

Journey in Pain Care (JiPC): A qualitative protocol for examining the lived experiences of children and families navigating chronic pain treatment

Devika Madgavkar, Amanda R. Van Orden, Amanda Wiseman Miner, Alex Tremblay-McGaw, Ellison Choate,

Courtney Hess, PhD* & Laura Simons, PhD*

Department of Anesthesiology, Perioperative and Pain Medicine, Stanford University School of Medicine

*Co-Senior authors supporting student work

BACKGROUND

Up to 5% of adolescents (~3.5 million in the US) suffer from debilitating, **chronic musculoskeletal (MSK) pain**. Despite the proliferation of treatments for chronic MSK pain, response is suboptimal with ~50% of patients refractory to current pain treatment approaches. There is growing recognition that improving care for patients requires engagement with patients to identify unmet needs and gaps. Despite the importance, few have endeavored to examine the lived experience of youth with chronic pain and their caregivers.

Need for Qualitative Research

Previous research has examined static constructs such as perceived injustice and diagnostic uncertainty. Thus far, studies have not been tied to the **pain care journey**.

This study aims to give voice to youth suffering with chronic MSK pain and their families by bridging this research gap and interrogating the **dynamic experience of seeking, receiving, and reflecting** on pain care, as well as defining **access** to and **engagement** with pain care for adolescents with chronic MSK pain.

METHODS

Participants:

- Recruited from the Stanford SPRINT cohort at various timepoints
- Adolescents ages 11-18 and Caregivers of teens with chronic pain
 - Parent cohort demographics will vary
 - Dyads are not necessary

Signature for Pain Recovery IN Teens (SPRINT):

SPRINT is a multisite study aimed at discovering a **prognostic signature of recovery vs persistence of pain** in adolescents with chronic MSK pain. fMRI scanning and Quantitative sensory testing done at initial study visit with longitudinal quantitative data on healthcare use and clinical endpoints of pain and function collected biweekly for 3 months and then at 6, 9, and 12-month follow-ups. Due to the plethora of psychological, biological, physiological data obtained through that study, this is an opportunity to gain a comprehensive understanding of the lived experience of chronic pain.

Measures:

- Semi-structured interviews conducted across 60-120 minutes
 - child interview focused on child's pain care journey
 - parent interview focused on the pain care journey as a caregiver
- Interviewee begins by drawing a visual timeline of their journey which prompts the flow through a set of **Grand Tour** questions and follow-up prompts
- Meaning** and **Impact** probes asked to deepen understanding of the meaning attached to and impact of various experiences throughout the pain care journey

Analysis:

- Interviews will be analyzed with a thematic analysis approach

INITIAL DATA

Some Initial Quotes

"It made me realize...I was handling something else...that other people weren't handling and I think that that was helpful because it took a lot of the blame off of myself before I just assumed that it was all me because I didn't really have any other explanation."

