Special Interest Group on Pain in Childhood
INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN

Pediatric Pain Letter
Commentaries on pain in infants, children, and adolescents

February 2025 **Vol. 27 No. 1** **pediatricpainletter.org**
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Commentary

Developing and Disseminating Accessible Resources for Pediatric Chronic Pain Education: Behind the Scenes of a Collective Action Initiative

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Pain education is an essential part of evidence-based pediatric chronic pain care (Leake et al., 2019; Ickmans et al., 2022), forming the foundation on which the tripartite rehabilitative model of care — including medical intervention, physical/occupational therapy, and psychology — is built. Although everyone involved in treatment carries the responsibility for teaching and reinforcing this education, pediatric psychologists who receive specialized training in cognitive development, parent-child interactions, and factors involved in motivation and behavior change, may be particularly well suited to developing targeted educational content. The unique expertise of pediatric pain psychologists and the existing gap in chronic pain education was a key topic of discussion at the Pediatric Pain Special Interest Group (SIG) Meeting at the Society of Pediatric Psychology Annual Conference in Portland, Oregon in 2017.

Dr. Rachael Coakley, the Chair of the Pediatric Pain SIG Clinical Committee at the time, led a group discussion with more than 30 pediatric pain psychologists in North America. Together, they discussed the collective power of pooling their expertise and creating evidence-based chronic pain education resources that could be widely disseminated across settings such as pediatrician offices, specialty clinics, and pain services. The Clinical Committee reasoned that a core set of materials would improve access to chronic pain education for providers and patients. Moreover, these materials could facilitate the use of a shared language for teaching the complex concepts inherent in pain management, thus enhancing specialized learning among multidisciplinary providers and patients alike.

Thus, we formed a collective action initiative with two core and interrelated dissemination goals. Broadly, dissemination is defined as "an active approach of spreading evidence-based information to a target audience via determined channels using planned strategies" (Brownson et al., 2018). With that definition in mind, our initiatives were to: 1) produce and transfer evidence-based education and research to professionals, and 2) mobilize knowledge direct to patients. Our first goal was guided by several key constructs in dissemination research including the selection of dissemination processes (planning the procedures within the initiative), evaluating determinants (factors that may impede or facilitate progress), and developing strategies (selecting specific and targeted actions within the initiative) (Baumann et al., 2022). Our second goal, geared towards the production and dissemination of health information direct to patients (consumers) is best conceptualized by constructs within the Knowledge-to-Action framework (Graham et al., 2006). This framework highlights the intentional spreading of knowledge or research to improve health through iterative processes of identifying patient-facing gaps in education or care, synthesizing knowledge, and evaluating the factors that promote the adoption of that knowledge.

With these key goals in mind, over the next year, Dr. Coakley directed the first phases of the project. SIG Clinical Committee members worked collaboratively to review literature and existing educational materials, identify gaps in knowledge, exchange knowledge and resources for content ideas, and co-develop core educational topics. Through this process, the Committee systematically identified several topics for content creation. Topic areas were selected if they met the criteria of being 1) widely addressed in pediatric chronic pain management, 2) had robust literature to support the education, and 3) had universal recommendations that were considered essential for youth and caregivers.

The overarching goal was to create succinct and engaging guides that included chronic pain education as well as concrete, actionable suggestions to address pain-related issues. The four content areas with core recommendations are summarized below:

1. **Functioning while Coping with Chronic Pain**: This 2-page guide includes education about the relationship between pain and function, highlights the chronic pain cycle, and directly addresses the paradox regarding the need to focus on function early in symptom recovery. Additionally, this resource includes "helpful tips" for functional recovery including the importance of following a schedule, daily movement, pacing, identifying valued activities, and the importance of reducing the focus on pain. Unique guides were developed for adolescents and caregivers to appropriately target and reinforce the separate learning and skills by role.
2. **Healthy Sleep for Kids and Teens with Chronic Pain.** This 4-page guide, jointly written for adolescents and caregivers, includes education and actionable tips. The education component defines sleep quality and quantity, identifies healthy goals for sleep, addresses the relationship between sleep and pain, and provides education about common sleep challenges such as hypersomnia/napping, spending too much time in bed, and the use of electronics at night. The actionable tips include specific adolescent-friendly recommendations for improving sleep cycles such as creating daytime and evening routines, addressing sleep conditions, planning for nighttime waking, and building a relaxation practice.
3. **Cognitive Behavioral Therapy (CBT) and Pain Management.** This 2-page guide, primarily targeting caregivers and older adolescents, explains how CBT can empower kids to better manage pain through relaxation techniques, positive thinking, and structured plans. It differentiates CBT from other types of psychotherapy and identifies several key targets of pain-focused CBT. Further, this guide includes practical tips for what to look for in a CBT therapist and resources for finding a CBT provider in the community (within the US).
4. **School Guidelines for Kids and Teens with Chronic Pain.** This 2-page guide, written primarily for an adolescent reader, provides education about the challenges of school while working through chronic pain. It identifies school disruption as a common problem, explains why attending school can help recovery, and emphasizes the need for a tailored school plan. Additionally, it explains common recommendations that can be built into a school plan to support a child's success.

