Swimming Against the Current
Work Experiences and Adaptations Made by Employees with Arthritis

Rebecca Purc-Stephenson, Ph.D.
Department of Social Sciences, Augustana Faculty
University of Alberta
What Will You Learn?

• What are the four most common challenges employees with arthritis experience at work
• What are the strategies employees with arthritis use to maintain employment for as long as possible.
  • The Job Sustainability Model
The good life?

About 3.8 million Canadians, or 13.7% of the population, have a physical disability.

What are the challenges of living with a physical disability?

Finding and sustaining durable employment.

What is “Physical Disability”?  

• World Health Organization (2005):
  • Defines as “a problem in body function or structure resulting from an accident, illness or disease that potentially impairs performing a task or action.”

• Visible vs invisible disabilities?
  • Many symptoms can be concealed
  • Employees with disabilities are still stereotyped as unproductive and incapable workers
Differences Across Canada

Percentage with disabilities, aged 15 years or older

- Nunavut: 6.9%
- Northwest Territories: 8.2%
- Yukon: 14.4%
- British Columbia: 14.8%
- Alberta: 12.5%
- Saskatchewan: 15%
- Manitoba: 15.6%
- Ontario: 15.4%
- Quebec: 9.6%
- New Brunswick: 16.4%
- Nova Scotia: 18.8%
- Prince Edward Island: 16%
- Newfoundland and Labrador: 14.1%
Focusing on Arthritis

Chart 2
Percentage reporting a diagnosis of arthritis, by age group and sex, household population aged 15 or older, Canada, 2014

Source: Canadian Community Health Survey, 2014.
Focusing on Arthritis

- Osteoarthritis: 27 million
- Fibromyalgia: 5 million
- Gout: 3 million
- Rheumatoid arthritis: 1.5 million
- Lupus: about 320,000
Arthritis & Work

• Leading cause of work disability among adults

• Employment rate is about 75%

• 3 out of 5 people with arthritis are of working age

• Not in labour force risk: women, older, less education, lower income

What’s common with other conditions?

• Limited in the type of work they can do

• Reduced work hours

• Employment rates drop over time
Purpose of the Study

• The goal was to:
  1. review qualitative research
  2. understand how successfully employed persons with arthritis maintain employment, and
  3. use this information to build a conceptual model.

What’s a “model”? 
Methods

Studies located 
\( (n = 7,330) \)

Duplicates removed 
\( (n = 2,090) \)

Records screened 
\( (n = 5,240) \)

Studies screened out based on title/abstract 
\( (n = 5,002) \)

Full-text studies reviewed 
\( (n = 238) \)

Studies screened out b/c did not meet criteria 
\( (n = 187) \)

Selected studies 
\( (n = 51) \)

Study 1: Mixed 
(19 studies, \( n = 450 \))

Study 2: Arthritis 
(17 studies, \( n = 873 \))

Study 3: MS 
(15 studies, \( n = 495 \))
Our Main Findings

Who was included?

- 17 studies (873 employees)
- 73% females
- RA & fibromyalgia
- Most studies from Sweden

4 Main Challenges:

1. Managing symptoms
2. Adjusting to a new work reality
3. Navigating people & place
4. Testing ways to adapt at work
(1) Managing Symptoms

Unpredictable Physical Symptoms

“…it’s episodic – it can come and go...I can be well enough that I can push and do things more than I normally can, but it sets me back into [a pain] episode.”

Emotional Issues

“It was devastating for me and it threw me into a real depression when I was told ‘you are either full-time or not at all.’ That was the most devastating thing they could have possibly said to me...”

Cognitive Struggles

“I’m totally exhausted some days...and it’s like my brain stops working, and that’s the thing I think is worst, that logical thinking disappears.”

“‘And I don’t think they understand the tiredness aspect of it because you look fine. ‘What is she complaining about? She looks fine, she’s not sick’.”

“When the pain goes over a certain limit, I can become a little... aggressive... I can answer in a way that I wouldn’t otherwise.”

It was exceptionally difficult ...keeping your concentration on work rather than thinking of which bit hurt now, and I was just exhausted most of the time because of the pain
(2) Adjusting to a New Work Reality

**Personal Meaning of Work**

“If it hadn’t been for the work, I don’t believe I would have recovered; my work provided the motivation to go back.”

