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Commentary

Development of an intensive pain rehabilitation program for children and adolescents with Complex Regional Pain Syndrome

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This commentary describes the process of developing and implementing a multidisciplinary pediatric pain rehabilitation program. This treatment approach has been evaluated with pediatric populations with promising results (Sherry et al., 1999; Eccleston et al., 2003; Maynard et al., 2009). For example, Eccleston et al. (2003) reported on 57 adolescents and their parents who underwent an interdisciplinary residential treatment program combining cognitive behavioral therapy (CBT) with physiotherapy (PT) to treat a variety of chronic pain conditions. At follow-up 3 months after discharge, adolescents reported significant reductions in functional disability, anxiety, and somatic focus and improvements in physical functioning and school attendance. Sherry et al. (1999) reported on the benefits of intensive exercise therapy combined with psychological screening and referral for psychological therapy for children with neuropathic pain. Results indicate that at 2 years posttreatment, 88% of the sample was symptom free, with an additional 10% fully functional despite remaining pain symptoms. In a prospective, randomized single blind trial of PT and CBT for children and adolescents with Complex Regional Pain Syndrome (CRPS), Lee and colleagues (2002) found evidence supporting this combined treatment approach with significant functional improvement at both short- and long-term follow-up.

Multidisciplinary models view chronic pain as a biopsychosocial phenomenon best treated through integrated physical, psychological, and medical approaches, typically with an emphasis on restoring function. Despite the growing empirical support for rehabilitative approaches to pediatric pain management (Eccleston et al., 2003; Howard, 2003; Maillard et al., 2004; Maynard et al., 2009), programs offering intensive functional pain rehabilitation for children and adolescents remain relatively scarce. Developing and funding such programs can be daunting given challenges such as the high staff-to-patient ratio and range of disciplines required, reimbursement hurdles, and questions regarding the types of patients that benefit most from this type of treatment. Therefore we offer this commentary describing one such program as a model for how intensive multidisciplinary treatment programs can be implemented.

Description of an intensive multi-disciplinary pain rehabilitation program and rationale for its implementation

The Mayo Family Pediatric Pain Rehabilitation Center (PPRC) at Children's Hospital Boston at Waltham is a multidisciplinary intensive rehabilitation program for children and adolescents with CRPS and related conditions. The mission of the PPRC is to help children manage pain and restore functional abilities. Enabling

individuals to return to their normal prepain activities is the primary treatment goal. Patients at the PPRC participate in a truly integrated and comprehensive treatment wherein they engage in physical, occupational and psychological therapies; all viewed as equally important aspects of care. Physician and nursing care also are provided. Educational services (tutoring, liaison with schools, psycho-educational testing if indicated) are also incorporated into the program.

The PPRC program grew out of the Pain Treatment Service (PTS) at Children's Hospital Boston, a multidisciplinary program established in 1986 consisting of an inpatient acute pain service and an outpatient chronic pain clinic. Over time, the leadership of the PTS recognized that available services did not fully meet the needs of some of their most complex patients: children and adolescents who had not achieved relief of chronic neuropathic pain symptoms through traditional outpatient physical, occupational, and psychological therapies or with inpatient admission to a medical-surgical unit, with or without procedural interventions such as temporary combined somatic-sympathetic local anesthetic blockade via catheters in epidural, lumbar sympathetic, brachial plexus, femoral or sciatic locations. After a long pursuit of ways to create and fund an alternative treatment approach for this population, the team was successful in securing philanthropic start-up funding 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.

The day-treatment model (providing 8.5 hours per day of treatment 5 days per week) was viewed as optimal because it provided a higher intensity of care and treatment coordination than could be afforded through outpatient services but also enabled patients to remain in their normal home environments during nontreatment hours. Keeping these patients out of the inpatient setting was also considered helpful in emphasizing function and de-emphasizing the sick role for these children and their families. In addition, a day-hospital program allowed for all providers to work together in one setting, with close contact among disciplines and

daily opportunities for formal and informal communication as well as for cross-disciplinary co-treatment. We believe this level of staff communication is crucial for managing the needs and behaviors of this patient population. Finally, a day-hospital treatment model involves a considerable reduction in cost compared to inpatient admission in a tertiary pediatric center.

