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Disability in the Inflammatory Bowel Diseases: Impact of Awareness of the Americans with Disabilities Act

by N.J. Procaccini, S.J. Bickston

Background and Goals—Morbidity from the inflammatory bowel diseases (IBD) can influence patients' ability to maintain employment. The Americans with Disabilities Act (ADA) protects workers with medical conditions to include IBD. Whether factors such as education or awareness of the ADA mediate employment has not been studied. We investigated employment outcomes for a subset of IBD patients and looked at whether this was influenced by education or ADA awareness. **Methods**—A database of nearly 2,000 patients diagnosed with IBD is maintained at the University of Virginia Digestive Health Center of Excellence as part of ongoing research studies. Study surveys were sent in an alphabetical fashion to potential subjects in the database. **Results**—One hundred seventy three subjects participated. Overall, 32.3% (46/142) of subjects who were not retired were unemployed, with a disability rate of 20.4% (20/142). Subjects with post-college education had an employment rate of 91.2% (31/34). College graduates and those with some college education were employed at rate of 72.0% (36/50). Finally subjects with high school education or less were employed at a rate of 41.9% (18/43) ($p < .001$). Of subjects who were employed, 66.0% (64/97) were aware of the ADA compared to 44.4% (20/45) for the unemployed ($p < .025$). **Conclusions**—Persons with IBD have high levels of unemployment. Educational level of patients may play a substantial role in employment outcomes. A significantly smaller percentage of unemployed subjects had awareness of the ADA than their employed counterparts. Interventions aimed at high risk patients may lead to better employment outcomes.

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INTRODUCTION

The inflammatory bowel diseases (IBD), Crohn's disease (CD) and ulcerative colitis (UC), are known to cause considerable morbidity. The incidence of IBD has a bimodal distribution, with peak incidence occurring in young adults between the ages of 15 and 30, and a second smaller peak arising between 50 and 80 years of age (1). Given the incidence of IBD in a young population in their productive years of employment, IBD can affect patients' ability to maintain meaningful employment. Individuals with significant disease require frequent physician visits, periodic hospitalizations or surgeries, all of which translate into lost workdays. Severe and persistent symptoms can lead to permanent disability.

The numbers of patients on disability or unemployed secondary to IBD has not been broadly studied in the United States. One study looked at rates of disability among individuals who identified themselves as having IBD when responding to the National Health Interview Survey (2). The data showed that 31.5% of patients with symptomatic IBD within the prior 12 months were not in the labor force (2). Asymptomatic patients with IBD had a rate of labor force participation similar to the general population (2). A study from Canada examining the relationship between IBD and socioeconomic variables has shown that employment rates for IBD patients fell significantly below their healthy counterparts (3). Unemployment rates after diagnosis (including those on disability) were approximately twice that of the general population (3).

A sub-study from the ACCENT trials, which evaluated safety and efficacy of long-term dosing of infliximab, showed that disease control plays an important role in employment for Crohn's patients (4). Patients with a Crohn's Disease Activity Index (CDAI) score indicating clinical remission were significantly more likely to be employed than their counterparts not in remission (4). A further analysis of patients in the ACCENT I study showed a full-time employment rate of 48% and a disability rate of 25% among an international group of subjects with active Crohn's disease (5). More specifically, another study identified age under 40, an initial requirement for steroid use, and perianal disease as independent risk factors for a disabling course over five years (6). Other factors that

may put patients at risk for disability or unemployment, such as education level, disease subtype (CD versus UC), and awareness of employment rights by federal legislation such as the Americans with Disabilities Act (ADA), have also not been widely studied in the United States.

The ADA was created in 1992 with the purpose of reducing discrimination in the workplace on the basis of disability. Title I of the ADA forbids employers with 15 or more employees from discriminating against a qualified applicant on the basis of a disability (7). Covered employers are required to make reasonable accommodations for employees with disabilities, when such accommodations would not require undue hardship. The ADA has been applied to individuals with IBD on numerous occasions. Recently, a Baltimore company, Browning-Ferris, settled a claim for \$194,000 for terminating an employee with Crohn's disease based on the conjecture that her exposure on the job coupled with her Crohn's disease could lead to life-threatening consequences, despite evidence to the contrary (8).

Given the relative dearth of information on IBD patients and workforce participation in the United States we sought to determine what percentage of a sample of IBD patients were on or had applied for disability or were not working. We then looked at what effect other factors such as education level and knowledge of the ADA had on employment outcomes in our IBD patients.

METHODS

The project was designed as a retrospective study on patients seen in the Inflammatory Bowel Disease clinic at the University of Virginia's Digestive Health Center of Excellence. This is a tertiary and quaternary referral center, drawing patients from several states, both for continuous care and for one-time opinions. A database of nearly 2,000 patients with IBD is maintained at the Digestive Health Center of Excellence as part of ongoing research efforts and through a Silvio M. Conte NIH Digestive Disease Research Center. Patients in the database have been diagnosed with and are undergoing treatment for IBD and have agreed to give blood and tissue samples for ongoing research studies in IBD.

