI <2	**Low-Medium** CD: SCDAI 73-128 UC: SCCAI 2-3	**High-Medium** CD: SCDAI 129-198 UC: SCCAI 4-5	**High** CD: SCDAI >198 UC: SCCAI ≥6	
CD: SIBDQ mean (sd)	58.4 (6.9)	51.6 (8.0)	44.9 (9.0)	35.4 (9.6)	<0.01
UC: SIBDQ mean (sd)	59.8 (6.5)	52.4 (8.3)	46.1 (8.6)	36.8 (10.2)	<0.01

*one-way anova

	Quartiles of disease duration				p value*
	Short 1-5 years	**Low-Medium** 6-11 years	**High-Medium** 12-21 years	**Long** >21 years	
SIBDQ mean (sd)	47.8 (12.0)	48.7 (11.9)	48.7 (11.5)	49.7 (11.4)	<0.01

*one-way anova

Using linear regression to control for disease activity, disease duration remained significantly associated with SIBDQ for both CD and UC (Beta coefficient 0.07, 0.06 respectively, p<0.01). SIBDQ in UC patients with more active

disease (defined as SCCAI>median) was significantly lower than SIBDQ in UC patients status post colectomy with pouch formation; 40.8 (sd 10.2) vs. 50.1 (sd 11.9), p<0.01.

Conclusions: CD is associated with significantly lower QoL than UC. Increasing levels of disease activity, as measured by validated indices for self-report in CD and UC, are associated with worsened QoL. Increasing IBD duration is associated with improvements in QoL. In UC, colectomy with pouch formation is associated with improved QoL when compared to active disease states. Future studies within CCFA Partners will include other measurements of QoL within the IBD population, and repeated measurements of QoL over time.