



Pediatric Pain Programs: A Day Treatment Model at Boston Children's Hospital

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Program Overview

Pediatric chronic pain is a significant health concern that impacts youth's daily functioning and quality of life (Hechler et al., 2015; Odell & Logan, 2013). Prevalence rates for pediatric common pain conditions, including headache, abdominal pain, back pain, and musculoskeletal pain, range from 11% to 38% (King et al., 2011). Youth with chronic pain often become disengaged from academic and physical activities, experience disruptions in social and familial relationships, and experience emotional distress associated with ongoing functional impairment (Hechler et al., 2015). Intensive interdisciplinary pain treatment (IIPT) programs demonstrate positive, robust, and long-term outcomes among youth with profound pain-related functional

impairment by prioritizing a rehabilitative model with a focus on returning to functioning rather than eliminating pain (Hirschfeld et al., 2013; Hechler et al., 2015; Simons et al., 2018). In addition to these functional improvements, some IIPT program patients also report improvements in pain intensity over time (Hechler et al., 2015; Stahlschmidt et al., 2016; Simons et al., 2018; Randall et al., 2018).

Patients

The Mayo Family Pediatric Pain Rehabilitation Center (PPRC) at Boston Children's Hospital is an IIPT program that serves youth ages 8–18. Families have traveled from 36 states across the USA and 14 countries around the world to seek treatment for their child's chronic pain conditions. Of the PPRC patients, 89.6% identified as White, and approximately 81% of participants identified as female. The mean age of patients is 14. These demographics are consistent with chronic pain population demographics across studies and US-based pain programs (Simons & Kaczynski, 2012; Simons et al., 2018; Randall et al., 2018). This homogeneity represents a consistent trend in the literature and is a larger issue of concern regarding populations who may not be receiving needed treatment.

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Youth admitted to the PPRC have been diagnosed with chronic pain, considered pain lasting more than 3 months (IASP, 2019). Common pain diagnoses among PPRC patients include complex regional pain syndrome (CRPS) (46.5%), conditions with features of musculoskeletal pain (21.9%), chronic headaches (12.8%), non-CRPS neuropathic pain (7.6%), and chronic abdominal pain (7.2%). IIPT is often the recommended treatment model for these pain conditions when traditional outpatient treatment has been ineffective and youth continue to experience significant pain-related functional impairment. Functional impairment may include disruption in a young person's daily activities, such as school refusal (e.g., minimal or no attendance, significant time spent in the nurse's office during school days), discontinuation of activities or sports, disengagement in family life (e.g., not completing chores or attending family outings), and requiring support or accommodation for activities of daily living (e.g., using crutches or wheelchair rather than ambulating).

Admission

Patients undergo an outpatient multidisciplinary pain treatment evaluation to be considered for the PPRC. This initial evaluation includes a pain physician, a psychologist, and a physical therapist, who assess and provide diagnostic clarification within each of their specific disciplines and offer recommendations for treatment. Recommendations might include initiation or continuation of outpatient treatment or a referral to the PPRC. The multidisciplinary evaluation also serves as an initial assessment to determine eligibility for the PPRC. Appropriate candidates will have made efforts to treat chronic pain via outpatient therapies, including physical therapy and psychological therapy. Individuals experiencing severe and acute psychopathology (e.g., active suicidality, psychosis, eating disorder) that warrants specialized intensive treatment or a higher level of psychiatric care are not eligible for admission to the PPRC.

Further exclusion criteria include patients presenting with episodes of unconsciousness that have resulted in injury, not receiving medical clearance for weight-bearing or intense activities, active arthritis flare, being within 8 weeks of major illness/injury/surgery including concussion, or active contagious infection. While not an absolute contraindication, lack of patient or family willingness to engage in a self-management, rehabilitation approach to chronic pain requires further review and, at times, an additional screening with the PPRC admission team. The referring providers also assess for any substance use and make recommendations for any appropriate treatment or weaning plans prior to admission. The PPRC also requires patients to be willing to avoid marijuana use while in the program. Patients can engage in treatment while undergoing medication weaning, as long as they are medically cleared to do so.

Program Goals and Expectations

Overarching program goals and expectations are centered around supporting patients' return to functioning with the ultimate, long-term goal of pain reduction (Simons et al., 2018; Randall et al., 2018). Interdisciplinary treatment goals include the understanding and implementation of self-management strategies for chronic pain; improving strength, endurance, and tolerance for daily activities, including exercise; and replacing an image of disability with one of wellness. Chronic pain treatment necessitates patients' acknowledgment of the value in returning to typical daily tasks and acceptance of improved functioning as progress. Patients who believe and adopt this mindset are often more inclined to achieve success (Gauntlett-Gilbert et al., 2013). As youth gradually resume more typical engagement in their lives and activities, chronic pain becomes less of a focus, which allows patients' continued engagement in preferred activities.

For this reason, the PPRC is an immersive treatment program, to which patients and families are expected to wholly commit. Patients achieve the best results by minimizing distractions

that may influence their engagement in treatment. During the day, staff engage patients in several therapeutic sessions. In the evening, patients complete evening assignments. Families are asked to support patients' full engagement in the treatment process. Specifically, families are requested to arrive on time daily and complete evening assignments, such as their home exercise program (HEP) and psychology home practice activities. Additionally, caregivers are expected to be engaged in treatment by attending family therapy sessions and supporting patients to complete their HEP and evening assignments. The PPRC encourages a self-management approach to chronic pain, which assures caregivers of their child's capacity to independently cope with pain. Related to this, caregivers do their own work to learn and refine their understanding of how to support their child with chronic pain by attending caregiver sessions and learning strategies and best practices to coach their child.

