

Strategies for employers to retain employees with fibromyalgia, a contested chronic illness

Margaret Oldfield, PhD

Webinar, Centre for Research on Work Disability Policy

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margaret.oldfield@alum.utoronto.ca

Overview

- Layers of social context surrounding employees with fibromyalgia
- Disclosure checklist
- Three kinds of accommodation
- Other strategies for retaining employees with fibromyalgia
- Take-home messages
- Research and outreach project currently developing with community partners

Thesis and projects since then

PhD thesis, Rehabilitation Science, U of Toronto

- Staying in the Workforce with Fibromyalgia

Cancerandwork.ca

- Website designed for cancer survivors who want to remain at or return to work, health professionals, and employers

Project for Mental Health Commission of Canada

- Explore organizational strategies and practices that promote retention of employees with mental illness
- Clear business case for retaining employees with mental illness

Presentation informed by thesis research and subsequent projects

Fibromyalgia

Chronic illness

- Widespread pain, extreme fatigue, unrestful sleep, brainfog etc.

Canadian Community Health Survey, 2014 (self-report)

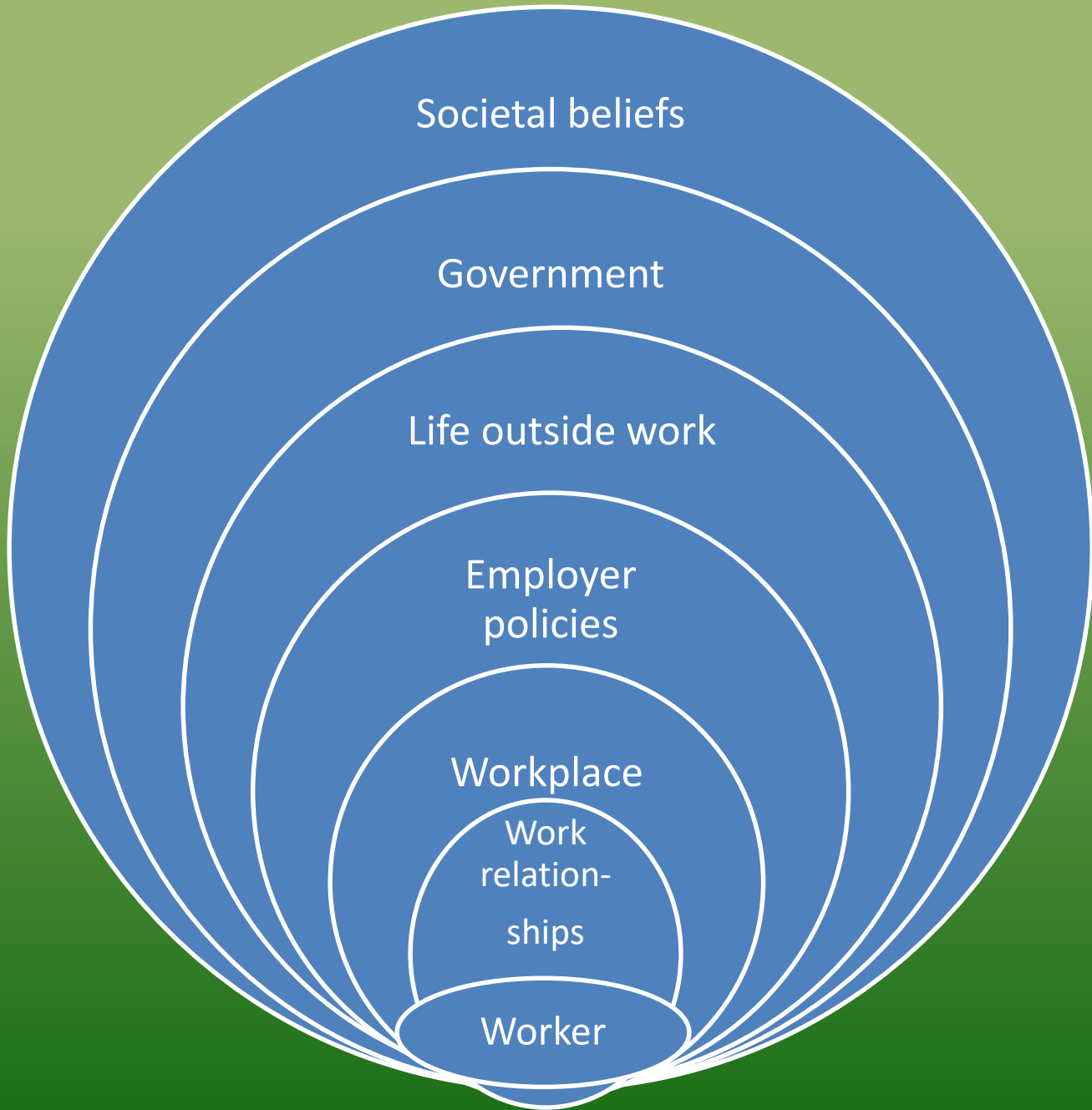
- 500,000 Canadians
- Mostly female (82%)
- Mostly age 45-74 (77%)
- Mostly White (82%)
- About 40% aged 25-75 had job in 2014

(Park & Gilmour, 2017)

Cause unknown, medically disputed → Stigma, invisibility

1 Myocardial infarction	14 Deafness	26 Dysmelia
2 Leukemia	15 Spina bifida	26 Anorexia
2 Brain tumor	16 Arthritis	26 Dyslexia
4 Lung cancer	17 Bechterew's disease	29 Psoriasis
5 Colon cancer	18 ADHD	30 Depression
6 Pancreatic cancer	18 Autism	30 Schizophrenia
6 Thyroid cancer	18 AIDS	32 Sciatica
6 Ovarian cancer	18 Cataract	33 Aphasia
9 Blindness	22 Cerebral palsy	33 Myalgic encephalomyelitis
10 Asthma	22 Huntington's disease	35 Anxiety neurosis
10 Pulmonary embolism	24 Muscle diseases	36 Restricted growth
12 Multiple sclerosis	24 Down syndrome	37 Fibromyalgia
13 Epilepsy		38 Cirrhosis of the liver

Adapted from Table 2 in Grue, Johannessen, & Rasmussen. (2015). Prestige rankings of chronic diseases and disabilities. A survey among professionals in the disability field. *Social Science & Medicine*, 124, 180-186. Note: Same rank = same mean score.



