Long COVID as an Episodic Disability: Implications for Workplace Communication, Disclosure and Accommodation Planning

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ACED
Accommodating and Communicating about Episodic Disabilities

A research partnership to support the sustained employment of people with intermittent, chronic health conditions

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Conseil de recherches en sciences humaines du Canada

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CIHR IRSC
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Instituts de recherche en santé du Canada

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Overview

How do we improve communication-support process for people living with long COVID and other episodic disabilities to enhance their ability to gain and sustain employment?

- What unique challenges do long COVID and other episodic conditions create for workers and workplaces that employers should be aware of?

What does research tell us about next steps and solutions?

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Long COVID

- Also called post-acute sequelae of SARS-CoV-2 (PASC) and Post COVID-19 Condition (PCC)

- 14.8% of Canadians who experienced COVID-19 have persistent symptoms for three months or more after their initial infection

- That translates into 4.6% of Canadians (1.4 million people) aged ≥18 years

- Common symptoms include tiredness, fatigue, brain fog, coughs and shortness of breath

- We currently lack good data on long COVID disability numbers at work and work disability

https://www150.statcan.gc.ca/n1/en/daily-quotidien/221017/dq221017b-eng.pdf?st=cFvuKTlT

What is meant by a disability?

- Living with a chronic or episodic health condition does not guarantee a disability

- A disability arises as a result of the interaction between a health condition **AND** personal and environmental factors, including negative attitudes, activity limitations, public policies and practices, inaccessible physical environments, and limited social support

- Changes to work demands or work practices may help to minimize or ameliorate disability

World Health Organization (WHO), https://www.who.int/health-topics/disability

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Episodic Disability

Long COVID shares characteristics of many episodic chronic conditions in being intermittent, unpredictable, and invisible

For workplaces there are unique challenges in balancing:

- Workplace disability communication, disclosure, and the protection of privacy

- Needs for support or accommodations and the maintenance of workplace productivity

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Disclosure of an Episodic Disability – Survey Studies
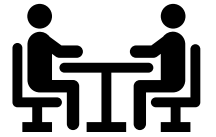
- In 5 Canadian surveys (n = 3387), 25%-49% of participants **had not shared** any information with their supervisor about mental or physical health limitations that created an episodic disability

- Decisions whether to share were ongoing and complex even when deciding not to say anything

- Decisions were often guided by **goals**, **needs**, **protecting one's reputation**, **perceived trust and support**, and **perceived job insecurity**

Gignac & Cao, 2009; Gignac, Cao & McAlpine, 2015; Gignac, Kristman, Smith et al., 2018; Gignac, Bowring, Jetha et al., 2020; Gignac, Jetha, Ginis & Ibrahim, 2021; Gignac, Shahidi, et al., 2022; Gignac et al., 2022 (ongoing)

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What do we know about communication decisions?

There is no single correct communication decision. There are examples of positive and negative experiences with both decisions.

	Positive outcomes include:	*Negative outcomes include:*
Disclose	• support • greater understanding	• having to prove oneself • stigma
Do not disclose	• less stress • less concern about how others view you	• absence of support • misperceptions about reasons for any job difficulties

(Gignac & Cao, 2009; Gignac, Bowring, Jetha, et al., 2020; Gignac, Jetha, Ginis, Ibrahim, 2021; Hayward et al., 2016; Stergiou-Kita et al., 2016; Stutterheim et al., 2017)

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Summary: Research on communication of a disability

- Similarities and few differences were found between workers living with physical versus mental health disabilities in disclosure decisions, reasons, and outcomes

- Workers with mental health/cognitive conditions reported more negative outcomes like stigma and negative performance evaluations when they chose NOT to disclose

- This may be because of "leaked" signs of a disability and misperceptions about the workers as lacking motivation, being unreliable, or having poor interpersonal skills

- Will this be a particular issue to watch in long COVID?