Average length of stay varies for each patient, though typically ranges between 4 and 6 weeks. This time frame typically varies based on patient readiness and progress in meeting shared treatment team goals. For patients, these goals are related to functional rehabilitation and self-management of pain; for caregivers, these goals are related to increased understanding of chronic pain and appropriate expectations for their child's level of functioning and self-management. Program staff, patients, and families work collaboratively during the admission to develop more specific, targeted, and individualized treatment goals that are in line with these more general shared treatment goals. As patients progress through the program, providers engage in regular check-ins to assess readiness for discharge. If patients maintain consistent progress toward individualized treatment goals, their treatment team will help them prepare for their next steps, which may include a lower level of care such as outpatient treatment for ongoing support and maintenance. If regular check-ins and assessments consistently indicate that patients are experiencing interference that inhibits their full participation and engagement at the PPRC and/or are struggling to meet their goals, staff may rec-

ommend a more appropriate program or treatment option. For example, new onset of psychiatric symptoms that would require a higher level of care would necessitate a transition from the PPRC to pursue a higher level of care.

Referral Process

All PPRC referrals are internal and require an initial referral to the outpatient multidisciplinary pain clinic. Often, referrals originate from providers within the hospital system who are aware of the outpatient multidisciplinary pain clinic or the PPRC. Importantly, providers outside of the clinic must be aware of one or both programs to provide the appropriate referral. Alternatively, families must be aware of one or both programs and advocate for these referrals or be directed to navigate the appropriate systems to gain access to treatment at the PPRC. The referral process certainly limits access to the PPRC to those who know about the program and understand the population treated at IIPT programs. However, it is possible that with the expansion of telehealth, there may be additional opportunities to broaden access and potentially expand the PPRC referral base.

Program Development and Implementation

The PPRC program was developed as part of the Pain Treatment Service (PTS) at Boston Children's Hospital, a multidisciplinary program established in 1986 consisting of an inpatient acute pain service and an outpatient chronic pain clinic. Prior to the development of the rehabilitation program, patients with chronic neuropathic pain were either treated with inpatient admissions to a medical unit or outpatient therapy. On the inpatient unit, they received physical therapy, consultation from psychiatry and procedural intervention, such as regional anesthetic nerve blocks. Outpatient services would typically include physical therapy and psychology. Pain leadership recognized that these models were not

adequately meeting the needs of the most complex patients.

The inpatient model provided more intensive medical supervision and access to round-the-clock care; however, this was not consistent with the recommendation that chronic pain patients engage in functional activities and minimize medical intervention when possible. It was challenging to try and establish a more typical daily schedule of activities on a hospital unit and even more challenging to generalize new skills and routines to the home environment. The outpatient model, however, did not provide the level of intensity of services that more complex patients required to make sustained progress despite the reduction in more medically focused management. The directors of the Pain Treatment Service made plans to develop a model that would address the needs of these patients.

The day treatment model was chosen due to a number of identified benefits. Patients could receive an increased intensity of treatment, 8 hours a day, 5 days per week, while also remaining in their home environments or with their families in the evenings and weekends. Avoiding an inpatient admission was also considered helpful in emphasizing normal function and de-emphasizing the sick role for these youth and their families. Increasing intensity from an outpatient model allowed complex patients to receive a beneficial increased “dose” of treatment (Simons et al., 2013). The day hospital model also allows for shared physical proximity of care providers, which results in frequent communication and care collaboration. This level of coordination and communication is critical in caring for youth with chronic pain who have not responded to outpatient treatment. Further, the day treatment model is less costly than an admission to an inpatient medical-surgical unit. Philanthropic funding was secured from a donor with a particular interest in the treatment of chronic neuropathic pain. In 2006, these funds were used to establish an intensive rehabilitative day hospital program for pediatric CRPS and other chronic pain conditions, and in 2008, the program officially opened its doors.

Physical Space

The day treatment facility was chosen to be located at a suburban satellite location of Boston Children’s Hospital, which allowed for an individualized design tailored to the clinic’s needs. Special attention was placed on the environment of the clinic and the intention for the space to avoid a more traditional hospital look and feel. The space was designed to include a large gym where all patients could work together, along with individual treatment spaces for each discipline. The layout also included additional group space for education time and family and team meetings.

Treatment Team

The treatment team provider disciplines included in the PPRC were initially based on a more traditional rehabilitation model and included medicine, nursing, psychology, and physical therapy (PT). After a brief period of operation, occupational therapy (OT) was included as well. The multidisciplinary approach to the treatment of pediatric chronic pain is well documented in the literature (Odell & Logan, 2013), and the disciplines at the PPRC were chosen to reflect the biopsychosocial model of understanding pediatric chronic pain (Lioffi & Howard, 2016). Development of the program included key stakeholders of the leadership groups of each discipline at the hospital. With the expansion of the program, census and innovation in treatment delivery, recreational therapy, music therapy, and social work have been added. Each discipline is involved in the training of clinicians from short clinical rotations to more long-term fellowships.

Insurance Coverage

Acquiring the support of insurance payers for a new model of care was a challenge faced in the opening of the program. Billing codes did not exist for the types of services that would be offered at the PPRC. PPRC leadership met with insurance executives from regional companies to

discuss the benefits of the program on health-care utilization and overall cost. The hospital and program leaders negotiated a per diem rate with each insurer, which included a bundled charge for PT, OT, psychology, and nursing services. Physicians' time is billed separately. Payment agreements have been met for a majority of local insurers, and single-case agreements have been provided for other out-of-state patients. Since opening, the program has been consistently financially viable.