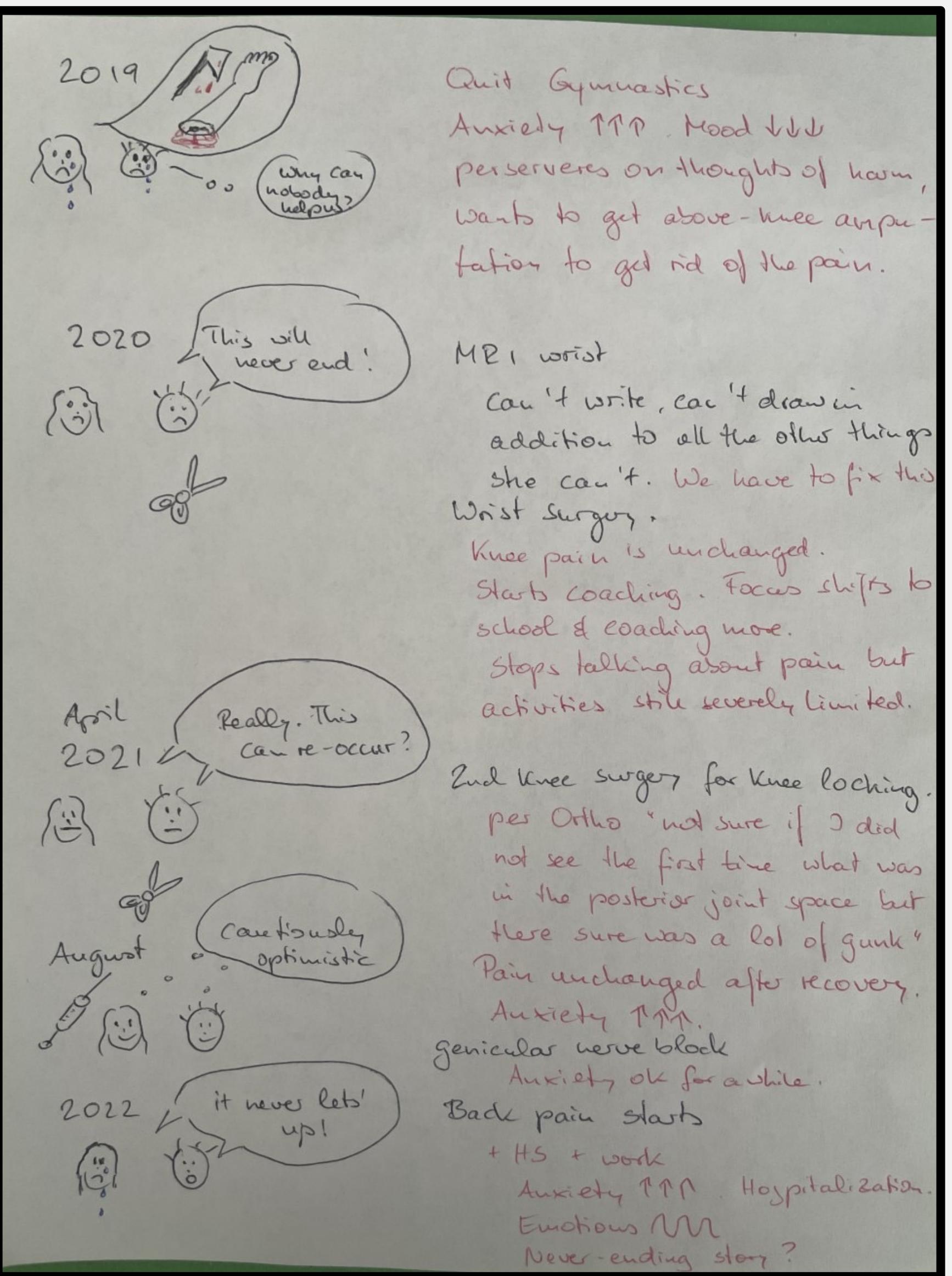


"It's nice to have like reasons behind why I am the way I am, and to have like confirmation that it's not all on my head kind of 'cause through a lot of my childhood I was told that I was just faking it, which is rough."



"...just realizing that, like, my illnesses are valid and I'm a valid person...I'm just going to make the best of it because YOLO I only have one life and...why be chronically ill and just like mope around when you can chronically ill and cool. That's been my motto."

Example Timeline



Feedback on Interview

"It's...a chance to talk to someone about...this process, and...at the end of it, ...even as good as this process has been...there's always room to grow and make improvements, and you know, hopefully, as people...discuss their stories,...you can kind of glean some...kind of correlations or patterns that would...help you know make this program even better."



"...just like by me like sharing... all this like I am helping...a little me try to like get that pushed further and not have to go through a 3-year journey and they can make it in a couple months"

INTERVIEW FLOW

Please take 10 minutes to create a visual timeline of your pain care journey that begins at the onset of you pain and continues to the present moment.

Take me through your journey. Can you tell me about what you drew?

DIAGNOSIS/ EVALUATIONS

Can you tell us about the explanations and diagnoses that you been given about your pain?

TREATMENTS

What are some of the treatments you have had over the course of your pain care journey?

PEOPLE/ CARE TEAM

Who are some of the people involved in your care and how have they impacted your journey?

IMPACTFUL MOMENTS

Can you describe some of the most impactful moments of your pain care journey?

REFLECTION

As you reflect today, can you tell me a little bit about where you think you are on your pain care journey?

Each Grand Tour followed by Meaning Probes to capture impact: How did that impact your journey? What was meaningful about that for you?

DISCUSSION & IMPLICATION

- This study will foster in-depth understanding of the lived experiences of navigating pain care and treatment for youth and caregivers , and
- Insight into how the systems and people who provide care and the processes in place to treat patients impact patient and family lives
- NEXT STEPS:** (1) Thematic Analysis of qualitative data and (2) Combine qualitative interview data with the longitudinal quantitative data from SPRINT