# Validation & diagnostic uncertainty in adolescent chronic pain: A project proposal

Queenie Li (1), Chad Shenk (2), Alexandra Neville (3), Ignasi Clemente (4), Marcia Meldrum (5), Lonnie Zeltzer (5), Melanie Noel (1) 1 - University of Calgary; 2 - Pennsylvania State University; 3 - Stanford University; 4 - City University of New York; University of California, Los Angeles

### Abstract

**BACKGROUND.** Pediatric chronic pain is often experienced in the absence of injury or organic pathology, has unknown etiology, and is complex to treat. Families reaching a chronic pain clinic have often undergone years of searching for the cause of pain, ineffective treatments, and invalidation by healthcare providers. This process fuels diagnostic uncertainty (DU), the perception that labels or explanations for a patient's health problem is missing or inaccurate. DU affects one third of youth seeking chronic pain treatment and is associated with worse pain outcomes and wellbeing. Our recent research revealed that DU is a socially co-constructed phenomenon; specifically, pain (in)validation by physicians has been identified as a critical aspect of clinical encounters that fuels and maintains DU.

**AIMS.** This study will examine how clinician (in)validating behaviors within a tertiary-level pediatric chronic pain clinic influence parent and child DU over time. Focusing on the initial physician-family encounter, the study will investigate: (1) how clinicians (in)validate youth and their parents throughout the encounter; (2) how (in)validation is related to DU over time; and (3) whether the influence of (in)validation on DU is strongest in particular parts of the encounter.

**METHODS.** Video recordings of twenty-three adolescents and their parents who presented to a pain clinic will be analyzed. Physician (in)validation towards families will be assessed using the Validating and Invalidating Behavior Coding Scale (VIBCS). Analyses will be completed to characterize the trajectory of (in)validation and explore the influence of (in)validating behaviors on consequent DU.

**CONTRIBUTIONS.** This project will improve our understanding of how and when physician (in)validating behaviours influence DU and the trajectory, course, and prognosis of pediatric chronic pain outcomes. Examining the role of (in)validation in physician-family encounters offers a potential transdiagnostic target for improving care alliance, diagnosis, and treatment. **KEYWORDS.** adolescent chronic pain, diagnostic uncertainty, validation

## **Challenges in Pain Care**

- Pain is uncertain: unknown etiology, complex to treat
- Diagnostic uncertainty (DU): perception that label or explanation for health problem is inaccurate or incomplete
- Patients overwhelmingly report invalidation by care providers
- DU is fueled by physician invalidation <u>uncharacterized in vivo</u>

### **Proposed Study**



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#### **Data & Measures**



One month pre-intake DU-checklist

Outcomes & Clinical Impact



 Systematic investigation of how & when physicians (in)validate patients & families



**Focuses on first** clinical encounter between doctors and adolescents

Measures pain behavior (DU)



Clinical encounter (In)validation—VIBCS

6-12 months post-intake

 Validation as transdiagnostic tool for improving care alliance: trust & buy-in

• **Biopsychosocial** treatment of chronic pain

Spur discussions of power & equity in healthcare

#### Timeline

Data collection—completed Video & transcript processing—Oct-Dec 2023 Data analysis—Jan-Feb 2024 Interpretation & manuscript—Mar-Apr 2024 Knowledge translation—2024-2025

#### Sex- and Gender-based Analysis (SGBA+)

Issues of equity, diversity, & inclusion (EDI) are tied to systemic power imbalances from which the institution of healthcare is not immune. Patients presenting in tertiary clinics are often unrepresentative of diversity in the general population; however, exploring the asymmetric relationship between physicians, patients, and families may reveal mechanisms by which systemic health inequities are created and sustained. All analyses and interpretation will consider the intersecting identities of youth, their families, and doctors where possible.

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queenie.li@ucalgary.ca