Day-to-Day Programming

PPRC days are structured with multiple therapy sessions throughout the day and week. Each day begins at 8:00 a.m., and patients engage in treatment until 4:00 p.m. During this time, each patient attends hour-long treatment sessions. Session formats alternate between individual, family, or group treatment modalities, with daily physical therapy, occupational therapy, and psychological therapy sessions. Patients also engage in rotating recreational therapy and music therapy sessions throughout the week. In addition to therapy sessions, patients engage in daily check-in meetings with PPRC medical staff (physician, nurse practitioner, and clinical assistant [typically a CNA]) and are allotted 1 hour each for study hall and lunch. See Table 18.1 for an exam-

ple of a daily schedule. In the early days of the COVID-19 pandemic, the PPRC paused operations for the safety of patients, families, and staff. After several months, and with new safety protocols in place, treatment resumed in a hybrid model of care. Within the hybrid model, patients attend the PPRC in person for a half day, and the remainder of the day is conducted virtually. This hybrid model prioritizes holding physical and occupational therapy sessions in person to gain the maximum effect of these treatments. Other therapies alternate between in person and virtual, such that only half of the patients are on-site at a time. Following federal, state, and hospital guidelines, the PPRC plans to return to full in-person treatment days as safety protocols allow.

Theoretical Framework

Interdisciplinary pain treatment at the PPRC is based on a biopsychosocial framework. This theoretical framing highlights the multidimensional nature of pain and indicates the need for a treatment plan that addresses each dimension. The biopsychosocial model of pain identifies that pain is associated with biological, psychological, and social factors of a person's experience and can likewise impact those same areas of functioning (Gatchel, 2004; Gatchel et al., 2007; Lioffi & Howard, 2016). Biological factors such as age, sex, family history, illness, or injuries influence an individual's predisposition for chronic pain (Lioffi & Howard, 2016). Psychological factors including an individual's mood, proclivity for worrying, temperament, expectations of themselves or others, and ways of thinking, feeling, and engaging with the world are also factors that can affect chronic pain (Gatchel, 2004; Gatchel et al., 2007; Lioffi & Howard, 2016). These factors often act in concert with social factors such as how important others in an individual's life respond to their pain experience as well as an individual's level of engagement in social or preferred activities with peers or family members (Gatchel, 2004; Gatchel et al., 2007; Lioffi & Howard, 2016).

Equally important to consider is the effect that these factors have on pain. When youth disengage from their lives as a result of chronic pain, their

Table 18.1 Example daily schedule of PPRC patient

Time	Activity
8:00–9:00 a.m.	Family therapy (e.g., family OT)
9:00–10:00 a.m.	Individual therapy (e.g., PT)
10:00–11:00 a.m.	Individual therapy (e.g., psychology)
11:00–12:00 p.m.	Group therapy (e.g., group PT)
12:00–1:00 p.m.	Medical team visits/study hall
1:00–2:00 p.m.	Lunch/study hall
2:00–3:00 p.m.	Group therapy (e.g., group recreational therapy)
3:00–4:00 p.m.	Individual therapy (e.g., OT)
4:00 p.m.	Dismissal

physical functioning often declines as they are more likely to become deconditioned (Liossi & Howard, 2016). Youth often experience increased anger, sadness, and anxiety as a result of the intense focus on pain and worries about pain, leading to less engagement at home or with peers (Gatchel, 2004; Gatchel et al., 2007). Lack of engagement further impacts social experiences, as youth are less likely to engage with peers and families often struggle to determine the most helpful response to their child's pain (Liossi & Howard, 2016).

Treatment Modalities

PPRC treatment modalities include psychology, physical therapy, occupational therapy, recreational therapy, music therapy, and medicine. In addition to the shared treatment goals, each discipline has its own treatment focus. Psychological therapy supports the development of coping skills and assessment of emotional and behavioral contributions to pain and provides family education and support. Physical therapy focuses on aerobic exercise, strengthening and balancing, and stretching, all in the context of specific and functional movement skills that are useful for day-to-day activities. Occupational therapy supports patients in identifying and meeting functional goals related to school, extracurricular activities, self-care, or other daily tasks; treatment activities may range from sensory retraining (desensitization) to engaging in schoolwork. Recreational therapy utilizes leisure activities to support patients' return to their preferred activities and become reengaged in their communities. Music therapy provides opportunities for patients to experience the therapeutic effects of music as a coping strategy and support their ability to manage pain and engage in self-expression through music.

Patients meet daily with the PPRC physician, nurse practitioners, and clinical assistant to assess clinical changes and manage or discontinue medications as necessary. The medical team's primary focus is collaboration with the PPRC therapists to ensure a holistic approach to treatment. Providers may also implement combined treatment sessions to encourage continuity across

disciplines; for example, psychology providers might join an occupational therapy session to coach patients to practice implementing diaphragmatic breathing during a desensitization activity in occupational therapy. Patients are also required to complete PT/OT HEPs, home practice of psychology skills, and evening or week-end recreational activities that align with therapeutic goals. This offers patients and caregivers an opportunity to practice what they learn in sessions and allows providers to engage in problem-solving with families.

Behavioral and Crisis Management

Challenges with behavior management often arise, as participant may experience significant behavioral responses to treatment. When patients engage in pain behaviors (e.g., avoidance, behavioral dysregulation) that interfere with treatment, PPRC providers will often collaborate to identify a behavior management plan to implement both on-site with staff and off-site with families. As a result, patients may have limited access to preferred items (e.g., electronics), when having difficulty engaging in treatment, and can earn these and other rewards for appropriate engagement in treatment. Consistency with such plans allows patients and families to practice generalizing skills learned at the PPRC across settings.

