INFLAMMATORY BOWEL DISEASE AND WORKPLACE DISABILITY – WHAT EMPLOYERS AND EMPLOYEES SHOULD KNOW

Dr Andrew McCombie
Research Fellow
Departments of Medicine and Surgery
University of Otago, Christchurch, New Zealand
Email: Andrew.mccombie@otago.ac.nz
OVERVIEW

- Who I am
- What is IBD?
- What is workplace disability
- Workplace disability among people with IBD
- Accommodations for overcoming workplace disability
- Why is bringing more people with IBD into the workplace advantageous
- Devil’s advocate – we need to be realistic
- Real life examples
- Resources
WHO I AM

- Research Fellow University of Otago, Christchurch
- Former Local IBD Support Group Co-ordinator
- PhD entitled “The Psychological Aspects of Inflammatory Bowel Disease”
- Psychology background
- NOT
  - Medical doctor
  - Employment law expert
  - Psychologist
WHAT IS IBD?

- IBD = inflammatory bowel disease (NOT irritable bowel syndrome or IBS)
  - Inflammatory Bowel Disease
    - Inflammatory = when a part of the body becomes reddened, swollen, and painful
    - Bowel = Bowel
    - Disease = disorder that causes symptoms and physical changes
  - Contrast with irritable bowel syndrome
    - Irritable = abnormally sensitive
    - Bowel = bowel
    - Syndrome = generally (1) symptoms caused by some unknown factor, (2) diagnosis usually by collection of symptoms and not a “test,” (3) does not produce visible changes in body
WHAT IS IBD?

- Crohn’s disease (CD), ulcerative colitis (UC), or IBD-Unspecified
  - UC = colon only; CD = mouth to anus
  - UC = continuous inflammation; CD = patchy inflammation
  - UC = inner most lining of colon; CD = deeper inflammation
WHAT A COLONOSCOPY LOOKS LIKE

Ulcerative colitis  Crohn's disease  Normal
WHAT IS IBD?

- Peak onset late teens early 20s

WHAT IS IBD?

- Phenotype variable
- “Montreal Classification”

Simple clinical colitis activity index

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Score</th>
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<tbody>
<tr>
<td>Bowel frequency (per day)</td>
<td></td>
</tr>
<tr>
<td>1-3</td>
<td>0</td>
</tr>
<tr>
<td>4-6</td>
<td>1</td>
</tr>
<tr>
<td>7-9</td>
<td>2</td>
</tr>
<tr>
<td>&gt;9</td>
<td>3</td>
</tr>
<tr>
<td>Bowel frequency (per night)</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1-3</td>
<td>1</td>
</tr>
<tr>
<td>4-6</td>
<td>2</td>
</tr>
<tr>
<td>Urgency of defecation</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
</tr>
<tr>
<td>Hurry</td>
<td>1</td>
</tr>
<tr>
<td>Immediately</td>
<td>2</td>
</tr>
<tr>
<td>Incontinence</td>
<td>3</td>
</tr>
<tr>
<td>Blood in stool</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
</tr>
<tr>
<td>Trace</td>
<td>1</td>
</tr>
<tr>
<td>Occasionally frank</td>
<td>2</td>
</tr>
<tr>
<td>Usually frank</td>
<td>3</td>
</tr>
<tr>
<td>General well-being</td>
<td></td>
</tr>
<tr>
<td>Very well</td>
<td>0</td>
</tr>
<tr>
<td>Slighty below par</td>
<td>1</td>
</tr>
<tr>
<td>Poor</td>
<td>2</td>
</tr>
<tr>
<td>Very poor</td>
<td>3</td>
</tr>
<tr>
<td>Terrible</td>
<td>4</td>
</tr>
<tr>
<td>Extracolonic manifestations</td>
<td></td>
</tr>
<tr>
<td>(Uveitis, pyoderma gangrenosum, erythema nodosum, arthropathy)</td>
<td>1 per manifestation</td>
</tr>
</tbody>
</table>

Source: Harvey RF, Bradshaw JM. A simple index of Crohn's disease activity. The Lancet. 1980;315(8167):514-.