In parallel with a central focus on expert content creation, the Pain SIG Clinical Committee also focused on the practical and logistical challenges associated with knowledge mobilization. Specifically, how could this important initiative move from content generation to "boots on the ground" production and widespread access? Some key questions that the committee wrestled with included:

- Who would fund the design of the guides?
- How would we support multilingual translations of the guides?
- Where would the guides "live" to ensure easy open access?

- How could these guides be branded to enhance legitimacy and foster widespread adoption?
- Who would be responsible for updating guides, so they remained aligned with best practice?

In 2018, with these essential questions in mind, the Pain SIG Clinical Committee drafted a formal proposal to the American Psychological Association (APA) Division 54 (SPP) including signatures of more than 50 pediatric pain psychologists. The ask was for permission to use APA or SPP logos on the guides to signify that this work was collectively generated and represented the field's best evidence-based education. However, this proposal was denied, citing the lack of a formalized plan to manage the resources once published as a primary concern. Thus, the Pediatric Pain SIG Clinical Committee planned to reconvene to develop a management protocol at the Annual SPP Conference in April 2019. However, COVID-19 temporarily halted the forward progression of the project.

In 2022, the SPP Pain SIG Clinical Committee, then led by Dr. Sara Fligelman, infused new energy into this initiative. Dr. Fligelman and Dr. Coakley convened to develop a structured knowledge mobilization and resource management plan. Together, they reached out to the Meg Foundation, an international non-profit specializing in pediatric pain management, seeking in-kind donor support and partnership in the production of the guides. Dr. Jody Thomas, the Founder and CEO of the Meg Foundation, eagerly engaged in this partnership offering graphic design support as well as numerous knowledge mobilization assets such as a dedicated web-based landing page, media and marketing support, and resources for language translations. The Meg Foundation was also able to offer expertise in healthcare communication and user experience to effectively communicate messages with the target audiences.

Simultaneously, Dr. Fligelman formalized a succession plan for the guides, ensuring that the future elected clinical chairs of the Pediatric Pain SIG would be responsible for reviewing and updating the materials as part of their Chair responsibilities. With the Meg Foundation partnership secured and a plan for continued management of the materials, Dr. Fligelman approached SPP leadership again to inquire about branding for representation of this body of work. This time, the Pediatric Pain SIG was successful in obtaining organizational support and was given permission to use the SPP logo on the materials.

All guides went into pre-production in early 2024. This process involved multiple design iterations and continued review of content by several members of the Pain SIG Clinical Committee - including Dr. Kate Turnage, the incoming Pediatric Pain SIG Clinical Chair - culminating with a set of finalized guides that were published in September 2024.

After several keystone events in this multi-year project, we are thrilled to share that our CHRONIC PAIN FAMILY EDUCATION SHEETS are now available to the public through the Meg Foundation website. Packed with evidence-based pain education, coping strategies, and expert tips, these guides will be published in multiple languages and distributed internationally in the coming years.

Through this dissemination initiative our team learned some valuable lessons. For example, knowing that psychological jargon and complex concepts can alienate patients, we invested significant time in clarifying language for improved accessibility and developing visuals to improve engagement and comprehension. One important lesson learned here was that the inclusion of too many professionals in the writing phase made it difficult to adopt a universal linguistic style and tone for the materials. Therefore, once we collected and synthesized the knowledge, a much smaller team worked to adjust the language and visuals. We learned another lesson related to our commitment to best practices for dissemination sustainability. Without long-term organizational support, education initiatives often fade. Therefore, we believed that securing organizational endorsement was essential. While we were initially deterred by the SPP denial of our proposed endorsement, this prompted the creation of a more formalized and sturdier succession process. Thus, ultimately this perceived roadblock – with continued persistence – strengthened our initiative.

Our collective hope is that these guides will eventually be available in every pediatrician and specialty provider office, right along with the tip sheets you might find about supporting a child's healthy diet or managing screen time. In this way, we may help professionals, caregivers, and kids effectively address persistent pain before it causes serious disruption to a child's life.

Importantly, this initiative has created a stronghold; an essential link between the SPP organization and the non-profit Meg Foundation. The pathway created by the Pediatric Pain SIG Clinical Committee has paved the way for other psychology special interest groups to similarly pool expertise and produce content for mainstream distribution. For example, presently, the Gender Diversity SIG of SPP is working with the Meg Foundation to produce guides for patients and providers.

This 4-year project (not including the 2-year hiatus over the pandemic) represents a collective action initiative in developing and disseminating accessible, evidence-based resources. The steps involved, including the needs assessment, collaborative research for content development, design, consideration of language adaptations, and distribution method, have been vetted by pediatric psychology pain experts in the field at every step. However, within the dissemination frameworks described above, there is still work to be done. Future goals for this initiative include the incorporation of patient feedback, analysis of metrics regarding the use or uptake of the materials, materials refinement, and continued engagement with active dissemination efforts.

Share: Please help to disseminate this important work by sharing these free chronic pain resources at your institution, with any pediatric healthcare provider you know, and on social media. Be sure to tag the @megfoundationforpain and @SPPDiv54 in your posts.

Help Improve Accessibility: If you need these materials in a specific language for your patients, contact the Meg Foundation. Are you a bilingual provider willing to help with a translation to increase accessibility? We really want to hear from you! Please email: jody.thomas@megfoundationforpain.org

Collaborate on Research: If you've got a research idea or are interested to collaborate in obtaining provider, patient, or family feedback, please reach out to: Cathleen (Kate) Turnage: turnage@ohsu.edu

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