PPRC staff make efforts to maintain open communication with patients and families to preempt any adverse reactions or crisis situations. Despite best efforts, if patients experience physical or emotional challenges that require additional support, providers are trained in behavior management principles to respond appropriately to ongoing dysregulation. Additionally, a psychologist is always on-site to support and offer assistance when patients are receiving in-person treatments. Should patients require additional support, the hospital behavioral response team is available for assistance. During the initial psychology assessment, or at any point during a patients' PPRC tenure, if providers become aware of acute psychiatric risk, including active suicidality, self-injurious behaviors, acute behavioral dysregulation, or other high-risk behaviors, they enact the psychiatric emergency plan. This

plan includes an assessment by an on-site psychologist, safety planning as needed, and disposition planning with the on-site crisis assessment team. The team works with on-site administrators on duty for potential transfer to the local emergency department if required. On-site psychology providers will engage in safety planning for passive suicidal ideation and continue to assess risk and potential need for higher level of care. If patients require acute support related to safety concerns while participating in virtual PPRC sessions, providers instruct caregivers to present with the patient to the local emergency department. If concerns persist and the family declines to report to the emergency department, providers contact the local authorities to perform a wellness check.

Assessment

Assessment of patients attending the PPRC is valuable for both clinical and research purposes. All patients admitted to the PPRC are given a multidisciplinary battery of assessments at admission, discharge, and three follow-up time points (6–8 weeks post-discharge, 6 months post-discharge, and 1 year post-discharge). The assessment of patients at these time points provides the treatment team with the ability to create individualized treatment plans, set realistic and measurable clinical goals, and evaluate treatment outcomes following discharge. Further, with consent of patients and caregivers, participation in clinical research provides valuable data to the growing field of intensive interdisciplinary treatment of pediatric chronic pain.

The PPRC assessment methods are influenced by the core outcome domains recommended for pediatric chronic pain trials as recommended by the PedIMMPACT consensus meeting (McGrath et al., 2008). These domains include pain intensity, physical functioning, emotional functioning, satisfaction with treatment, economic factors, role functioning, and sleep. These outcome domains map onto the biopsychosocial model of chronic pain and the treatment areas of the program. Prior to admission, patients are adminis-

tered an assessment battery of psychosocial measures, including assessment of pain intensity and frequency, physical functioning, school attendance and attitudes toward school, pain-specific anxiety, general anxiety and depression, and perfectionism (see Table 18.2). Caregivers are also administered a battery assessing for caregiver response to their child's pain, pain-related fears, and perfectionism. Given the significant participation of caregivers in the treatment program and the influence of caregiver behavior and response on child outcomes, assessment of caregiver outcomes is equally as important as those of their children (Palermo et al., 2014).

In addition to the psychosocial battery prior to admission, each discipline conducts an initial assessment upon admission. Physical therapists

Table 18.2 List of core psychosocial assessment measures

<i>Child measures</i>
Functional Disability Inventory (<i>FDI</i> ; Walker & Greene, 1991)
Fear of Pain Questionnaire (<i>FOPQ-C</i> ; Simons et al., 2011)
Pain Catastrophizing Scale (<i>PCS-C</i> ; Goubert et al., 2003)
Adolescent Sleep-Wake Scale (<i>ASWS</i> ; LeBourgeois et al., 2005).
Child-Adolescent Perfectionism Scale (<i>CAPS</i> ; Flett et al., 2016)
PROMIS Depression – short form (Cella et al., 2010)
PROMIS Anxiety – short form (Cella et al., 2010)
Frost Multidimensional Perfectionism Scale (<i>FMPS</i> ; Frost et al., 1990)
<i>Caregiver measures</i>
Pediatric Quality of Life Inventory (<i>PEDSQL</i> ; Varni et al., 1999)
Fear of Pain Questionnaire (<i>FOPQ-P</i> ; Simons et al., 2011)
Pain Catastrophizing Scale (<i>PCS-P</i> ; Goubert et al., 2003)
Adult Response to Child Symptoms (<i>ARCS</i> ; Van Slyke & Walker, 2006)
Bath Adolescent Pain – Parental Impact Questionnaire (<i>BAP-PIQ</i> ; Jordan et al., 2008)
Depression-Anxiety-Stress Survey – short form (<i>DASS 21</i> ; Lovibond & Lovibond, 1995)
Helping for Health Inventory (<i>HHI</i> ; Harris et al., 2008)
Frost Multidimensional Perfectionism Scale (<i>FMPS</i> ; Frost et al., 1990)

spend the initial days of the patient's admission, administering developmentally appropriate and empirically validated measures of strength, endurance, functioning, coordination, balance, and agility. They also assess for pain interference with tasks of physical functioning. Occupational therapists assess the patient's participation in activities of daily living, school functioning, coordination and agility, pain sensitivity, sensory profile, and the patient's self-identified occupational goals. Medical and nursing staff also conduct a thorough evaluation at the time of admission, assessing for any biomedical contributing factors to the patient's pain presentation. At the end of a patient's admission, the treatment team will repeat the assessment battery and meet with the patient and caregivers to review treatment outcomes. The progress demonstrated in these assessments helps the team to set goals for the next touchpoint in the treatment, the follow-up visit. Follow-up evaluations occur at the 6- to 8-week, 6-month, and 1-year post-discharge time points.

Over time, the PPRC has made important adjustments to the battery of assessment measures, influenced by the broadening research on pediatric chronic pain as well as the developing research inquiries of the treatment staff. The assessment process has become more interdisciplinary over time, including the development of measures that cut across disciplines and reflect the nature of the program to set patient treatment goals that span specific disciplines. For example, the PPRC staff is developing an interdisciplinary adherence measure to assess patient commitment to the treatment recommendations post-discharge. The measure includes goals that are created by the team, rather than by one specific discipline.

Empirically validated and evidence-based assessment in intensive interdisciplinary pain is important in the evaluation of the patient as well as the evaluation of the program itself. Growing the body of research on assessment measures in pediatric IIPPT will help ensure that the treatment provided is successful in accomplishing its intended goals and meeting patients' needs. Research suggests that there may be a number of influential patient and caregiver factors on patient

outcomes following pain treatment, including but not limited to patient emotional, cognitive, and behavioral factors, pain-specific factors like intensity and duration, and environmental influences like family system functioning (Palermo et al., 2014; Simons et al., 2018; Williams et al., 2020). Further knowledge of these contributing factors will assist IIPPTs in development of empirically validated treatments and targeted interventions.

