Shared decision-making around the world:

Informing an equitable, patient-oriented decision aid for in-person vs virtual care of pediatric chronic pain



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Abstract

Background: Chronic pain (CP; i.e., pain > 3 months) affects 20% of youth and is associated with several deleterious outcomes. While the COVID-19 pandemic required virtual delivery of health services, no current guidelines exist for virtual pediatric CP management. Little is known regarding virtual versus in-person treatment efficacy. Equity-seeking groups are disproportionately impacted by CP and face systemic barriers to virtual care. Reducing treatment disparities is a patient-identified priority. Youth with CP and their families must have a voice in treatment decisions. Shared decision-making (SDM) allows patients, families, and health professionals to decide on treatment collaboratively based on evidence and patient preferences. As part of a multiphase project to promote SDM and develop a decision aid for in-person versus virtual pediatric CP management, this study examined decision-making practices for in-person versus virtual CP care.

General Methods: An electronic survey was distributed to health professionals from 102 pediatric CP clinics around the world. Participants reported on demographics, decisionmaking practices, perceptions of in-person versus virtual care, and patient and professional decision-making roles. Descriptive statistics were used to identify commonalities across current practices.

Results: Respondents (N = 68) most identified as women, not of colour, anesthesiologists, and from the United States. Types of virtual care most endorsed were video conference platforms, email with patients/families, and telephone consultation. Overall, virtual care constituted <25% of CP treatment. Families were commonly reported to have the largest role in decision-making. New referrals, patient demographics and location, and patient values/preferences most influenced in-person versus virtual care decisions. Most clinics did not evaluate their in-person versus virtual care treatment decisions.

Conclusions: New referrals, patient demographics, and patient preferences most impact virtual care decisions. Most clinics do not evaluate their in-person versus virtual care decisions, suggesting a lack of general treatment outcome assessment. Keywords: shared decision-making, pediatric pain, virtual care

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Previously...

In Phase 1 of our project to develop a decision aid for in-person versus virtual care for pediatric chronic pain management, our systematic review revealed insufficient evidence comparing in-person versus virtual care for pediatric chronic pain. Only 2 studies were included, both of which had mostly white samples and inadequately represented ethnically diverse groups.

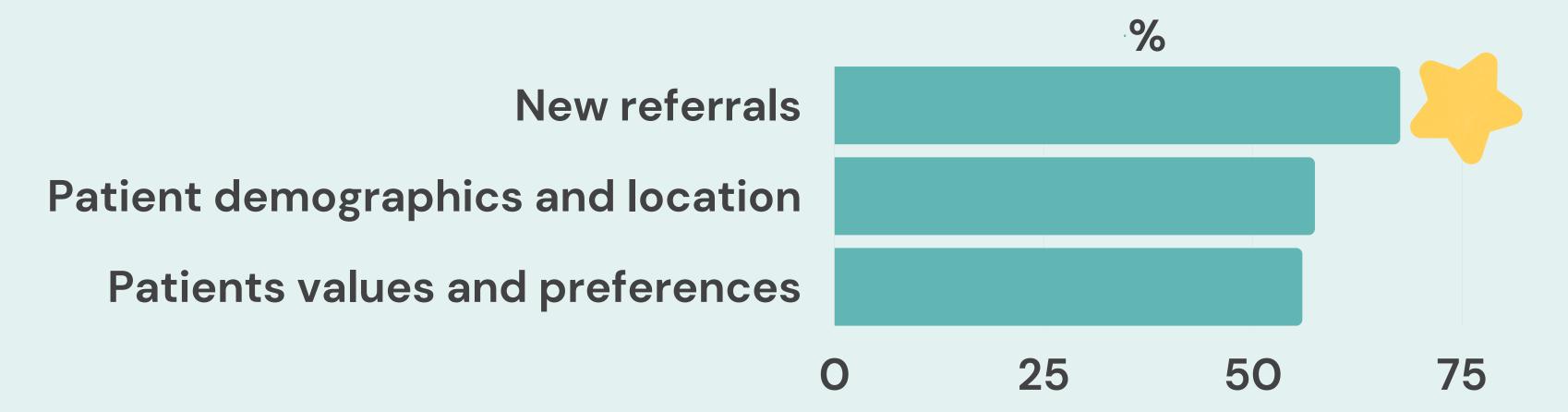


Our current work:

Most respondents were women (57%), female (54%), physicians (52%), and not of a racial or ethnic minority group (84%).

Virtual care constitutes <25% of overall pediatric chronic pain treatment, regardless of discipline.

The top 3 factors influencing virtual care decisions are:

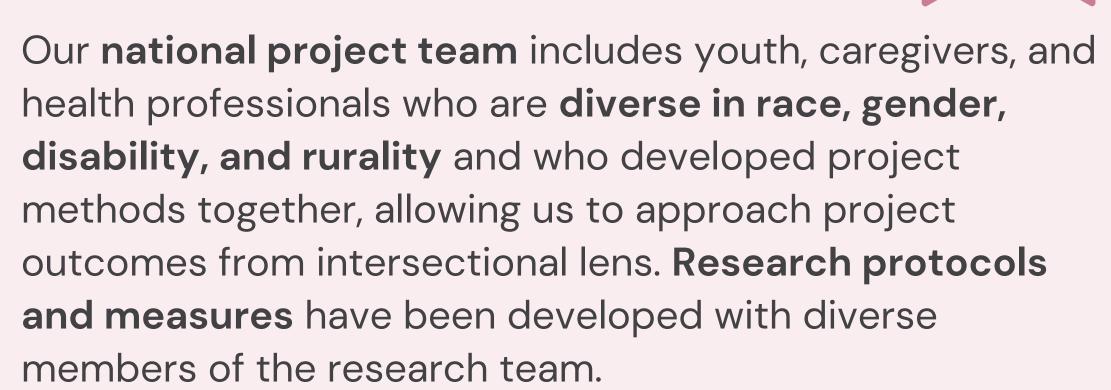


Evidence was least commonly ranked among top 3 (n = 13, 19.1%).

Most clinics (n = 56, 82.4%) do not evaluate in-person vs virtual care decisions.

Those that did most often used mixed method feedback (e.g., satisfaction surveys) or electronic health records to evaluate decisions.

Equity, Diversity & Inclusion



This phase involved multinational engagement with health professionals around the world to capture SDM practices. The next phase will have direct participation from youth and caregivers who identify as being of racialized groups, and of complex medical needs or brain-based disabilities.

Sex- & Gender-Based Analysis (SGBA+)



Sex and gender are not primary outcomes, as it is unclear if these impact virtual pediatric chronic pain management. However, we integrated separate measures of sex and gender in our demographic questionnaires.

As girls experience more severe pain (Dunn et al., 2011), and youth with chronic pain who do not identify as cisgender are underrepresented in research, we will purposefully seek diverse representation among youth and caregivers in the next study phase to ensure their perspectives are reflected in the resulting decision aid.

Next Steps...

In phase 3, we will interview diverse youth with chronic pain, their caregivers, and healthcare professionals, recruited through partner organizations, to determine critical features of the decision aid.