This study met the requirements of our institutional review board.

Study surveys were sent in an alphabetical fashion to members of the survey database. Participation in the study was strictly voluntary. The multiple choice questionnaire queried subjects on demographic information including age, sex, race, disease identifier, (CD UC, or indeterminate colitis), current employment or disability status, and current and past medications or surgeries. Educational level was divided into six categories (graduate/professional degree, some post-college education, college graduate, some college, high school graduate, and some high school and below). For purposes of data analysis these six categories were collapsed into three (post college education, college graduate/some college, and high school education and below). Subjects were specifically queried on their awareness of the Americans with Disabilities Act, but were not questioned on whether they had ever used the ADA. Finally, there was a free-text section of the survey where subjects were invited to add additional information they thought would be helpful.

Data were analyzed for employment/disability outcomes, effect of education on employment/disability outcomes, and the effect of ADA awareness on employment/disability outcomes. For purposes of analysis of employment, the 31 subjects who classified themselves as retired were excluded. Results were analyzed using 2X2 and 2X3 two tailed Chi-Square tests. Statistical significance was set a p-value of < 0.05.

RESULTS

Approximately 330 of the surveys sent out reached potential subjects at their listed addresses. One hundred and seventy three subjects agreed to participate in the survey by filling out the postal survey. The overall response rate was 52.4% (173/330). The majority of patients identified themselves as having Crohn's disease (67.6%), with 22.0% identifying themselves as having UC, and 10.4% with indeterminate IBD.

Our study showed a high rate of non-participation in the labor force. For non-retired, non-student subjects, 56.5% (76/138) were engaged in full-time employment, classified for study purposes as greater than 31 hours per week. Overall, 32.3% (46/142) of our non-retired subjects identified themselves as not currently working. Of these, 20.4% (29/142) were on disability, 7.0% were denied disability and not working (10/142), and 4.9% (7/142) were otherwise unemployed (For employment outcomes by age see Table 1). No substantial differences in disability or employment rates were seen between subjects with CD, UC, or indeterminate colitis.

Overall education level and its effect on work outcomes were evaluated. Among our non-retired subjects there was a significant difference in employment among the most and least educated subjects. Those subjects with some post-college education including those with graduate/professional degrees were employed at a rate of 91.2% (31/34). College graduates and those with some college education were

Table 1
Patient Characteristics

	<i>18–30 years</i>	<i>31–40 years</i>	<i>41–50 years</i>	<i>51–60 years</i>	<i>61–70 years</i>
% employed (n)	87.5 (20)	62.1 (23)	72.4 (21)	51.2 (21)	47.6 (10)
% disabled (n)	8.3 (2)	21.6 (8)	17.2 (5)	19.5 (8)	19.0 (4)
% unemployed (not disabled)	8.3 (2)	16.2 (6)	10.3 (3)	9.8 (4)	0
% retired (n)	0	0	0	19.5 (8)	42.9 (9)

Ages 71–80, one subject currently working, all others retired

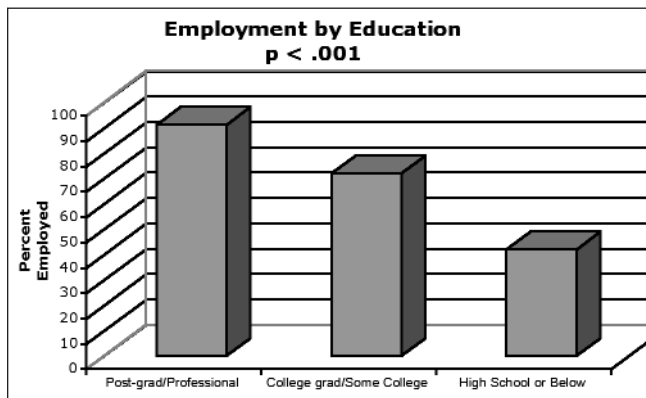


Figure 1: Employment by Education

employed at rate of 72.0% (36/50). Finally, subjects with high school education or less were employed at a rate of 41.9% (18/43) (Chi-square = 21.82, $p < .001$, Figure 1).

We also evaluated our patients' familiarity with the Americans with Disabilities Act and whether this had any correlation with employment in our sample. Overall, a majority of subjects (62.4%) indicated familiarity with the ADA. Among the non-retired subset of subjects a slightly smaller majority were familiar with the ADA (59.9%). A significant difference in ADA awareness was seen among employed and unemployed subjects. Of the patients who were employed, 66.0% (64/97) were familiar with the ADA. Those subjects who were not employed (and not retired) had significantly lower levels of ADA awareness 44.4% (20/45) (Chi square = 5.90, $p < .025$, Figure 2).