WHAT IS IBD?

- Severity variable
WHAT IS IBD?

- Relapse/remit
WHAT IS IBD?

- Symptoms
  - Inflammation in intestines
  - Fever
  - Fatigue
  - Bowel frequency and urgency
  - Extraintestinal manifestations – skin, eyes, joints
  - Abdominal pain/cramping
  - Fistulae/abscesses

- “Chained to a toilet”
HOW IBD CAN BE TREATED

- Medication
  - 5-ASAs
  - Biologicals (expensive)
  - Thiopurines
HOW IBD CAN BE TREATED

- Diet
  - E.g., low FODMAP; low residue during flares
HOW IBD CAN BE TREATED

- Surgery
  - E.g., bowel resection, colectomy, abscess drainage
HOW IBD CAN BE TREATED

- Psychological
  - E.g., mindfulness, cognitive behavioural therapy, problem solving
WHAT IS WORKPLACE DISABILITY?

- “A disability is a limitation, impairment or restriction that may limit full and effective participation in society—it may be physical, mental, intellectual or sensory.”

- Workplace disability is impaired ability in the workplace caused by illness (e.g., IBD) or injury (e.g., from a surgery for IBD)
  - Absenteeism/Job loss/Underemployment
  - Presenteeism/Productivity loss
WORKPLACE DISABILITY IN IBD

- Why might IBD patients experience workplace disability?
  - Flares/symptoms causing:
    - Sick days/absenteeism
    - Loss of productivity – mental and physical
    - Depression/Anxiety/Agoraphobia – fear of working/loss of confidence
    - Lack of career advancement
    - Impairment of education
    - Unemployment/job loss
HOW CAN IBD WORKPLACE DISABILITY BE OVERCOME?

- Treating the illness
- Workplace accommodations
  - To be discussed

<a href="https://www.freepik.com/free-photos-vectors/background">Background vector created by lexamer - www.freepik.com</a>
ACCOMMODATIONS AND ADAPTATIONS TO OVERCOME WORKPLACE DISABILITY IN INFLAMMATORY BOWEL DISEASE PATIENTS: A SYSTEMATIC REVIEW

Paulides E, Garry RB, de Boer NKH, Mulder CJJ, Bernstein CN, McCombie AM. Accommodations and Adaptations to Overcome Workplace Disability in Inflammatory Bowel Disease Patients: A Systematic Review. Inflammatory Intestinal Diseases. 2018;3(3):138-44.

- Databases: PubMed, MEDLINE (Ovid), Cochrane Central Register of Controlled Trials, and CINAHL

- Inclusion: studies that addressed workplace needs, accommodations and adaptations using survey tools.
# Overview of Studies

<table>
<thead>
<tr>
<th>First author, year, country</th>
<th>Patients, n</th>
<th>Details, n</th>
<th>Response rate (study total)</th>
<th>Method</th>
<th>Outcomes reported quantitatively</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gay [13], 2011, UK</td>
<td>1,304/1,906</td>
<td>currently employed</td>
<td>–</td>
<td>questionnaire</td>
<td>x</td>
</tr>
<tr>
<td>Chhibba [16], 2017, Canada</td>
<td>881/1,143</td>
<td>experienced symptoms at some time while working</td>
<td>46%</td>
<td>questionnaire</td>
<td>x</td>
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<tr>
<td>Lönnfors [14], 2014, Europe (25 countries)</td>
<td>4,670</td>
<td>undefined</td>
<td>–</td>
<td>questionnaire</td>
<td>x</td>
</tr>
<tr>
<td>Zand [15], 2015, US</td>
<td>152/440</td>
<td>currently employed</td>
<td>–</td>
<td>questionnaire</td>
<td>x</td>
</tr>
<tr>
<td>Mayberry [17], 1992, UK</td>
<td>46</td>
<td>currently employed</td>
<td>70%</td>
<td>questionnaire</td>
<td>x</td>
</tr>
<tr>
<td>Restall [18], 2016, Canada(^a)</td>
<td>45</td>
<td>employed/previously employed</td>
<td>–</td>
<td>individual interviews</td>
<td>N/A</td>
</tr>
</tbody>
</table>