Societal beliefs

Government

Life outside work

Employer
policies

Workplace

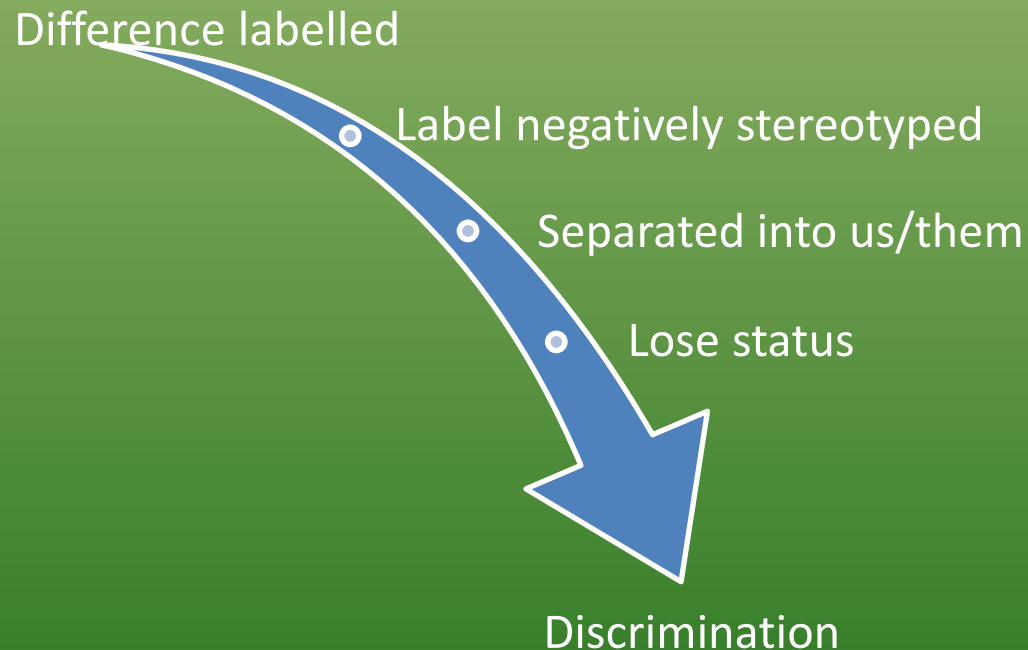
Work
relation-
ships

Worker

Disclosing illness at work may be risky

- Disbelief, not physically ill
- Impairments seen as not serious
- Assumed to be less capable →
damaged reputation
- Uninvited advice, comparison

The stigma process



Disclosure checklist

Things to think about before disclosing

Adapted with permission from Oldfield, M., Parkinson, M., Maheu, C., and Stergiou-Kita, M. (2016).

Personal preferences

- Prefer to keep personal matters private at work?
- Or feel that sharing personal information with fellow employees is best?
- Feel comfortable talking about personal situations?

Workplace relationships

- What are relationships with supervisor and co-workers like?
- Were there any tensions in these relationships before the fibromyalgia?
- Who can be trusted with personal matters?

Culture of the workplace

- How have other employees been treated when they revealed health-related difficulties?
- Is the workplace friendly and close-knit, or formal and business focused?
- Are employees with disabilities respected and fully included?

Organizational policies

- Does the employer have policies and practices to help ill or injured employees stay at work?
- Is there an accommodation policy and process?
- Is there an anti-harassment policy?

Three types of accommodations

Formal

- Requires disclosing need
- Formal application process
- Must be medically approved
- Documented in worker's personnel file
- Follows worker in job transfer or change of supervisor

Informal

- Negotiated with the supervisor
- Depends on a trusting relationship
- Requires disclosing need
- No need for medical approval
- May not follow worker to new job or new supervisor
- Should be documented in writing

Universal supports

- Generally available to all employees, depending on job
- Don't have to disclose need
- Flexible hours
- Work at home
- Drug plan, extended healthcare coverage
- Sick leave
- Time-in-lieu of overtime pay
- Vacation leave
- Leaves of absence
- Personal days, mental health days, floating days

Other strategies for retaining employees with fibromyalgia

- Frequent breaks
- Resting room or couch
- Transfer to a better job fit within company
- Allow part time or job sharing
- Permanent partial long-term disability insurance

Take-home messages

Think big

- Multiple contextual layers surrounding employees with fibromyalgia
- Extend beyond organization

Disclosure may be risky, need to consider carefully

Facilitate informal accommodations, document them

Expand employee benefits, universal supports

References

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Research and outreach project under development

- Share information widely with employers on how to retain employees with fibromyalgia
- Explore how workers with myalgic encephalomyelitis (ME) stay at work
- Welcome academic researchers interested in joining project team
- Also employers

Please contact me at
margaret.oldfield@alum.utoronto.ca

