

# Exploring the Lived Experiences of Adult Survivors of Childhood Cancer with Chronic Pain: A Qualitative Examination

Jada Benedictson<sup>1</sup>, Lindsay Jibb (PhD)<sup>2</sup>, Paul Nathan (MD, MSc)<sup>2</sup>, Michelle Gagnon (PhD)<sup>3</sup>, Rachael Bull<sup>4</sup>, Nicole M. Alberts (PhD)<sup>1</sup>

<sup>1</sup>Concordia University, Montréal Canada, <sup>2</sup>The Hospital for Sick Children, Toronto Canada, <sup>3</sup>University of Regina, Saskatchewan Canada, <sup>4</sup>Partner with Lived Experience

## Background

- Chronic pain (lasting/recurring for ≥3 months) affects 41% of adult survivors of childhood cancer (Alberts et al. 2024; *PAIN*) and is associated with substantial disability.
- Pain is frequently undertreated and overlooked in survivorship.
- Despite the prevalence and impact of chronic pain as well as its undertreatment, no studies have qualitatively examined the pain experiences of adult survivors of childhood cancer with chronic pain, including their experiences accessing pain management.

### Long-Term Goal of this Line of Research:

- Reduce the undertreatment of pain and improve functional outcomes in survivorship

 Two people with lived experience of childhood cancer and chronic pain have been involved in this project since study conception and will play a role in all elements of this work.



The primary objective of this study is to better understand the chronic pain experiences of adult survivors of childhood cancer.

### Aim 1

Explore the pain experiences of adult survivors of childhood cancer, including characteristics of pain, physical and psychosocial impacts of pain, and interactions with the health care system, including resources and treatments, pain communication, and potential barriers

### Aim 2

Examine pain (e.g., duration, intensity), psychosocial, sociodemographic, and medical characteristics of adult survivors of childhood cancer experiencing chronic pain in relation to their qualitative pain experiences (described via Aim 1)

### Aim 3

Evaluate intervention needs and preferences for adult survivors of childhood cancer

## Study Methods

### Study Design

#### Mixed methods

- Individual semi-structured interviews supplemented by a baseline online survey administered via Qualtrics

### Recruitment

#### Recruited via:

- Social media, Childhood cancer networks and our lab database

### Eligibility

#### Inclusion criteria:

- <18 years when diagnosed/treated
- ≥18 years of age currently
- ≥5-years post diagnosis
- No current evidence of active cancer or cancer treatment
- Currently experiencing chronic pain (Reside in Canada or the US)
- Ability to read/speak English

### Sample

#### Participants

- (N=25) adult survivors of childhood cancer



### Needs Assessment

#### Digital intervention

- Needs and preferences for an online digital health intervention will be assessed via interviews and survey

### Online Survey

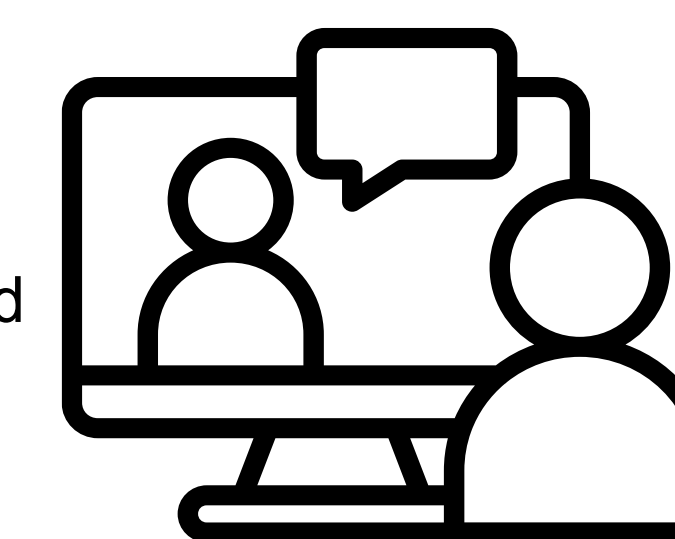
Demographic, medical and pain questions  
**Validated measures**

- Pain intensity - PROMIS Pain Intensity
- Pain interference – PROMIS Pain Interference (8a)
- Pain chronicity (2 items)
- Depression – Patient Health Questionnaire (PHQ-8)
- Anxiety – Generalized Anxiety Disorder (GAD-7)
- Fear of cancer recurrence – Fear of Cancer Recurrence Inventory (FCRI-SF)
- Patient disease management – Partners in Health Scale (PIH)
- Communication self-efficacy – Perceived Efficacy in Patient-Physician Interaction (PEPPI)

### Zoom Interview

#### Semi-structured interviews

- ~60 mins
- Conducted via Zoom by a trained graduate student



#### Interviews will explore:

- Cancer history and pain trajectories
- Pain communication experiences and challenges
- Experience with pain supports and services (on and off treatment)

## Planned Analyses

### Interviews

- Audio recorded and transcribed using NVivo software
- Analyzed using thematic analysis (Braun & Clarke, 2019)

### Survey

- Descriptive statistics will be used to characterize the sample and report pain intervention needs and preferences

## Anticipated Results

- Survivors will describe pain in the context of their cancer history
- Survivors will describe unique pain-related communication challenges
- Survivors will report barriers to accessing pain supports and services

- Survivors will report long durations of pain and using tools for pain self-management
- Chronic pain in survivorship will be associated with physical and psychological challenges
- Survivors will report challenges with pain management and communication self-efficacy

- Survivors will describe needs and preferences for online digital health tools to support pain management, mental health, and/or pain communication needs

## Impact

- Findings will provide a nuanced understanding of chronic pain in survivorship, with implications for improved pain assessment, management, and care pathways
- This study addresses a need identified by PWLE and includes PWLE in all study elements, with qualitative methods further uplifting survivor voices
- Survivor needs and preferences will inform the development and testing of an online digital health intervention with direct implications for improved pain management in survivorship

## Project Timeline