\(^a\) Qualitative, so no listed outcomes reported.
WORKING FROM HOME

- 3 studies
  - Crohn’s and Colitis UK (Gay et al)
    - 41% said this was important but 21% said this was an option
- 2 Other studies
  - 10-20% adjusted to working at home

FLEXIBLE HOURS (OR START TIME)

- Four studies
  - Important in 65%, available for 41% (Gay et al)
  - Available for 25% who needed them (Chhibba et al)
  - 15-25% work flexible hours (Lönnfors et al and Zand et al)
CHANCE TO TAKE A BREAK (REST OR TOILET)

- 2 large studies
- Frequent toilet breaks required by 83% but not available for 29% (Gay et al)
- 45% needed chance to take 30-60 min break when not feeling well but available to 26% when asked for it (Chhibba et al)
EASY ACCESS TO TOILET

1 study (Chhibba et al)
- Needed by 71%, available to 43%
- 22% who needed it answered it was somewhat or very difficult to arrange when asked
TIME FOR MEDICAL APPOINTMENT

- 3 studies
  - Most important adjustment in 2 studies (Gay et al and Chhibba et al)
  - Important to 88% available to 69% (Gay et al)
  - Needed by 81%, available for 72% (Chhibba et al)
  - Somewhat or very difficult to arrange in 11% (Chhibba et al)
  - 78% of employers allowed this in a small study (n = 46; Mayberry et al)
REDUCED WORKDAYS EACH WEEK/PART-TIME

- 3 studies
  - Required by 35%, available when asked for by 17%, difficult to arrange in 35% (Chhibba et al)
  - In other studies, 11-15% worked part time (Lönnfors et al and Zand et al)
PREDICTORS OF NEEDING MORE ACCOMMODATIONS

- Chhibba et al 2017
- Predictors of needing 2 or more accommodations
  - Severe or very severe symptoms
  - Not self employed
  - High current emotional distress
  - Female sex
  - Higher educational attainment
- Predictors of need for 1 accommodation that was difficult to obtain
  - High current emotional distress
  - High symptom severity
  - Female sex
WHY MIGHT BRINGING PEOPLE WITH IBD INTO THE WORKPLACE BE ADVANTAGEOUS?

- Person with IBD
  - Self esteem
  - Income
  - Connectedness/contribution to society
  - Purpose

- Employer
  - Diversity
  - Societal good
BEING REALISTIC: THINGS TO CONSIDER

- Career choice
- Employer
  - Cost
  - Practicality
COMMON QUESTIONS

- What should I say in my job interview? Should I disclose my condition?
- If I need an operation for my Crohn’s disease requiring a few months recovery, can I expect to keep my job?
- What accommodations am I allowed to ask for?
- Should I tell my workmates the real reason my performance has dropped for the past month?
REAL LIFE EXAMPLE- AMAZON LAWSUIT

- Former Amazon Employee With Crohn's Disease Files Lawsuit Over Lack of Bathroom Access.
- Nicholas Stover, a former Amazon employee who lives with Crohn’s disease, has filed a lawsuit against the company for discrimination under the Americans With Disabilities Act (ADA) and Kentucky law.
- Stover alleges the company refused to accommodate his need for more frequent bathroom access as a result of his illness.
- Employed from November 2016 until he was fired in December 2017.
- Disclosed the details of his disease when he applied and during his training, but claims he was not informed of the company’s break and schedule policies before he was hired.
- Employees at the Winchester call center typically work nine-hour shifts, including a one-hour break for meals and two additional 15-minute breaks.
- These breaks are scheduled by Amazon and can’t be changed by employees. Employees are also given up to 10 minutes of unscheduled personal time per shift, but no more than 20 minutes per week.

