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

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

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Commentary

Bridging the Gap: How Creative Healing for Youth in Pain (CHYP) Harnesses the Power of Creativity and Support

Megan Sweeney, Ashley Matejka, Kimberly Poston Miller, and Lonnie Zeltzer

Chronic pain is a complex experience resulting from biological, psychological, and social interactions (Tracey & Bushnell, 2009). The global burden and cost of pediatric chronic pain are tremendous – amounting to \$635 billion annually (Bhatt et al., 2020). However, the paucity of multidisciplinary pain clinics for teens with chronic pain leads to multiple points of subspecialty evaluations and often failed treatments focused on specific organ systems. A recent study showed that adolescents suffering from chronic pain will experience a 34% decrease in the likelihood of graduating high school, a 17% reduction in achieving a college degree, a 20% decrease in receiving employer-provided insurance benefits, and a 13% reduction in the likelihood of employment related to long-term career goals (Murray et al., 2020). These findings underscore the urgent need for support and intervention, as these roadblocks to education and professional aspirations are not just individual challenges but a greater societal issue calling for collective action.

There are a variety of organizations offering online resources that provide support to children and teens with chronic pain: Pediatric Pain Warriors, the teen support program for the U.S. Pain Foundation (<https://uspainfoundation.org/pediatricpainwarriors/>), Comfort Ability, a program based at Boston Children's Hospital providing online support and in-person cognitive-behavioral workshops for parents and teens with chronic pain, also incorporated by other pain centers globally (www.thecomfortability.com), SKIP (<https://kidsinpain.ca>) the government supported

Canadian program which educates families and clinicians about pain, The MEG Foundation, which provides information necessary to manage pain and medical anxiety in children in addition to clinician training resources, but without online workshops or programming (<https://www.megfoundationforpain.org/>), and ChildKind, focused on improving care children receive for pain in the hospital (<https://childkindinternational.org/>). An increasing number of digital health interventions for pediatric pain conditions, such as WebMAP have also been developed (Palermo, 2020; Palermo et al., 2022).

Creative Healing for Youth with Pain (CHYP) is a nonprofit that empowers, educates, and supports youth between ages 13 to 24 years experiencing chronic pain along with their families. CHYP provides free services, relying on donations to develop and administer non-clinical interventions informed by rigorous pain science. CHYP's goal is to help individuals rethink chronic pain, engage in creative healing experiences, and receive education and peer support. CHYP leverages the advantages of online interventions, including reduced barriers to healthcare like cost, location, socioeconomic status, and transportation (Birnie et al., 2021; Darnall et al., 2023). CHYP also utilizes the power of group-based programming. CHYP is unique among online programs for pediatric pain

in its focus on creativity and the arts as a route to managing pain successfully.



CURRENT CHYP YOUTH PROGRAMS

YOUTH CHYPCHAT

Join our monthly Zoom meetings for youth ages 13-24, where we provide structured discussion and community. This occurs on the last Tuesday of the month from 5-6pm PT.

CREATIVE HEALING WORKSHOPS

Participate in On-Demand workshops for youth ages 13-24 offering an array of immersive experiences led by experts who specialize in diverse creative techniques.

CHYP SUMMER CAMP

Be a part of our 2 week-long virtual experience for youth ages 13-18, featuring artistic workshops, CHYPchat community time, and connection with other peers having similar experiences.

NAVIGATING PAIN FOR YOUTH

CHYP's On-Demand module program for youth ages 13-24, placing a strong emphasis on the power of knowledge to support youth living with chronic pain.

Figure 1. Current CHYP Youth Programs

While studies show meditation, yoga, hypnosis, and physical therapy can help improve function and well-being in teens with chronic pain, there are an increasing number of studies indicating the value of creative arts (Deng & Cassileth, 2015), e.g. music,

writing, and art. Interventions focused on creativity and community support help reduce pain and isolation (Angheluta & Lee, 2011). Johnson et. al. (2023) found creative activities aid chronic pain management and reduce mental distress by strengthening the mind-body connection. Often it is easier for teens to express negative emotions indirectly through music lyrics, art, dance, and other forms of expression. Creative activities carried out in groups can help engage isolated youth in stronger social relationships, reduce stress, and allow youth to develop a deeper appreciation for themselves and their surroundings. CHYP provides guided creative activities to harness the power of the creative brain and utilize neuroplasticity. On-demand online creative healing experiences and live virtual camp sessions are two ways that CHYP helps focus youth on their creative processes to reduce pain, strengthen the mind-body connection, and stimulate the development of new neural circuits.