After considering a variety of physical locations for this program including sites within our main hospital and partnerships with local pediatric rehabilitation hospitals, the program was ultimately situated at our hospital's newly-acquired suburban satellite facility. In this setting, space could be designed to meet the unique program needs, resulting in a clinic with a wellness emphasis rather than a hospital feel. The space was designed to include a large gym where all participants could work together, along with individual treatment spaces for each discipline. Despite the challenges it presented to construction, a therapy pool was considered a crucial resource and was incorporated into the space. The layout also included additional group space for tutoring time and family and team meetings. In June 2008 the PPRC opened its doors for operation.

Who is treated at the PPRC and why?

For the first year of existence the program treated four patients at a time. Currently it has a census of five with future plans to accommodate six patients. The average length of stay is 3 to 4 weeks (range to date = 2 to 9 weeks) depending on individual needs and progress. The program has focused primarily on treating children and adolescents with regional neuropathic pain because this type of pain problem has been most clearly shown to respond to intensive physical rehabilitation (Stanton et al., 1993; Lee et al., 2002; Maillard et al., 2004; Wilder, 2006). It is not clear from existing research whether intensive exercise therapy is equally beneficial to other pain populations. As the program has grown, however, the scope of treatment is expanding and patients with primary conditions such as juvenile fibromyalgia syndrome, widespread musculoskeletal pain, and functional abdominal pain also have been admitted in cases when the individual appears likely

to benefit from intensive physical rehabilitation and psychological treatment. We anticipate looking carefully at outcomes for these patients when assessing treatment effectiveness. Beyond diagnosis, other criteria for admission include age (7-17 years, with exceptions considered on a case-by-case basis), determination that patients are psychologically stable in terms of their current risk of suicidality, absence of a current psychiatric condition for which intensive exercise therapy would be contraindicated (e.g. eating disorder), not currently in need of care in a more intensive psychiatric setting (i.e. inpatient unit) and ability to participate adaptively in a group setting. These psychological inclusion/exclusion criteria are determined on psychological evaluation prior to admission.

How are patients referred to the program and how does referral progress to treatment?

Prospective patients come to the PPRC from several sources. Thus far, 151 children and adolescents have been referred for possible treatment. The primary route is through the PTS chronic pain clinic. In many cases, patients presenting to the outpatient clinic have previously seen specialists in other departments of the hospital (e.g. rheumatology, orthopedics) and are referred from there to the pain clinic. To date, 55% of patients who have participated in the program were preexisting patients within our larger PTS. Family self-referrals are the second most common route to treatment, with 40% of patients self-referring. Remaining referrals have come from other pediatric pain programs across the country who do not provide intensive rehabilitation services. To be considered for admission, patients must undergo a comprehensive evaluation through our PTS clinic including psychology, medicine, and physical therapy assessments. The evaluating team then makes the final recommendation regarding a patient's suitability for the PPRC program. Of the 151 referrals received to date, 123 (81%) have followed through with this required preadmission evaluation. Common reasons for lack of follow through include travel required to come to the clinic (e.g. costs of travel, finding alternative programs closer to home), insurance barriers, and recovery

from pain with outpatient treatments. Sixty-three percent (77) of those evaluated for the program were admitted for treatment.

The business model – how the program is funded and sustained

As a new model of care within an acute hospital organization in the U.S., the importance of acquiring the support of insurance payers was essential to the program's financial viability. A traditional inpatient rehabilitation model familiar to U.S. insurance payers (i.e. a minimum of 3 total hours of at least two disciplines of therapy per day) was used as a foundation, although one challenge was that most insurance companies had no existing billing codes that precisely matched the services that the program planned to offer. Prior to opening the program, the PPRC leadership met with executives at major regional insurance companies to present the program, underscoring how it would reduce overall healthcare utilization by typically costly patients. Program leadership and hospital finance officers negotiated with each insurer, recommending a per diem charge model with bundled PT, OT, nursing and psychology services. Physician time is billed with a separate daily (follow up type) fee. Using this approach, we have successfully attained payment agreements from most insurance companies in the region, although in some cases extended lengths of time have been required to obtain admission approval.

Given our national and international referral base, numerous single-case agreements have been negotiated with out of state insurance payers. This is a time consuming process but one that we hope will ultimately result in insurance companies acknowledging the benefits of this treatment approach and approving it more readily in the future, both at our site and others. A significant challenge has been working with insurance companies' mental health carve-out systems. Most companies have agreed to the bundled per diem rate for the day-hospital program including psychology costs, recognizing the importance of this aspect of care for this population. However, they have often denied any follow-up psychology visits after day-program discharge.

