

Pediatric Pain Letter

Commentaries on pain in infants, children, and adolescents

June 2022 Vol. 24 No. 2 www.childpain.org/ppl

Editor: Deirdre E. Logan, PhD, deirdre.logan@childrens.harvard.edu

Associate Editor: Abbie L. Jordan, PhD, a.l.jordan@bath.ac.uk

© 2022, Special Interest Group on Pain in Childhood, International Association for the Study of Pain®

Commentary

Feasibility of implementing interdisciplinary pediatric pain services in Alaska

Wendy Gaultney and Ben Ekstrom

Pediatric chronic pain in Alaska

Little is known about youth with chronic pain in Alaska. To take a bird's eye view, approximately 732,673 people live in the state of Alaska, and 180,000 are under 18 years of age (Census, 2021). According to estimates of chronic pain prevalence, between 11% and 38% of youth will experience some form of chronic pain (King et al., 2011). Therefore somewhere between 19,800 and 68,400 Alaskan youth will meet International Association for the Study of Pain (IASP; Raja et al., 2020) criteria for chronic pain before they turn 18.

Although there is no evidence that Alaskan youth overall differ from youth worldwide, there are aspects to life in Alaska that are relevant for understanding the context of chronic pain in the state. First, Alaska is the largest US state and the state with the lowest population density. Many Alaskan residents live in remote areas. As such, distance to healthcare centers is one barrier for many in Alaska.

Low access to care is especially concerning for Alaska Natives, who account for 15.6% of the population (Census, 2019), many of whom live in small rural communities. Although there is no research to date describing disparities in chronic pain prevalence in Alaskan youth specifically, research shows that adult Alaska Natives experience higher rates of chronic pain compared to the general adult US population (Jimenez et al., 2011). There may be relevant parallels to First Nations people in Canada; research has shown that First Nations

children in Canada have higher rates of painful conditions compared to non-First Nations children, but are less likely to see specialists for treatment (Latimer et al., 2018).

Taken together, the evidence available suggests that chronic pain likely affects a large number of youth in Alaska, that it likely disproportionately affects native populations and that geographic challenges present a barrier to access to pediatric chronic pain treatment.

To address the unmet need for evidence-based pediatric pain care in Alaska, we formed an interdisciplinary program in Anchorage, Alaska in May 2021. Our core team consists of a pain physician/anesthesiologist, a licensed psychologist, a physical therapist and a medical assistant.

This manuscript describes the initial phase of a feasibility study (Orsmond & Cohn, 2015). In other words, in our first year we aimed to answer an initial question: how do we successfully develop an interdisciplinary pain program in Alaska? The secondary aim of this manuscript is to spark conversation and facilitate collaboration among programs that are being created outside of large academic institutions, as part of the important call to action to expand access to interdisciplinary pain care for youth globally (Eccleston et al., 2021).

Team composition and the start-up phase

As with many pediatric pain programs historically, the conversations and planning phase of program development started years before the

first patient was seen. Our team physician (B. Ekstrom) grew up in Alaska. He left the state to complete medical school, both general and pediatric anesthesiology residencies and a multidisciplinary pain medicine fellowship. During his training he recognized the gaps in pediatric pain care in Alaska. After fellowship he moved back to Alaska and procured a practice setting to establish a program. An adult pain physician/practice owner provided necessary supports (e.g. space, psychologist salary support) for program development. The effort of building relationships with health professionals in community neurologists, the (e.g. gastroenterologists, physical therapists) began during this timeframe.

In May 2021, a full-time pediatric pain psychologist (W. Gaultney) was brought on staff. Shortly thereafter a collaboration was formed with a physical therapy practice in the community. Simultaneous processes included capitalizing on the existing infrastructure (e.g. practice administrative and clinical support).

Some of the other early work included conversations with established pediatric pain clinics, creating triage criteria for referrals and curating interdisciplinary intake questionnaires. Also during this time, team members met with healthcare professionals in the community (e.g. local pediatric oncology office, pediatricians) to advertise the new interdisciplinary services. Finally, we started to schedule patients who were trickling in from referral sources.

Current pain service model

We currently conduct interdisciplinary pain clinics once or twice per month. In a single clinic morning we see three patients. Our evaluation model is consistent with many other programs: a team-based approach during which providers meet with the family together to introduce the goals of the clinic and to learn about the pain problem. Then each provider conducts their unique components of a thorough biopsychosocial pain evaluation. The providers then meet together as a team to briefly discuss impressions and recommendations. To conclude the appointment, the patient and family collaborate with the team on a treatment plan.

Our follow-up model consists of multidisciplinary appointments. Depending on their specific treatment plan, the majority of patients are encouraged to engage in outpatient pain psychology, physical therapy, and medical follow-up. These recommendations are tailored for patients according to level of functional impairment noted at the evaluation. Treatment focuses on providing pain education and a comprehensive approach to support functional improvements as the path to recovery.