Interventions

Evidence Base

The treatment provided at the PPRC is based upon evidence-based interventions from existing literature on chronic pain treatment as a whole and from research within each discipline. Existing literature on pediatric chronic pain supports the use of multidisciplinary treatment as an effective model for the treatment of youth with this condition (Odell & Logan, 2013; Hechler et al., 2015). Disciplines included in treatment may depend on the type of chronic pain (e.g., primary headache, gastrointestinal or neuropathic pain) and range from outpatient coordination between two disciplines to inpatient treatment with a variety of disciplines included. It is unclear if there is a specific treatment level of care that is more effective as there are few published studies focused on day treatment models exclusively treating youth with chronic pain. In one study by Simons et al. (2013), more intensive treatment was associated with larger gains in functional disability and pain-related fear than matched controls in traditional outpatient multidisciplinary care.

Key Components of Intervention

The goal of multidisciplinary treatment generally, and in the PPRC specifically, is to help patients improve their physical functioning and engage in developmentally appropriate daily activities, including engagement in school, sports, recreation, and family life. Interventions used within the PPRC are centered in the biopsychosocial model described earlier and

draw from a framework of the fear-avoidance model of chronic pain as well as the vicious cycle of pain. These models have been described in existing literature (Simons et al., 2012; Dobe & Zernikow, 2014). These models acknowledge the contributions of cognitive appraisals of pain as dangerous or catastrophic, emotional and physical responses to pain and fear, and the role of avoidance of activity and pain as a significant contributor to pain-related disability. Interventions in the PPRC focus on breaking the cycle of avoidance through graded activity progression and exposure to feared activities within a supportive and structured environment. The intervention allows the patient to challenge catastrophic thinking about pain, receive coaching in active coping strategies, and break cycles of avoidance that have contributed to isolation, deconditioning, and mood disruption.

This progression is supported with active coping education, founded in cognitive behavioral therapy, acceptance and commitment therapy, family support and education, and psychological support for any identified mood or behavioral barriers. The interventions utilized are individualized to each patient but are founded in evidence-based treatments for pediatric mental health as well as pediatric chronic pain (Fisher et al., 2014). Examples of interventions used to achieve physical functioning goals are varied. They include biobehavioral strategies, such as relaxation, guided imagery, progressive muscle relaxation, and mindfulness. Cognitive strategies include the education for the patient and caregivers about the science of pain and the biopsychosocial model of understanding pain. Psychologists engage patients in identification of unhelpful thinking patterns, fears, and depressive thoughts and develop strategies to manage these thinking patterns through cognitive behavioral and acceptance-based models. Other acceptance-based techniques include identification of patient and family values, enhancing patient and parent distress tolerance, and engaging in problem-solving techniques with the aim of helping the patient to adopt a confident, self-management approach to their pain. Behavioral reinforcement plans, graded exposure ladders, emotional regu-

lation strategies, and use of physical movement are also included and implemented throughout all disciplines' treatment. The key to the success of these interventions is the consistency and frequency in which they are carried out.

Keys for Success

The PPRC treatment team utilizes the day treatment model to its full extent. The collocation of disciplines within one physical area, the frequency of team communication, and the development of shared goals allow for the consistency that is required for success. Psychologists, physical therapists, and occupational therapists collaborate on the setting of short-term goals and utilize the same language, techniques, and strategies to encourage patient participation and progress. The combination of the consistency among providers and frequency of daily sessions allows for many opportunities for rehearsal of new skills. This shared approach is taught to caregivers so that they can learn to provide the same consistency in their home setting. The day treatment model allows them to practice these approaches each evening and on weekends when their children are not in the care of the PPRC. Staff provide patients and caregivers homework to complete in the evenings and on weekends to assess the acquisition of this approach.

In addition to the benefits of consistency and frequency afforded by the day treatment model, the benefit of flexibility is also available. While the PPRC has a structured daily schedule for patients and families, there is unique flexibility within that schedule to provide tailored treatment. For example, patients who struggle with school attendance can participate in a school simulation session with one of our occupational therapists where they are coached in how to implement school-based coping strategies. A patient with a goal to return to sports may work with our physical therapist and psychologist together to work on both the mechanics of their physical participation and the emotions, like fear, that may contribute to avoidance of this activity. While the PPRC utilizes evidence-based inter-

ventions in the treatment of pediatric pain, it is the creative application of these interventions within a unique care model that is often identified by patients and families as the key to their success.

Collaborations and Generalizing Treatment

PPRC treatment prioritizes the inclusion of family and caregivers through formal caregiver sessions and additional programming. Families are included in the treatment through daily family sessions with each of the therapies. Caregivers will have opportunities to observe their child's progress in physical therapy, occupational therapy, or psychology on a daily basis. Though less frequent, family sessions for recreational therapy and music therapy also engage caregivers in supporting their child's coping and self-management of pain. Meeting regularly with caregivers allows providers to discuss and problem-solve around caregiver engagement with their child in the context of pain and model helpful strategies for responding when patients experience challenges.

In addition to caregiver engagement with patients, caregivers have programming designed specifically for their edification. PPRC providers lead caregiver education sessions in a variety of interdisciplinary topics, which also allow for group conversation and discussion of common themes in pediatric chronic pain. Both in this context and in family sessions, providers take care to openly communicate caregiver expectations in the program and encourage caregivers to consider current patterns of engagement that contribute to their child's impairment. Caregivers also have access to a weekly support group, which provides opportunities to connect with other PPRC caregivers, as well as an informal coffee hour for ongoing community connection. PPRC providers also encourage caregivers to take advantage of opportunities to schedule regular individual meetings with the PPRC social worker. These individual meetings are useful when caregivers require additional support or would like to gain an improved understanding of

their role in supporting their child's recovery and self-management of pain.