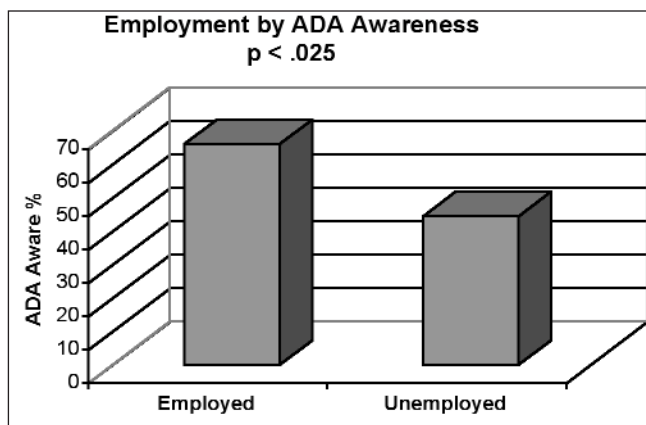


Figure 2: Employment by ADA Awareness

DISCUSSION

Cost assessment of IBD has become an increasingly popular topic with the advent of biologic therapies. The indirect costs of IBD, such as chronic disability, work/school absenteeism, and overall decline in quality of life have largely been neglected in cost analyses of IBD. Studies examining indirect costs have generally come from Europe and Canada; their different health care and welfare systems make the results difficult to extrapolate to the United States. Results from the National Health Interview Survey estimated that symptomatic patients with IBD in the U.S. incurred an annual indirect cost of \$5,228 (1999 figures) (2). The authors conceded that this was likely an under-estimate since factors such as productivity losses from absenteeism, early retirement, and unpaid employment were omitted.

Approaches to reduce indirect costs of IBD related to work loss include improving the overall health of IBD patients through refined therapies. We posit that interventions aimed at preserving participation in the work force are another promising method. This study examines the role IBD plays in employment outcomes, specifically the prevalence of work disability and unemployment among IBD patients. About 32% of our patients were either on disability, denied disability and not currently working, or currently unemployed and looking for work. This confirms the findings of low employment from studies in Canada and Europe (4, 9). This study coupled with prior research indicates that morbidity from IBD is linked to significant disruption in work patterns. Ultimately, this dramatically increases the indirect costs to society.

It makes sense that disease control preserves workforce participation as patients in clinical remission are significantly more likely to be employed (2). Educational level appears to play a similarly intuitive role. Research in disability among patients with rheumatoid arthritis showed lower educational level as a predictor of leaving the workforce prematurely (10). We found a similar trend among our IBD subjects. The distribution of higher levels of employment among subjects with higher levels of education was statistically significant in our population. There are several

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possible explanations for this correlation. Those who are more educated may be in positions with greater authority, allowing them more flexibility in their jobs. There may also be attitudinal differences towards work for those patients who have sought higher education.

In our study we looked at whether a legislative act such as the ADA could have an effect of keeping IBD patients in the workforce. Overall, a majority of our subjects were aware of the ADA. For the subjects in our study who were employed 66.0% were aware of the ADA. Of the patients who had applied for or were on disability only 44.4% were aware of the ADA. Employed patients were significantly more likely to be aware of the ADA than those on disability or unemployed. Such awareness was significantly associated in maintaining employment.

This study has notable limitations inherent to survey based research. There is the potential problem of bias in those subjects who agreed to participate in our database, and further in returning the survey. Illiterate patients would be unlikely to participate in the survey. It is also uncertain whether the data can be generalized from our center to the overall US population of patients with IBD. Referral bias may be a meaningful confounder, but our center does serve a large community based population. Additionally, overall education level is a potential confounder with knowledge of the ADA and employment. Despite these possible limitations, the results of the study are consistent with prior investigations from other countries regarding IBD patients and employment outcomes as well as a U.S. study based on the 1999 National Health Interview Survey.

Ultimately, the causes of disability among IBD patients are multi-factorial. The role of components such as disease control and education levels had already been demonstrated (2). Our data suggest that awareness of the ADA may also be important in the work status of patients with IBD. This is consistent with findings in a study among patients with rheumatologic disease, which showed that employed patients were more knowledgeable of the ADA than the unemployed (11).

These findings suggest that physicians may be able to identify patients who are at high risk for unemployment or disability and target interventions on their behalf. An example of a high risk subject based on data

from prior studies and this study would be a less educated patient with active disease. Options for intervention could include education regarding options for accommodations mandated under the Americans with Disabilities Act, support groups, etc.

Our results point to the need for active intervention among patients with IBD who are at higher risk for disability and unemployment. Morbidity from IBD appears to play a significant role in IBD patients' ability to work. The American Gastroenterological Association estimated in 2000 that indirect costs of IBD from lost wages amounted to \$116.6 million (12). We believe that making more patients aware of the ADA has great potential to help them maintain employment. This can translate to lower rates of disability and underemployment, reduced indirect costs and greater productivity for IBD patients. ■

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