Prior research has shown expressive and creative writing for 15-20 minutes can be helpful in healing (Pennebaker & Beall, 1986; Pennebaker & Chung, 2011). Specifically, expressive writing about traumatic, stressful, or emotional events has been associated with improvements in physical and psychological health including reductions in depression and anxiety (Baikie & Wilhelm, 2005). Participating in creative arts and expressive offerings through CHYP allows youth with pain to feel enhanced control over their minds and bodies, via a non-clinical intervention.

Engaging in creative therapeutic experiences in a group setting has added benefits over individually focused interventions. Teens with chronic pain often become isolated via school absenteeism and reduced participation in social and physical activities. Social support from teens experiencing similar issues provides positive experiences, reducing feelings of isolation (Forgeron et al., 2010; Kavanagh et al., 2023; López-Martínez et al., 2008; Ross et al., 2018). In keeping with the framework of the biopsychosocial model, CHYP provides monthly Zoom meetings for youth, ages 13-24, to develop connections to peers in similar circumstances,

and a live, virtual creative arts summer camp to address these feelings of isolation. Similarly, it provides peer support to caregivers through a psychologist-led “Creating Bonds” series in a live, online format to foster social interaction for those experiencing similar challenges.

CHYP provides evidence-based education about pain and associated contributors in a way that makes sense to those affected by chronic pain. The program seeks to ease anxiety resulting from diagnostic uncertainty which often drives families toward frequent visits to numerous specialty care providers. These visits are responsible for increasing healthcare spending in addition to contributing to depression, anxiety, feelings of helplessness, and school absenteeism (Bateman et al., 2023; Eytan & Elkis-Abuhoff, 2013; Soltani et al., 2022; Wildeboer et al., 2023). Since there are many functional pain disorders for which subspecialists have not found the root causes, this often results in confusing explanations (Jordan et al., 2023; Neville et al., 2021). CHYP seeks to clarify patient understanding of these disorders, to reduce uncertainty for many with “doctor-seeking” behaviors (Beveridge et al., 2024; Neville et al., 2020; Soltani et al., 2022). Through the enhancement of teens’ self-agency, CHYP strives to assist in reducing uncertainty and minimize parents’ “diagnosis-seeking” behaviors. Education that “makes sense” is a significant contributor to recovery and function (Sun et al., 2023). CHYP seeks to address this through virtual meetings and webinars for parents with clinical experts offering supplementary education. Additionally, weekly blogs and vlogs provide parents with further information and education.

CHYP Closes the Gap in Comprehensive Pediatric Pain Management

CHYP does not provide clinical treatment but supports clinicians in scientifically based value-added ways. While organizations similar to CHYP exist, CHYP’s focus on creative arts is unique, addressing both pediatric pain psychology and the dynamics of parent-child interactions. The importance of addressing challenges faced by parents as their children transition to adulthood cannot be understated (Lunde et al., 2022). In addition to providing resources about chronic pain, CHYP also has a plethora of programs for parents of adolescents with pain to help parents support their

child’s development of self-agency. This helps supplement treatments from academic pediatric pain centers.



Figure 2. CHYP Support for Parents and Caregivers

Pain clinics often have lengthy waitlists, leaving patients and their families with questions and

without support for long time periods. CHYP bridges the gap for families waiting for an initial pain clinic appointment or between appointments by providing evidence-based pain education, self-help tools, creative arts, and support programs rooted in science, regardless of geography, minority status, or financial need. Through the use of a safe, heterogeneous online community with pain as the common denominator, CHYP can accomplish goals that are difficult to attain in a traditional medical setting. Each of CHYP's programs has been ethically designed to meet the needs of patients and parents and promote equitable virtual delivery (Marbil & Birnie, 2024). Through CHYP, youth and parents can interact with others in similar situations, become connected to a community, and utilize tools like creativity that they may not have previously explored. A goal is for "CHYPers" entering

Megan Sweeney, MPH
 Creative Healing for Youth in Pain;
 Loma Linda University School of Behavioral Health
 Email: meg@mychyp.org

Ashley Matejka, DHA, MBA
 Creative Healing for Youth in Pain

Kimberly Poston Miller, MBA
 Creative Healing for Youth in Pain

Lonnie Zeltzer, MD
 Creative Healing for Youth in Pain

a multidisciplinary pain program to feel more focused in their questions and comfortable with the explanations and treatment plans provided.