The existence of philanthropic start-up funding was extremely beneficial in convincing the hospital to support the PPRC, and for the initial construction and hiring costs, but the center has been financially viable from the start. The center is currently fully funded from reimbursement of charges. Donor funds have been utilized for large equipment needs, for supporting the integration of trainees into the program, and for initial research efforts.

Staffing and treatment model

The clinical team at the PPRC currently consists of two physical therapists, one occupational therapist, three psychologists, one nurse/clinical coordinator and a daily attending physician. All staff are specialized pediatric providers, most with advanced education in pain management. An educational tutor provides 2 hours per day of services on a contractual basis, reimbursed through the patients' school districts. With a census of five patients, clearly this is a staff-heavy treatment model. However, we believe that the success of the program relies upon the intensity of treatment and the close collaboration of its staff, both of which necessitate a low patient-to-provider ratio. Providing staff with time for clinical research is also a priority in order to establish an evidence base supporting our treatment approach. An informal survey of similar programs in this country and abroad indicates that this staffing level is typical of intensive pain rehabilitation programs, with some differences in the specific mix of providers involved.

A central component of the PPRC's philosophy is that participants learn to self-manage pain and not view themselves as helpless in its wake. The psychological, physical, and occupational therapies are designed with this goal in mind. Specifics of these treatment approaches and their outcomes are forthcoming in subsequent publications, but a brief overview is provided here. The psychological component of the program is grounded in a cognitive-behavioral approach (see Eccleston et al., 2009). Given recent empirical evidence supporting acceptance and commitment therapy (ACT) approaches to coping with chronic pain (e.g. Wicksell et al., 2009), these techniques are integrated into the care to help participants focus on returning to a full, rewarding life in spite of pain.

At admission to the PPRC, families undergo a clinical interview with their primary psychology clinician and complete standardized questionnaires assessing pain, emotional distress, sleep habits, and parental responses to pain in order to inform treatment and measure progress in these domains. Families are actively incorporated into treatment throughout the child's stay. Patients receive individual and group therapy daily. Family therapy occurs at least twice weekly (more if warranted), and parents attend weekly parent education and support groups, can request additional psychology consultation, and are asked to observe PT and OT sessions (on a scheduled basis) to help transfer gains back to the home environment.

Intensive physical and occupational therapies are cornerstones of the treatment model. Compared to outpatient services or inpatient care in an acute medical setting, the full day rehabilitative PPRC program allows for a large dose of PT, with patients receiving an average of 3 hours of individual and group PT daily along with an additional hour of OT. The intensity of this approach benefits the child in multiple ways, including facilitating a strong rapport with treating therapists which helps to reduce fear and avoidance responses (de Jong et al., 2005; Moseley et al., 2008). Although a specific dose-response relationship of PT for pediatric chronic pain has not been demonstrated, programs offering intensive PT/OT components (e.g. Sherry et al., 1999; Eccleston et al., 2003) have demonstrated better outcomes compared to 1-3 hours per week of outpatient PT (Lee et al., 2002).

Physical therapy activities at the PPRC promote increasing weight bearing through the affected limb (stress loading), flexibility, strength, coordination and endurance. Tasks that translate easily to functional goals (e.g. walking, stair climbing) are emphasized. In OT, changes in sensory responses are facilitated through an intensive individualized program of functional sensory experiences. In order to promote the child's autonomy in managing their condition, all children are placed on PT and OT home programs that are initiated during their PPRC stay with exercises to be completed nightly and over the weekends. Modified versions of these programs are sent home with the participants to be continued upon discharge. All

patients are expected to continue daily physical activity after discharge, but programs are tailored to accommodate individuals' normative activities such as involvement on sports teams.

Summary

To date, the PPRC has treated 82 children and adolescents with CRPS and similar conditions. As a group, these youth have made impressive gains in treatment. Treatment outcomes for the first year's cohort of patients are currently being analyzed and will be reported on in detail upon completion of standardized follow-up assessments on this group. Anecdotally we can report that many participants have returned to sports, daily school attendance, and other important activities that previously had been given up due to pain. In exit interviews, both patients and parents emphasize the benefits of the supportive environment provided in the PPRC as well as the opportunity to meet and learn from other families facing similar pain problems. The program has recently incorporated in-person follow up visits with the treatment team at 1 month, 4 months, and 12 months after discharge, to assess long-term progress and provide additional interventions to improve function and reduce pain. By monitoring how patients function over time, we hope to learn what modifiable factors predict successful long-term functional outcomes. This knowledge will allow us to tailor the treatment program to help each individual patient maximize their long term functional abilities and minimize pain.

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