PPRC providers support caregivers throughout the program and provide anticipatory guidance about transitioning home, as patients are likely returning to environmental and situational stressors. Self-management and pacing are important goals of IIPT, and determining ways to incorporate both as patients reintegrate into their home lives can be difficult. While patients should be expected to engage in their required tasks (school, chores) and preferred activities (sports, socializing with friends) and independently manage their pain, it is important to do so in a sustainable way. Caregivers are expected to be available for support while encouraging a developmentally appropriate level of independent functioning to promote and maintain increased self-efficacy to manage pain. Providers engage in relapse prevention by helping to prepare families for this transition prior to discharge. This coordination of care can often reduce conflict between patients and families while also improving mood and building confidence to manage challenging situations.

Working with Schools

Another significant part of the treatment includes working with schools throughout patients' PPRC admission. With caregiver consent, psychology providers and occupational therapists collaborate with patients' schools to inform them of the treatment and identify realistic goals for accessing and completing schoolwork. Providers work collaboratively with schools and caregivers to conduct school meetings during treatment and develop school reentry plans prior to discharge as a pertinent part of treatment. Prior to discharge, a formal school conference call is held with the patients' primary treatment team, parents, and key stakeholders from their school. Patients are typically not in attendance, though older adolescents may request to join the meeting. Psychoeducation about chronic pain management within the academic environment is discussed and supported by written documentation. School staff receive copies of the written docu-

mentation and copies of the coping plans developed during the participant's admission.

Outpatient Follow-Up Care

In addition to support with school reintegration, PPRC providers regularly coordinate care with outside treatment providers to ensure patients can return to an environment with ongoing support. If caregivers approve, PPRC providers contact outpatient therapists, coaches, and physicians to offer insight regarding patients' treatment and progress toward functional restoration. Providers offer education and resources to facilitate additional knowledge of chronic pain treatment for outpatient providers. When appropriate and helpful, PPRC providers also communicate with other community members with whom patients typically interact, such as athletic coaches, dance instructors, gym teachers, and other extracurricular activity leaders, to provide recommendations about paced reentry into sports and activities. Collaboration with these helpers is often essential to support the patients' safe and appropriate return to functioning at home, in school, and in athletic and leisure activities. Following discharge, PPRC providers maintain communication with families and outpatient providers for ongoing support and collaboration as necessary.

Following discharge, patients and their families receive a check-in phone call during their first week back at home. PPRC nurse practitioners place these calls and ask patients about their adjustment to school or other activities, compliance with their post-discharge recommendations, and field any questions on the transition process. Caregivers receive guidance prior to discharge on the appropriate times to call the PPRC for guidance, including difficulties with compliance, poor school attendance, significant declines in functioning, or questions regarding any medication plans initiated while at the PPRC. Families are advised to reach out to their local providers (primary care physician [PCP], mental health provider, or any treating PT or OT) for more general health concerns, assessment of new injury, or

treatment plans initiated by the outpatient provider.

Case Example

Alexa is a 12-year-old white female who presented for treatment at the PPRC due to persistent pain in her right leg following an injury she sustained during a dance competition 9 months prior. Alexa was initially evaluated for her injury, which was diagnosed as an ankle sprain, treated with conservative measures such as ice, rest, and staying off of her right ankle until her swelling and pain subsided. Despite these interventions, Alexa's pain continued, and she followed up with her PCP, who recommended a walking boot for a period of 1 month. During that time, Alexa's pain worsened and after a period of 3 months post-injury, her pain was severe. She had started to develop new symptoms including sensitivity to touch and discoloration of the skin on her leg. Her pain had increased beyond her ankle and included her entire lower leg beneath her knee.

Alexa was referred to the Pain Treatment Service at Boston Children's Hospital and was seen for a multidisciplinary evaluation with a pain physician, a pain psychologist, and a physical therapist. Alexa received a diagnosis of complex regional pain syndrome, or CRPS. CRPS is a chronic pain condition characterized by persistent pain, typically in the extremities, as well as other specific features including increased sensitivity of the skin, color and temperature changes of the affected area, swelling, and/or motor impairments. Her initial physical therapy assessment indicated that Alexa had experienced some muscle loss in her right leg and a decrease in her range of motion and strength. Her psychology evaluation indicated that Alexa was endorsing symptoms of generalized anxiety and pain-specific fear and avoidance and she endorsed passive suicidal thoughts. She was prescribed a course of outpatient physical therapy and recommended to pursue treatment with a psychologist with a focus on cognitive behavioral therapy. She was also provided with a prescription for

gabapentin in an effort to try and control her significant nerve pain.

Alexa returned for a follow-up visit with her pain physician 3 months later. She had been engaging in outpatient physical therapy and had started to see a counselor. However, she continued to endorse significant levels of pain, and her functioning had declined. Alexa was no longer able to attend school regularly and was advised to engage in homebound instruction as a result. She had not been able to participate in her dance classes, and her social activities had decreased in frequency. Alexa's parents reported frustration and anxiety about the lack of progress and felt that they did not have the tools they needed to help Alexa succeed.

Alexa and her family were referred for admission at the PPRC. Alexa's case was reviewed by the PPRC admission team, and she was determined to be an appropriate candidate. Given her history of passive suicidal ideation, a psychologist at the PPRC consulted with her treating provider to discuss potential safety risks. The treating therapist felt that Alexa had developed a good safety plan and shared this plan with the treatment team at the PPRC, with parental consent and release of information.