Workplace Perspectives

What do those whose job it is to support workers with episodic disabilities believe are the key issues and challenges to disability support?
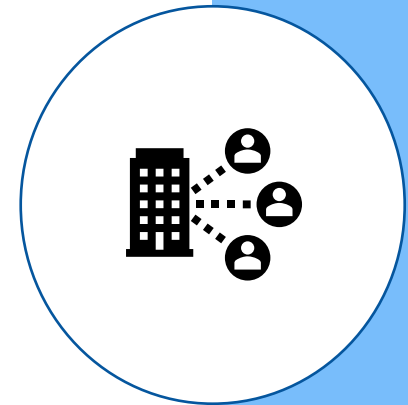
Springer Link

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Disclosure, Privacy and Workplace Accommodation of Episodic Disabilities: Organizational Perspectives on Disability Communication-Support Processes to Sustain Employment

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Abstract

Purpose Employers increasingly are asked to accommodate workers living with physical and mental health conditions that cause episodic disability, where periods of wellness are punctuated by intermittent and often unpredictable activity limitations (e.g., depression, anxiety, arthritis, colitis). Episodic disabilities may be challenging for workplaces which must comply with legislation protecting the privacy of health information while believing they

Medical versus biopsychosocial models of support

- Workplaces have different models to frame disability and support

- Medical models are common (i.e., focus is on the worker; health information needs to be validated and closely monitored)

- Biopsychosocial models are increasing (i.e., disability goes beyond a medical diagnosis to include the workplace environment). Participants noted:

    a) Health professionals were not able to provide relevant information

    b) Workers could not get timely or appropriate access to specialist care

    c) A worker's condition didn't remain private depending on the specialization of the health professional providing a medical note

Challenge 2: Misgivings about others in workplace support

- Participants acknowledge that others play important roles in supporting individuals with health and disability needs

- Yet, comments frequently include concerns about others' skills, training, motivation and involvement in support efforts

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Challenge 3: Casting disability as a performance problem

- In large organizations, formal communication is often triggered by a threshold of work absences (e.g., attendance management/ attendance support programs)

- Workers AND workplace parties acknowledge they can:
  1. Pressure workers into disclosing *something*
  2. Re-cast disability as a performance problem (i.e., progressive disciplinary actions needed)
  3. Focus future discussion on performance deficits and not skills and abilities
  4. Erode trust and confidence in the disability support process

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Challenge 4: Difficulties Arising When a Worker Denies a Problem

- In rare instances, workers with mental health conditions deny a problem when confronted by a supervisor or HR professional

- These are among the most challenging, prolonged, and stressful situations for all parties

- Success in managing was variable and often resulted in heightened interpersonal tensions

- This can have implications for long COVID

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Bottom Lines:

Workers often want guidance on their options, whether to communicate, and what, when and how to share information.

Workplaces want a transparent, consistent and comprehensive approach to assessing worker job demands and support strategies

Accommodating and Communicating about Episodic Disabilities (ACED)

New Workplace Tools: https://aced.iwh.on.ca/

- Job Demands and Accommodation Planning Tool (JDAPT)

- Communication Decision-Support Tool

Job Demands and Accommodation Planning Tool (JDAPT)

- Focuses on work demands that may be challenging at times or on a regular basis

- Guides the user through a series of simple questions about their job tasks and working conditions

- Provides a personalized list of suggested ideas relevant to an individual's job demands. The ideas can help generate solutions that work for a person's needs

- Can be used to discuss support needs with others and focus on work solutions, not a health or disability diagnosis or symptoms

The JDAPT prototype was the grand prize winner in the MaRS-CIBC Inclusive Design Challenge: Support at Work

Grand Prize

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Job Demands & Accommodation Planning Tool (JDAPT)

24 types of job demands and working conditions organized in four domains:

Physical tasks (5 items)

Cognitive or "thinking" tasks (6 items)

Working with others (5 items)

Working conditions (8 items)

- **Worker version**: self-assessment of job demands & challenges

- **Organizational version**: can be completed by workplace staff & employee for planning

Job Demands & Accommodation Planning Tool (JDAPT)

24 types of job demands and working condition organized in four domains:

Physical tasks (5 items)

e.g., working with your hands

Cognitive or "thinking" tasks (6 items)

e.g., concentrating for long periods

Working with others (5 items)

e.g., communicating, negotiating or motivating others

Working conditions (8 items)

e.g., working with hazardous equipment or situations

For each demand, user rates
  a) **Importance** *to the job*
  b) **Difficulty** *due to health*
  c) **Change** *in ability over time*

↓

Personalized Report

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Linked Support Strategies & Accommodation List

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Job Demands & Accommodation Planning Tool (JDAPT)

Physical endurance or stamina

Things you might try on your own

- Try to maintain a good posture to reduce pain and/or fatigue when working
- Wear comfortable shoes with a good grip and support

Adjustments you could try at work
(you may or may not need to request permission to do these)