Conclusions

Tapping into the innate creativity of an individual with chronic pain and leveraging support networks early in life can lay the foundation for a brighter future where pain is not the central focus. CHYP emphasizes the importance of the biopsychosocial model to empower youth, focusing on services which channel creativity, increase self-efficacy, and leverage peer support to address multiple facets of pediatric pain, through programs carefully developed and supported by scientific research.

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Podcast Review

What a Pain Podcast [Audio Podcast] (2023-2024)

Jennifer L. Christofferson and Liana R. Galtieri

The podcast series, *What a Pain*, explores the field of chronic pain through interviews with individuals from different pain disciplines and patients with lived experiences. The co-hosts of the podcast are Glyn Williams, a pediatric anesthetist at Great Ormond Street Hospital, and Konrad Jacobs, a clinical psychologist at Oxford. Through their involvement in pain medicine, they have met and collaborated with many of the leaders in the field, which they reflect has helped grow their knowledge and perspectives on pain management. Their main goals are to share these perspectives and help to explain and understand the many factors that contribute to the complex presentation of pain that healthcare providers see in clinics. Each episode is structured by introducing the topic and speaker, interviewing the guest speaker, and providing their thoughts after the discussion. In our review of the podcast, we noticed several themes covered across the episodes: mental health and pain, treatment options for chronic pain, and patient-focused topics. While this review separates the podcasts by themes, it's important to recognize that these themes are present across many of the episodes.

In the pilot episode of the podcast, Williams and Jacobs reflect on the multifaceted nature of pain and its treatment in children and adults. They interview Dr. Allison Bliss, a pediatric anesthetist at Leeds General Hospital, as their first guest. The co-hosts and Dr. Bliss discuss the importance of understanding the interdisciplinary nature of treating chronic pain. Dr. Bliss emphasizes the importance of “finding the voice of the child” and “the wider

context of everything” to help better treat the pain. The three speakers reflect on a recent meeting of leaders of chronic pain services in the United Kingdom and the future directions of the field. They highlight the challenges and complexities of working with patients with chronic pain and note the importance of thinking about the whole person and their context, not just the presenting pain.

One of the primary themes highlighted throughout the podcast is the association between mental health and pain. Psychological and emotional distress can both contribute to and be a potential outcome of chronic pain (Caes et al., 2021; Liossi & Howard, 2016). In Episode 2 of Season 1, they interview Dr. Jeremy Gauntlett-Gilbert and explore the vulnerability to pain in individuals with autism spectrum disorder due to increased hypersensitivity. They point to the role of sensory sensitivity in the perception of pain and how pain rehabilitation may be more challenging for neurodiverse individuals compared to neurotypical individuals, based on neurodiverse individuals' greater struggles with cognitive and sensory load. They discuss potential ways to tailor treatments for neurodiverse patients. In Season 1, Episode 10, they interview Dr. Jane McNicholas and speak about common mental health diagnoses seen in pain clinic populations (e.g., anxiety, low mood and depression, PTSD). Importantly, they discuss the bidirectional relationship between mental health and pain and how this interplay can add to the complexity of the patient's presentation, potentially impacting conceptualization and treatment recommendations.

They note that it is crucial to have collaborative conversations with the family when discussing mental health and chronic pain.

Another theme threaded throughout the podcast is different treatment approaches to managing chronic pain. Importantly throughout their episodes, Jacobs and Williams highlight the interdisciplinary approach to managing chronic pain, as this is often the most evidence-based approach for better quality of life outcomes in children (Claus et al., 2022; Randall et al., 2018). In Episodes 3 and 4 in Season 1, they interview Julia Smith, a physiotherapist (PT), and Anne Marie van Es, an occupational therapist (OT), both working at the Oxford Center for Children and Young People in Pain. During Episode 3, they emphasize the importance of patient education about their disorder, as this helps patients and families understand the rationale for PT/OT. Additionally, they emphasize the importance of building rapport with patients and families and getting to know their specific interests, as it is often through those interests/hobbies that they are able to get more engagement in treatment. In Episode 9 of Season 1, they speak with Dr. Navil Sethna, MD, and Clinical Director of the Mayo Family Pediatric Pain Rehabilitation Center at Boston Children's Hospital. They discuss how IIPT came to be developed through clinical experiences, the difference between interdisciplinary care and multidisciplinary care, and barriers to engagement and recovery. Interestingly, Dr. Sethna highlights how psychosocial factors (e.g., family relationships, finances, anxiety) might interfere with patient and family engagement in IIPT as well as long-term recovery.