Alexa was admitted for a 6-week admission at the PPRC. During her initial assessment at the PPRC, Alexa continued to endorse high levels of pain-related fear, general anxiety, sleep disruption, and a high level of perceived disability. She continued to use a walking boot and crutches for ambulation and vocalized anxiety about the potential for these devices to be discontinued. During Alexa's admission, her therapists worked together on creating graded exposures and activity hierarchies to treat Alexa's fear and avoidance behaviors. In psychology sessions, she worked to develop skills to enhance her engagement in treatment and address symptoms of anxiety, such as relaxation strategies, cognitive restructuring of anxious and depressive thinking, motivational enhancement, and use of behavioral contingency plans to reinforce engagement in treatment. Her parents engaged in family therapy sessions to learn about how they could support Alexa's independent management of her pain. They initially

struggled with the recommendation to reduce pain assessment and passive strategies, such as rest or avoidance of painful activities, and they benefited from the supplemental support provided by the social worker at the PPRC.

Alexa was able to successfully wean out of her walking boot and off of her crutches after the third week of treatment. She started to walk with a more normalized gait pattern and engaged in desensitization of her sensitivity on her lower leg, allowing her to wear preferred clothing (e.g., leggings, jeans) and place her leg in a running water stream, both of which had been avoided due to pain. In her fifth week, however, Alexa appeared to plateau in her progress, and her affect was increasingly irritable and anxious. A team meeting was arranged to discuss the potential contributing factors to this shift. Alexa's parents and her primary team members met to discuss the potential barriers. Alexa's parents discussed their impression that Alexa was anxious about the expectations that might be placed upon her now that she was able to return to school and sports. Alexa was previously a very accomplished dancer and a high-achieving student. Her movement toward functioning may also represent a movement toward the pressure associated with these activities.

In the remaining treatment days, the team assisted Alexa and her family to discuss reasonable expectations for Alexa's return to dance. A conference call was held with administration from Alexa's school to provide them with education about her condition and recommendations for her return to school. The education emphasized the importance of the focus on functioning and the recognition of the role of stress on function. Alexa developed a plan with her psychologist of how to talk with her classmates about her condition, and her dance teacher set up sessions where she would gradually return to her previous class. Alexa's progress became more consistent, and at discharge, she was expressing more confidence in her abilities. Discharge results indicated significant gains in strength, endurance, range of motion, sensitivity, and speed. She also endorsed clinically significant improvements in anxiety and depressive symptoms, as well as reductions

in pain-related fear and avoidance. She denied ongoing passive suicidal ideation. Her parents endorsed a reduction in protective responses and overall anxiety.

After discharge, Alexa reintegrated back into school, attending full time with an added academic support class in her schedule to provide some time during her day to complete homework, go for a short walk or stretch, or engage in some relaxation exercises. She continued to endorse pain in her lower extremity but at a lower level than preadmission. She contacted the PPRC on two occasions due to experiencing a rapid increase in her pain, also called a "pain flare," that was increasing her distress and anxiety symptoms. Alexa's primary treatment providers at the PPRC met with her and her parents via phone to review her coping plans and ensure that she was attending her outpatient counseling sessions. At her first post-discharge follow-up, Alexa had met her short-term goals of continued improvement in strength and agility, full return to school, and reintegration to her dance class.

Integrating Research and Practice

The interdisciplinary team at the PPRC is invested in conducting research with the aims of investigating the clinical outcomes of the treatment program as well as contributing to the field of research on intensive interdisciplinary pain treatment. Data collection starts prior to admission and continues well beyond discharge from the program. Each discipline collects data within their field, and different disciplines frequently collaborate with each other. Research efforts are supported by a dedicated research assistant and data coordinator along with a dedicated research committee comprised of an interdisciplinary group of staff clinicians. This research effort is part of the larger efforts of the Pain Treatment Service at Boston Children's Hospital and the commitment to investigation, understanding, and treatment of pediatric pain.

The data collected within the discipline of psychology includes important outcome measures, as detailed in the PedIMPACT (2008)

statement for chronic pain, such as physical functioning, emotional and behavioral functioning, school attendance and functioning, and sleep. Data collected also includes areas of interest in the potential influence of pediatric pain treatment outcomes, such as pain-specific outcomes like fear, avoidance, and catastrophizing. These specific psychological constructs have been detailed in the literature as influential in the outcomes of pediatric pain rehabilitation (Simons et al., 2012; Weiss et al., 2013). Further, psychological research at the PPRC evolved over time to include new areas of interest and incorporate observations of the treatment population. For example, perfectionistic tendencies have been noted in the pediatric chronic pain population, but the empirical data supporting such observations is minimal. The PPRC is currently exploring the clinical data to support this observation (Randall et al., 2021).

Patients at the PPRC participate in clinical research upon consent at five time points; admission, discharge, 6–8-week post-discharge, 6-month post-discharge, and 1-year post-discharge. The post-discharge time points coincide with clinical follow-up evaluations with the treatment team and as such are useful for clinical data as well. Data collection occurs via online survey and occurs during the in-person evaluation. Post-discharge data collection is crucial in helping to draw conclusions about the short- and long-term impact of treatment. Longer-term data collection is also included in the PPRC research efforts, although long-term clinical follow-up is not.

Published research from the PPRC focuses primarily on clinical outcomes of the program and the various factors that influence these outcomes. Initial outcomes from the first year of patient data found improvements across nearly every domain from admission to discharge, including physical functioning, pain intensity, and emotional functioning (Logan et al., 2012a). This study was followed later by a 5-year outcome study that described maintained improvements over time in the areas of functioning in 80% of respondents. Thirty percent of respondents reporting being pain free, and 89% had graduated from school on-time (Simons et al.,

2018). In addition to these broad-reaching publications on the outcomes of the patients over time, research has also been published on specific factors of interest, including the changes in sleep and changes in willingness to self-manage pain after participation in the treatment (Logan et al., 2012b, 2015).