**Preserving a Work Identity**

“We are taught that without work we are not worth anything . . . It is as if I exist when I get out [to work] . . . you are confirmed in some way... otherwise you are nobody, just a burden on others.”

“To me, work means having social contacts and getting back into society again. Not living on the outside and looking in . . . Even if you are in pain . . . That does not matter . . . because it is worth it.”

“So I would like to engage in working life as everyone else . . . I would like to live as usual . . . I used to bite the bullet to be able to continue to work.”
(3) Navigating the People & Place

**Managing Disclosure**

“They treat you as if you’re mentally frail as well as physically frail… People talk to me as though I am dependent on them.”

**Gaining Co-worker Support**

“You cannot pass work over to a workmate, because they are working at full steam too.”

**Understanding the Organizational Culture**

“It is a little company . . . either you work as everyone else does or you have to stay at home.”

“I wouldn’t have told people in my previous job only things got really bad.”

“Co-workers are always the first ones I tell. Because if my disease may affect them and I want them to understand that I’m not just faking”

“You guys talked about going slower. I don’t have that option. I’m not allowed to go slower. I have to go faster every single day and … I’m forced to compensate for what I can’t …”
(4) Testing ways to Adapt at Work

"I pace my work so that I get lots of work done at a time when I'm not in too much pain."

Making Personal Adjustments

"Leisure activities have to be postponed because of tiredness after work ... there is no energy left, it is empty."

Using Social Support

"I have one workmate who I actually think she has it, just the way she describes her pain and her tiredness...She gets it, she totally gets it and that's really nice."

Changing to less demanding jobs:

"The maintenance job was so easy compared to the job I used to have."

Using Workplace Accommodations

"And they got in an ergonomic specialist to make sure that everything was within reaching distance for me."

"My family is conscious about my problem. ...[T]hey are helping me ..."
Job Sustainability Model

Personal Factors
- Work identity
- Self worth
- Symptom management

Trigger Event

Self-Assessment & Information Gathering
Perceived benefits
- Financial security
- Social inclusion
- Sense of purpose
- Distract from symptoms

Perceived barriers
- Fear of stigma
- Fear of discrimination
- Unwanted advice

Personal thoughts & feelings
(weigh benefits & costs)

Interpersonal Influences
- Co-worker support
- Supervisor support

Work Environment Influences
- Physical workspace
- Job design
- Social climate

Organizational Culture
(norms, expectations, diversity)

Evaluate + Make adjustments

Work Sustainability Strategies

Make Personal Adjustments
- Take rests
- Pace & plan work
- Avoid certain activities

Use Social Support
- Redistribute chores
- Reduce social activities
- Limit leisure activities

Explore Medical Interventions
- Try medications
- See healthcare provider
- Try new treatments

Disclosure

Use Workplace Accommodations
- Modify hours
- Modify workspace
- Use assistive devices

Use Social Support
- Work with co-workers
- Use supervisor support
- Use HR resources & Disability Specialists
Take-Home Messages

• Employees with arthritis face a range of challenges that can seriously disrupt their work and potentially shorten their career length
  • Willing push through the pain and fatigue
  • Wants to avoid “disabled” label

• Identity Theory (Striker, 1968)
Take-Home Messages

• Differences between the other disability groups?
  • Adapting to work is sometimes a two-phase approach

• Dealing with fatigue and exploring strategies
  • Lack of understanding from others ➔ more awareness
  • Few resources on how to cope ➔ more opportunities to share
Take-Home Messages

• The pros & cons to disclosure
  • Employees are generally uncomfortable to tell others
  • Consider who, when, & how much to share
  • Advice for co-workers & supervisors?

• What gaps in research did this study uncover?
  • 17 studies from 7 countries
  • 7 of these studies from Sweden, 4 from Canada
Next Steps & Questions?

- Next steps?
  - We’re looking at the organizational context
    - What can organizations can do to make the workplace more disability-friendly?
    - What are the barriers to return to work?
    - Want to be involved? Contact me purcstep@ualberta.ca

- Questions?