Source: https://themighty.com/2019/02/nicholas-stover-amazon-crohns-disease-lawsuit-bathroom-access/?fbclid=IwAR0ETyeebDBbou8Xa437vcj7Llh5mX7BF150mKXjiCSFGHJl8vGvHS4eU
REAL LIFE EXAMPLE- AMAZON LAWSUIT
(CONTINUED)

- After six months of working at Amazon, and being continually reprimanded for using the bathroom more frequently than was allowed, Stover requested an accommodation.
  - His doctor filled out an Amazon accommodation request form, stating that Stover “must have [a] bathroom facility readily available.”

- However, according to Stover’s complaint, Amazon did not offer to make any changes or accommodations for him. He alleges a human resources officer told him that if the company accommodated his bathroom needs, they would have to accommodate everyone’s bathroom needs.

- The Seattle Times reported that disability law experts who examined Stover’s complaint believed his requests for more frequent bathroom access would be considered “reasonable.”

- Source: https://themighty.com/2019/02/nicholas-stover-amazon-crohns-disease-lawsuit-bathroom-access/?fbclid=IwAR0ETyeebDBbonBXa437_vwJ17Li5mX7FTs0mKXjCSPGJi8vCrHS4eU
RESOURCES

- Crohn’s and Colitis United Kingdom website
  - https://www.employment.govt.nz/workplace-policies/employment-for-disabled-people/reasonable-accommodation-measures/?fbclid=IwAR0qN9xJUiD1MCh9l4ZLZepAYiuVjWLmYy1gsj8JA4mJt8BVQojn8N1jw1A

- Employment New Zealand Website
WHAT DO THESE RESOURCES SAY?

CROHN'S & COLITIS UK

FIGHTING INFLAMMATORY BOWEL DISEASE TOGETHER

INFORMATION SHEET

EMPLOYMENT AND IBD: A GUIDE FOR EMPLOYEES
Deciding whether to disclose your IBD
  ▪ During recruitment
  ▪ Once you’ve been offered the job
  ▪ In your current job

Choosing whether to tell colleagues

What are my employment rights?

When is IBD a disability?

What protection do I have under the equality act?

What are reasonable adjustments?

What is access to work?

Living with a stoma at work

Travelling to work

What can I do if I feel I have been treated unfairly?

Etc.
CROHN’S AND COLITIS UK — ADVICE FOR EMPLOYERS

- What are the symptoms of IBD?
- What IBD is not
- What causes IBD
- What can be the effects of treatment?
- Does IBD affect the employee’s ability to do their job?
- How can employers help?
- What are the needs of people with IBD likely to be?
- Is IBD covered by the Equality Act 2010?
- Deciding on reasonable adjustments
- Examples of reasonable adjustments for people with IBD
- What is access to work?
- What to do if an employee feels that they have been unfairly treated or discriminated against?
- Etc.
EMPLOYMENT NEW ZEALAND WEBSITE

- https://www.employment.govt.nz/workplace-policies/employment-for-disabled-people/reasonable-accommodation-measures/?fbclid=IwAR0qN9xJUiD1MCh9l4ZLZepAYiuVjWLmYy1gsj8JA4mJt8BVQojn8N1jw1A
FUTURE RESEARCH

- Resources needed for more countries
- How many IBD patients understand their rights?
- How many employers understand IBD and rights of IBD patients?
- Interventions to improve employment outcomes for IBD patients
CONCLUSIONS

- IBD is serious and lifelong
- IBD affects employment outcomes
- Accommodations useful
- More work needed to help employers and employees understand rights of IBD patients
REFERENCE LIST (OVERCOMING WORKPLACE DISABILITY)

- Paulides E, Gearry RB, de Boer NKH, Mulder CJJ, Bernstein CN, McCombie AM. Accommodations and Adaptations to Overcome Workplace Disability in Inflammatory Bowel Disease Patients: A Systematic Review. Inflammatory Intestinal Diseases. 2018;3(3):138-44.