Preliminary data of patients seen for interdisciplinary care

Twenty patients attended evaluations from June 2021 through January 2022. Patients were by pediatric neurologists, referred gastroenterologists, primary care providers and selfreferred. Ages ranged from 8 to 21 years (M =14.55, SD = 3.72); 65% identified as female, 25% male and 10% non-binary. Patients identified as white non-Hispanic or Latino (70%), Multi-racial (i.e. Asian/Black/Hawaiian and white; 10%), Asian non-Hispanic or Latino (5%), white Hispanic (5%), declined to specify ethnicity (5%), and Alaska Native (5%). In comparison, Alaskan racial classifications show that the population overall consists of 15.6% Alaska Native. Pain problems included head, abdomen, neck, back, limb and multisite pain. Patients resided in largely urban areas: Anchorage (55%), the Kenai Peninsula (15%), Matanuska-Susitna (15%), Fairbanks (10%) and Southeast Fairbanks (5%). Geographically, our patient sample closely matches that of population estimates in each borough (Census, 2019). Patients were evaluated in-person (n = 18) and via telehealth (n = 2).

Reflections on pediatric pain program development in Alaska

One ongoing challenge includes prioritizing equitable interdisciplinary services. This is a high need, as it is notable that Alaska Natives represent more of the state population than our sample of healthcare-seekers reflects. This discrepancy is consistent with the Latimer and colleagues' (2018) findings in Canada. Initially to address equitable access, we have sought opportunities to reach a broad variety of healthcare professionals. As a team,

we presented at a state pediatric healthcare conference and pediatric grand rounds. Additionally, the first author serves on the Alaska Pain and Opioid Extension for Community Healthcare Outcomes (ECHO) series to serve as a resource for professionals statewide. These efforts over time are aimed at reducing barriers and reaching diverse youth across the state for interdisciplinary pain services. Moving forward we are being particularly thoughtful about approaching equitable care with Native communities. We intend to partner with Alaska Native communities to improve pain care that is consistent with community priorities and healing practices (Latimer et al., 2020; Sylliboy et al., 2021).

Although all interdisciplinary pediatric pain programs likely confront some similar challenges, the unique aspects to being situated in a privately-owned practice are worth discussion in the spirit of our second aim of sparking conversation among programs outside of large academic institutions. First, we ran into challenges of accessing support to conduct research. We navigated this challenge by partnering with the psychology department at a local academic institution for research oversight. This was a novel request for the institution to review a non-institutional clinical protocol, and required multiple levels of approval and additional

Wendy Gaultney, PhD Neuroversion, Anchorage, AK, USA email: wgaultney@neuroversion.net

Ben Ekstrom, MD Neuroversion, Anchorage, AK, USA

Census. US Department of Commerce. Alaska QuickFacts, 2021. www.census.gov/quickfacts/AK

Eccleston C, Fisher E, Howard RF, Slater R, Forgeron P, Palermo TM, et al. Delivering transformative action in paediatric pain: a Lancet Child & Adolescent Health Commission. Lancet Child Adolesc Health 2021;5:47-87. www.pubmed.gov/33064998

Jimenez N, Garroutte E, Kundu A, Morales L, Buchwald D. A review of the experience, epidemiology, and management of pain among American Indian, Alaska

time for review. We note this as an important lesson learned because there are likely many other pain programs that would similarly benefit from reduced barriers between academic and clinical spheres. An ongoing challenge includes achieving financial sustainability, and we will publish a manuscript in the coming year to discuss those barriers and solutions in detail.

Conclusion and future directions

Despite the challenges, we are forging ahead to develop services to address the unmet need for Alaskan youth with chronic pain. With recognition that quality improvement is a never-ending process, we are pleased to have opened our doors to twenty patients and to have learned along the way. Our next steps for further developing the clinic include establishing patient and community partners in program development and research and further developing services that meet the needs of patients and communities across Alaska in various settings (e.g. inpatient, outpatient, community- and schoolbased care). We hope that we will also meet our second aim to spark conversation and welcome discussion among other novel programs with the similar goal of expanding access to interdisciplinary pain care for youth globally (Eccleston et al., 2021).

Acknowledgements

The authors thank Fiona Campbell, MD, for her mentorship and feedback on an early draft of the manuscript and Charlee Laurie, BA, for her dedication and support in program development.

References

Native, and Aboriginal Canadian peoples. J Pain 2011;12:511-522. www.pubmed.gov/21330217

King S, Chambers CT, Huguet A, MacNevin RC, McGrath PJ, Parker L, et al. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. Pain 2011;152:2729-2738. www.pubmed.gov/22078064

Latimer M, Rudderham S, Lethbridge L, MacLeod E, Harman K, Sylliboy JR, et al. Occurrence of and referral to specialists for pain-related diagnoses in First Nations

and non-First Nations children and youth. CMAJ 2018;190:E1434-E1440. www.pubmed.gov/30530610

Latimer M, Sylliboy JR, Francis J, Amey S, Rudderham S, Finley GA, et al. Co-creating better healthcare experiences for First Nations children and youth: the FIRST approach emerges from Two-Eyed Seeing. Paediatr Neonatal Pain 2020;2:104-112. www.pubmed.gov/35548261

Orsmond GI, Cohn ES. The distinctive features of a feasibility study: objectives and guiding questions. OTJR (Thorofare NJ) 2015;35:169-177. www.pubmed.gov/26594739

Raja SN, Carr DB, Cohen M, Finnerup NB, Flor H, Gibson S, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. Pain 2020;161:1976-1982. www.pubmed.gov/32694387

Sylliboy JR, Latimer M, Marshall EA, MacLeod E. Communities take the lead: exploring Indigenous health research practices through Two-Eyed Seeing & kinship. Int J Circumpolar Health 2021;80:1929755. www.pubmed.gov/34061729