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

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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:

1) Cancer history and pain trajectories
2) Pain communication experiences and challenges
3) 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

Jun 2025	Received ACCESS Psychosocial and Survivorship Pilot Grant (PI: Alberts, Co-PI, Benedictson)
Dec 2025	Completed all study set-up tasks and submitted to Concordia Research Ethics Board
Jan 2026	Received conditional ethics approval from the Concordia Research Ethics Board
Feb 2026	Begin recruitment with interviews conducted on a rolling basis (approximately 3-4 per month)
Sep 2026	End of recruitment and data analysis begins
Dec 2026	Complete analyses and begin writing up results
Mar 2027	Finalize manuscript and submit associated abstract to a pediatric oncology and/or pain scientific conference
May 2027	Submit manuscript to peer reviewed journal

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