A final theme noted is patient-focused topics. In Episodes 5 and 6 of Season 1, the podcasters interview 18-year-old Sofia Fateh, a patient who developed chronic widespread pain at 12 years old. Sofia shares her pain journey, including describing the tremendous impact it had on her life and her time at an interdisciplinary pain treatment program in Boston. Sofia presents a story of resilience and hope for other patients and serves as a helpful guide for providers. The podcasters and interviewee have a collaborative discussion on what is and is not helpful for patients, including tangible take-aways for providers. In Season 1, Episode 11, Jacobs and

Williams interview Professor Chris Eccleston from Bath University, and they review and discuss a recent Lancet Commission report focused on improving care for pediatric pain (Eccleston et al., 2021). Eccleston stresses that in order for providers to improve treatment and management of pediatric chronic pain, they must focus on four tenets: (1) make pain matter, (2) make it understood, (3) make it visible, and (4) make it better. He highlights the importance of healthcare providers listening to patients' complaints and symptoms, as well as validating patients' pain when reported. He also argues that for pain to be better understood, research about pain should be more interdisciplinary and should involve patients and families. More interdisciplinary research would allow for providers from various backgrounds to gain a fuller understanding of the mechanisms (biological, mechanical, psychosocial) that contribute to pain. Additionally, by involving patients and families in research, they can help to inform language and communication about pain.

In Episode 8, Season 1, interviewee Dr. Kashikar-Zuck discusses what happens with young people with chronic pain when they become adults. The focus of this discussion is that chronic pain in childhood can have long-term outcomes (e.g., pain, social, emotional, and developmental; Kashikar-Zuck et al., 2019). Dr. Kashikar-Zuck discusses potential trajectories of chronic pain in adulthood, pointing to a small subgroup that end up with more severe pain. She and the interviewers discuss potential ways to identify the patients who may fall into that subgroup in order to potentially intervene sooner. In Episode 1 of Season 2, they interview Dr. Katie Vincent, an adolescent gynecologist. They discuss how pelvic pain (e.g., severe menstrual pain, endometriosis) is often addressed with surgical interventions or procedures that may not relieve the pain fully. Dr. Vincent urges for the focus to be on the quality of life of patients, which for chronic pelvic pain may include an interdisciplinary approach. She points to the importance of psychology with chronic pelvic pain (Powell, 2014; Sieberg, 2020) to help address the stigma associated with pelvic pain and particularly for gender-diverse patients who often associate pelvic pain with tremendous distress related to their identity.

Overall, *What a Pain* with Konrad Jacobs and Glyn Williams presents a wide variety of topics associated with pediatric chronic pain disorders, from episodes focused on specific types of pain disorders to those with a focus on approaches to treatment. Similar to a multidisciplinary approach to pain treatment, their podcast episodes include a wide variety of speakers from different specialties (e.g., physicians, physical therapists, etc.). This allows the listener to learn more about treatment and management of chronic pain. Generally, the podcast seems oriented toward healthcare providers. Each episode is peppered with education and facts about chronic pain as well as evidence-based treatment for chronic pain, which could be of particular interest to trainees in pediatric pain and providers who are

interested in learning more about chronic pain conditions. In addition, Episodes 5 and 6 of Season 1 would be good resources for a clinician to recommend to patients. The speakers include helpful metaphors and tips that providers can use in their clinical practice. To expand the reach of their podcast, Jacobs and Williams might consider including more patient perspectives throughout their episodes. It is possible that joining more patients and families in conversation with healthcare providers might lead to richer discussion about chronic pain and its treatment. Not only would more patient-focused episodes allow for broader representation and for patient voices to be heard, but this would also potentially increase the reach to be suited to a wider audience of patients and families.

Jennifer L. Christofferson, PhD

Boston Children's Hospital, Department of Anesthesia, Critical Care, and Pain Medicine
Department of Psychiatry, Harvard Medical School
email: Jen.Christofferson@childrens.harvard.edu

Liana R. Galtieri, PhD

Boston Children's Hospital, Department of Anesthesia, Critical Care, and Pain Medicine
Department of Psychiatry, Harvard Medical School

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