- Use a stool or footrest to help you change positions while working
- Pace your work to avoid becoming tired
- Take the time you need to follow workplace safety guidelines and keep your attention up to avoid injuries
- Plan your more difficult tasks for when you are feeling better
- Switch between tasks to vary your position and reduce strain
- When doing the same task, take the time to change your position to reduce strain
- Adjust your breaks to help maintain your energy – this could mean either taking regular or more frequent breaks, or fewer but longer breaks, depending on your needs
- Ask others for assistance
- Ask your supervisor for adjustments for work meetings or events

Formal accommodations to consider requesting

- Furniture or equipment that can help reduce strain
- Request a flexible or alternative work schedule which allows you to work when feeling better and have more energy
- Permission to work at home on some days if this is possible in your job
- Temporary or permanent job modification, which means re-assigning or reducing time spent on less important or less essential tasks

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Use a stool or footrest to help you change positions while working
- high stool for alternative sitting and standing at a counter
- low stool or rail to rest feet on one at a time when standing
- footrest to raise feet while sitting

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Job Demands & Accommodation Planning Tool (JDAPT)

Concentrating for Long Periods

Things you might try on your own

- Do calming or refreshing activities during breaks to bring back focus or to "reset"

Adjustments you could try at work
(you may or may not need to request permission to do these)

- Turn off phone and/or computer notifications while working on a specific task
- Use a timer to set working times and mini breaks which can help with concentration
- Use applications to reduce distractions
- If there are no safety or interpersonal concerns, wear headphones or ear plugs to exclude other sounds
- Introduce background noise if that helps you focus
- Adjust light and/or heat to enhance concentration
- Plan your more difficult tasks for when you are feeling better
- Schedule blocks of time to concentrate on one task without distractions or interruptions
- Adjust your breaks to help maintain your energy, either regular or more frequent breaks, or fewer but longer breaks
- Move your work temporarily to a less distracting location and/or new surroundings which may help with focus

Formal accommodations to consider requesting

- Changes to your workstation to reduce distractions
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Use a timer to set working times and mini breaks which can help with concentration
- work at one task for 30 minutes, then take a mini break to stretch or walk around before working for another 30-minute session

JDAPT Testing
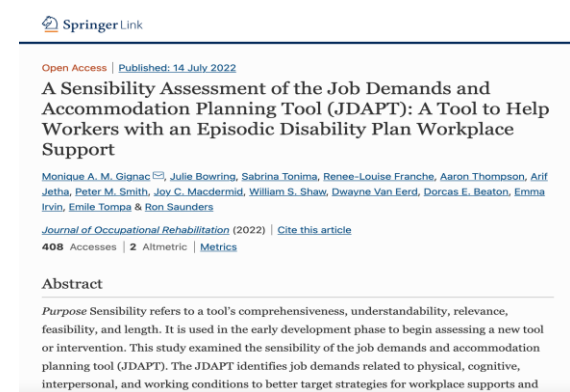
In-depth pilot testing and cognitive debriefing of the JDAPT conducted with:

- ~ 20 research experts

- ~ 12 partner representatives from different health charities

- 46 workers living with diverse types of episodic health conditions

- 23 organizational representatives (e.g., supervisors, HR personnel, disability managers)

- Diverse organizations and job types (e.g., sales/service, education, manufacturing, health, government, transportation, financial, hospitality)

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JDAPT Testing

- Participants liked the JDAPT overall and reported high need for it

- Participants living with episodic conditions reported somewhat more usefulness than organizational representatives

- The JDAPT was relatively easy to understand and relevant to a range of different episodic disabilities, occupations, and personal characteristics (e.g., gender, age)

- An evaluation testing the JDAPT is underway (n = 289). Participants complete:

  - An initial assessment and the JDAPT

  - A 3-month follow-up

  - A 9-month follow-up

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Five Take-Home Messages

Long COVID shares many characteristics of common chronic physical and mental health conditions that contribute to an episodic disability at work.

A condition alone does not create disability at work. Disability arises when health and work demands, situations, and environments interact.

The impact of a disability can often be minimized or ameliorated with support and accommodations.

The decision whether or not to disclose personal information about one's needs is complex, ongoing, and often stressful.

New tools can facilitate support provision in the workplace.

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Thank you!

Questions? Comments?

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ACED website with JDAPT:
https://aced.iwh.on.ca/jdapt/worker-en

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