Research efforts at the PPRC have also focused on predictors of treatment success. Specifically, readiness to change, fear of pain, caregiver protective responses, and level of disability have been identified as important variables that can shape success. These patient and caregiver factors have been associated with both short-term success during the admission and longer-term success after discharge (Logan et al., 2012b; Simons et al., 2012; Sieberg et al., 2017). In one such study, Simons et al. (2018) utilized a trajectory model of data analysis to determine variables associated with treatment response or nonresponse. Older age, higher levels of pain, and lower readiness to take a self-management approach to pain were variables associated with a lack of response to treatment (did not report significant changes in pain or functioning).

Ongoing research continues to evaluate the short- and long-term outcomes of treatment in the PPRC. Interdisciplinary collaboration is a growing initiative in our research efforts with the intention to replicate our treatment philosophy in our research efforts. Education, mentorship, and dedicated research time are starting to be offered to all disciplines at the PPRC, and publications including a diverse spectrum of authors are increasing. Clinician researchers on staff are currently exploring unique contributing factors to pediatric pain treatment, including the role of perfectionism in youth and caregivers and the impact of caregiver mental health on child outcomes. Projects are also exploring novel treatment approaches such as virtual reality and piloting clinical protocols to increase patients' preparedness to participate in treatment. Physical therapy and occupational therapy staff are focusing on the development of more accurate assessment tools so that treatment response may be

more reliably measured. Staff are also engaging in local, national, and international conferences to disseminate research findings, collaborate with the global pediatric pain community, and continue to educate our staff on the latest research in the field.

Lessons Learned and Next Steps

The development of the PPRC was the result of key stakeholder's efforts recognizing the need for a method of care delivery that would best suit the needs of the patients as well as the interests of payers to reduce health-care costs. Fortunately, philanthropic donors were also interested in supporting the access to health care for youth and families with complex needs. It is likely that other clinics may not have access to this type of funding or individualized space to develop a free-standing pediatric pain rehabilitation program. More likely is the possibility of offering a more intensive outpatient or day treatment model through existing pain treatment clinics and staff.

When planning the development of an outpatient pediatric pain treatment program, there are a number of important considerations in this process. The PPRC has some unique features that are keys for promoting the success of the patients and the model in general. First, is the high staff-to-patient ratio. The initial census of the PPRC was four patients, all with a primary diagnosis of complex regional pain syndrome (CRPS), with seven treating clinicians. Each patient has a core team of providers who provide both individual and family-based treatments at a high dose of intervention. Previous literature has highlighted the value of increased dose of treatment for patients with CRPS, and this is only possible if there are available staff (Simons et al., 2012). Additionally, the staff at the PPRC primarily work in the pain rehabilitation center and are not dispersed among other clinics during their workday. This staffing model allows for frequent communication, colocation, and consistency that helps patients succeed and contributes to staff cohesion. Staff also

have opportunities to participate in clinic leadership, committee membership, and research initiatives, all of which have the potential for creating a healthy work environment and commitment to improvement of the program. Acquiring approval for a high staff-to-patient ratio may present a challenge for many institutions. Demonstrating financial solvency, putting forth a detailed yearly budget, and highlighting the outcomes research for chronic pain rehabilitation may all be useful in advocating for these resources.

The PPRC has expanded to treat eight patients at one time with a variety of chronic pain diagnoses with 14 full-time clinicians. The next steps for the PPRC are to continue to expand our services not only to our current patient population but also to new populations. Since its opening in 2008, the diagnoses treated have expanded to include chronic headaches, chronic abdominal pain, and widespread musculoskeletal pain. Future growth of the clinic is expected with the hope of continuing to provide unique and individualized treatment to a broader spectrum of patients with debilitating chronic pain. For example, one potential population in need of more intensive services is the young adult population. Young adults present with unique challenges, developmental tasks, and neurobiological and functional deficits and likely require a more specialized approach (Rosenbloom et al., 2017). Unfortunately, there is a lack of rehabilitation programs for this unique population.

In addition to clinical growth, the PPRC plans to continue its research and clinical innovation growth as well. Interdisciplinary projects are currently moving forward with hopes to utilize advancing technology in addition to the established evidenced-based treatments to aid in the treatment of chronic pain. Current research and clinical efforts are ongoing to incorporate virtual reality technology to assist in the exposure-based treatment of youth with chronic pain. Virtual reality technology use in the pediatric pain population is in its beginning phases and is showing good promise for enhancing engagement in activity, reducing fear, and promoting relaxation

(Griffin et al., 2020). The use of this technology may also provide an opportunity to simulate environments not found in a clinic setting. Other ongoing initiatives in the PPRC include the development and validation of accurate assessment measures for symptoms of chronic pain such as phono- and photophobia, allodynia, and pain efficacy. Many projects are in collaboration with national and international pediatric pain colleagues. The PPRC continues to collect caregiver and patient information about satisfaction, experience in treatment, and ways to improve the patients' engagement in treatment. This is some of the most valuable data collected and greatly assists the program in our continued mission to provide quality care to youth with chronic pain.

Conclusion

The Mayo Family Pediatric Pain Rehabilitation Center at Boston Children's Hospital effectively utilizes the day treatment model of care to provide integrated health services to a population of youth with high health-care needs. Using the biopsychosocial framework, the treatment of youth with chronic pain requires the provision of multiple services in a coordinated effort, which can be most successfully achieved when those providers have the flexibility and shared physical location afforded by the free-standing day treatment model. Further, the day treatment model itself serves as an intervention, allowing patients and families to learn and practice new skills in the structured environment of the clinic as well as outside of the clinic with their caregivers and family members. Key components of the success of this model include assessment and intervention based in evidence from the field of pediatric chronic pain, education of staff members in the theoretical framework that results in consistency of the intervention, connection and collaboration with community providers, and follow-up post-discharge with patients and families to promote generalization of the skills acquired in treatment.

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