The Effect Of Inflammatory Bowel Disease On Patients’ Caregivers

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Background

Crohn’s disease (CD) and ulcerative colitis (UC) usually follow a relapsing clinical course with phases of remission alternating with periods of active inflammation. This dramatically affects the quality of life (QoL) of IBD patients. However, the impact on informal caregivers of IBD patients is frequently overlooked by clinicians. Caregivers – often family members or close friends – aid IBD patients with medical tasks and activities of daily life without receiving compensation. In this study, we aim to assess the impact associated with caregiving for an IBD patient, and to identify potential predictors of such impact that might inform future interventions.

Methods

Online questionnaires were distributed via e-mail in November 2015 to adult IBD patients of the UCLA Centre for Inflammatory Bowel Diseases and their self-identified caregivers. IBD patients filled out the Work Productivity and Activity Impairment (WPAI) questionnaire, the short Inflammatory Bowel Disease Questionnaire (sIBDQ) for QoL and the Mobile Health Index (mHI) for disease activity. The caregivers filled out the Zarit Burden Interview (ZBI) and a caregiver version of the WPAI. Both groups provided information about their demographics and medical history. The survey results were then analysed to assess caregiver burden in different subsets of IBD patient and caregiver populations.

Results

51 IBD patients (41.7 ± 13.9 years, 59% females, 82% employed, 47% CD) and 18 caregivers (45.5 ± 17.5 years, 61% females, 83% wife/husband of patient, 56% employed) responded thus far. Using the mHI, we calculated that 78% of the IBD patients were in remission. An average of 5.8 ± 11 hours were spent on caregiving per week. Also, 22% of the caregivers suffer from a chronic disease. Further, 30% of the employed caregivers had missed work hours as a result of caring for an IBD patient and 70% of the employed caregivers experienced decreased productivity at work due to caregiving. Use of the ZBI showed that 44% of caregivers experienced mild-to-moderate burden as a result of caregiving. Additionally, the ZBI showed that 67% of caregivers felt they could do a better job in caregiving.

Conclusion

The burden that caregivers face as a result of caring for IBD patients is possibly influenced by multiple factors, including both patient and caregiver characteristics. Our results show that, although a large majority of our IBD patients are in remission, a substantial impact remains on the productivity and emotional well-being of their respective caregivers. As this problem is frequently overlooked by clinicians, potential interventions might seek to provide caregiver support to those who care for IBD patients.