

# Bureaucracy, Chronic Pain, and Poverty:

# Disability Benefits as Structural Violence

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# PRESENTER DISCLOSURE



Presenter: **Ginetta Salvalaggio**

Relationships with financial sponsors:

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# PRESENTER DISCLOSURE



**Presenter: Kathleen Rice**

**Relationships with financial sponsors:**

 **Any direct financial relationships, including receipt of honoraria:**

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Canadian Health Experiences Expert Panel on Perinatal Mental Health

 **Patents for drugs or devices :**

 **Other :**

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# Introduction

- Chronic pain
    - Common, complex, invisible, misunderstood
    - Intersections with structural vulnerability and individual / collective trauma
    - Marginalization via exclusion from workforce and livable income
  - Structural violence
    - = Longstanding, interrelated, and normalized harms “built into” structures, histories, ideologies, and institutions
    - ***Navigation of bureaucratic income support systems as harm***
- 
- OBJECTIVE: Document patient experiences of structural violence in the context of chronic pain and disability benefits

# Methods

- Subanalysis of Chronic Pain Ethnography (COPEII) study
  - Institutional ethnography
  - “Work” of PWLE, i.e. efforts and actions undertaken in the navigation of systems
  - People identifying with both chronic pain and socioeconomic marginalization
- Data sources
  - 28 transcripts with previously coded “experience of being on social or disability assistance”
  - Textual analysis of public-facing provincial disability documents
  - Discussion with clinician collaborators experienced in disability benefit application process



- REB Approval from Western University

# Findings

The Work of Filling  
out Forms

Embedded  
Assumptions and  
Ideologies

Entrenched  
Marginalization

Bureaucracy-  
Ambiguity  
Misalignment

# The Work of Filling out Forms

- Onerous and time-consuming paperwork
- Involving support people, sometimes at personal expense
- Contingent on cooperation
- Opacity and contradiction
- Aggravated pain and suffering

*It's hard to do that paperwork because of the fact of my disability; I can't really write and I can't type at all. And I don't have a computer in my home because of the low income, (...). So, it was a real struggle in that sense. (...) [However]), I've been blessed with a support worker through the YWCA for abused women and that is an amazing organization with the services that they provide for the communities. And she actually spent two afternoons [helping me]. It took us probably about probably six hours I want say to do the disability paperwork that I had to do prior to giving it to the doctors to do. (Winnie)*

# Embedded Assumptions and Ideologies

- Hierarchy of deservingness
- Ableism
- Retelling and recounting
- Abuse

*You get yelled at, you get belittled, like “you’re not sick”, “why are you not going to work”, and it’s like what’s going on here? There’s all the mind manipulation. They make you feel bad. And they make you literally hate your case manager and that’s their job because they don’t want you to keep going on disability, they want you just to walk away literally. (...)And I had numerous times where she would just literally yell at me, and scream, and it’s like “I’m sick, what do you want from me, you know?” So, it was just the way that they treat their people. I was in shock, I was just, I can’t even, like I get a panic attack when I see her calling on my phone and I have never answered the phone for what – seven months from her now, I just refuse to answer it. I let it go to voicemail and then I send her an email with all the answers that she’s looking for. (Helen)*

# Entrenched Marginalization

- "Disability Math"
- Denial and delay
- Enforced stagnation

*I understand the math. I can work up to twenty, I think it's twenty hours a week or sixteen hours a week or something like that. I can make up to an extra I think four hundred dollars a month before they start taking anything off. But then, at the same time, where the hell is someone like me going to find a job I am capable of doing where they only want me for like twelve hours a week?  
(Alex)*

# Bureaucracy – Ambiguity Misalignment

- Diagnostic (ergo therapeutic) uncertainty
- Lack of recognition
- Coerced treatment vs “non-compliance”

*I basically approached [Workers] Compensation at that time and I said “look this is killing me to do this [all the treatments that they required in order to obtain WC].” They basically shut me down, cut me off, and said I wasn’t cooperating with them, so I couldn’t be paid. Like they were sons of bitches right from day one. [Because] If you don’t cooperate with them, if you don’t shove your finger in your nose when they tell you to do it, trust me, you’re cut off. I just questioned the front staff there about the anti-inflammatories and muscle relaxants. I had a pretty wicked reaction to it from about 3 or 4 years back, right through to about two years ago. On a regular basis, I’d have a swollen face like a chipmunk. I mean your throat’s swollen, your mouth is swollen, and this is all from the Naproxen, or the Ibuprofen. I was on Gabapentin, I was on Lyrica. I was on everything that could help with inflammation. (Richard)*

# Conclusion

- People living with chronic pain and disability are subjected to compounding structural violence when navigating the disability benefit process
- Structural change is necessary to support the health and well-being of people living with chronic pain, and reduce the moral distress experienced by their healthcare providers



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