

Development of an Interdisciplinary Pediatric Pain Rehabilitation Program: The First 1000 Consecutive Patients

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Abstract

Objective: To describe the development of a clinically and financially successful interdisciplinary pediatric pain rehabilitation program at a large tertiary academic medical center and present demographic and clinical information on the first 1000 patients.

Patients and Methods: All patients who were consecutively admitted to this program between October 1, 2008, and March 31, 2015 were included in this review. The patients ranged in age from 9 to 24 years. The program is a 3-week, hospital-based outpatient treatment program that requires substantial parental involvement. At admission and discharge, patients completed the Center for Epidemiologic Studies of Depression Scale for Children, the Functional Disability Inventory, and the Pain Catastrophizing Scale for Children. Opioid use was also assessed.

Results: At admission, patients reported substantial pain-associated disability and depressive symptoms; they had elevated pain catastrophizing scores, and 16% were taking opioids. Primary sites/types of pain included head, abdomen, and generalized. Functional disability scores decreased significantly, from 27 to 9 after the program ($P < .001$). Depression scale scores improved from 27 to 14 ($P < .001$). Pain catastrophizing scores decreased significantly, from 26 to 14 ($P < .001$), at discharge from the program. All but 4 patients successfully tapered off of all opioid use by the conclusion of the program.

Conclusion: Participation in a multidisciplinary pediatric pain rehabilitation program can be successful, with significant decreases in disability, depression symptoms, and pain catastrophizing, as well as discontinuation of opioid use.

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Chronic pain is common in pediatric patients. Approximately 25% to 37% of children and adolescents report frequent and severe pain.^{1,2} Some of these patients have pain-related disability, absences from school and social activities, and disrupted eating routines, sleep, and mood.^{2,3}

An interdisciplinary approach to pain rehabilitation was developed more than 40 years ago and has been studied extensively in adults.⁴⁻⁷ These programs have provided significant lessening of pain severity, improvements in physical functioning and mood, and discontinuation of opioid use across various pain diagnoses and locations.⁸⁻¹⁰ Given their proven clinical and cost effectiveness,^{7,11} these programs are now considered the treatment of choice for adults who have chronic pain.

Interdisciplinary rehabilitation programs to provide similar pain management strategies for children and adolescents have been developed only recently.¹²⁻¹⁷ Despite awareness that children and adolescents need access to intensive treatment programs, availability is limited.¹⁸

This article describes the development of an interdisciplinary pediatric pain rehabilitation program and reviews the first 1000 consecutive patients treated. Functioning and psychological distress of the patients were assessed at admission and discharge from the 3-week program. Patients were expected to experience improvement on these measures at discharge. Young adults in a subsample treated in this program were expected to have similar improvement.

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PROGRAM DEVELOPMENT MODEL

In 2008, a pilot pediatric pain rehabilitation program was conducted in response to growing demand for treatment of adolescents who have chronic pain. Initial attempts to treat teenagers in an adult interdisciplinary pain rehabilitation program were suboptimal because the adolescents required developmentally appropriate teaching, activities, goals, and parent involvement. The 3-week program described here provided intensive, outpatient, hospital-based treatment for adolescents and young adults who had severe chronic pain and other chronic physical symptoms such as fatigue. The program resides within a large, tertiary, academic medical center, which allows ongoing collaboration and support from colleagues across medical, surgical, and psychiatric subspecialties. Psychiatric and medical comorbidities could often be addressed within this interdisciplinary structure.

The program is based on an empirically supported interdisciplinary treatment structure initially designed for adults who have chronic pain. Programs with this structure grew out of the early behavioral (respondent and operant) models of managing chronic pain.^{19,20} These factors, along with cognitive behavioral therapy (CBT) that targets patients' beliefs, attitudes, and expectations, provide the basis for interdisciplinary pain rehabilitation programs that address adaptation to chronic pain and the use of self-management strategies.²¹ The success of adult pain rehabilitation programs seems to result from the interdisciplinary approach, as well as a focus on restoring functioning rather than alleviating pain.^{20,21} In developing the pediatric program, we anticipated that these elements would similarly benefit children, adolescents, and young adults, but programming was modified to be more developmentally appropriate, and parents were included to increase the likelihood that patients would maintain progress at home. Research has long stressed the importance of parents in reinforcing behavior in children.^{22,23}

Young adults are included in this program if they were not yet living independently because of their chronic health problems. In an effort to report on all 1000 consecutive patients admitted to the program, data for these young adults and a small pilot group of latency-age children are included here.

PROGRAM STRUCTURE

The program's interdisciplinary treatment team is co-led by a pain physician and a pain psychologist and included colleagues in physical therapy, occupational therapy, advanced practice nursing, registered nursing, recreational therapy, chaplaincy, and dietetics. The programming runs Monday through Friday, from 8:00 AM to 5:00 PM, over a 3-week period. When patients and parents first arrived, they participated in 2 days of comprehensive assessment by pain psychologists, nurses, and physical and occupational therapists. From these assessments, individualized goals were developed to increase functioning, and potential barriers to treatment were identified, such as comorbid depression, anxiety, and/or learning struggles. Then patients and parents worked on treatment goals within a group setting, with individual meetings with various health care professionals as needed. They attended groups that provided a curriculum of structured CBT, physical therapy, occupational therapy, relaxation strategies, and biofeedback.

A parent was required to accompany each child and to attend classes with and without the child over the course of the 3 weeks and received approximately 60 hours of CBT skills training and intervention. Research has revealed that parents of children with chronic pain experience high levels of anxiety and depression themselves, as well as parenting stress and poorer quality of life.²⁴⁻²⁶ On admission of their child to the program, parents reported substantial levels of depression, pain catastrophizing, and feelings of being overprotective parents. The goals of the parenting program included reducing psychological distress in parents and improving effective parenting of their chronically ill children. The children learned more effective strategies for managing pain and other physical symptoms, while improving their ability to function.

Although ample evidence suggests that parents of a child who struggles with pain are distressed^{24,27} and that parent behaviors predict functional disability in children with pain,^{28,29} only one study has examined a parent intervention within the context of intensive pediatric pain rehabilitation.³⁰ This study revealed positive changes in parent behavior regarding their children's pain and

parents' overall mental well-being. Clearly, more research in this area is warranted. Similar to other intensive rehabilitation programs (both adult and pediatric), the program's primary treatment goal was functional restoration.^{11,31} Treatment was individualized, and goals often included independent ambulation, return to regular eating habits, return to full-time school or employment, and re-engagement in social activities. Another primary goal was the discontinuation of all opioid use, under close supervision by the treatment team, by the end of the 3-week program. Effective opioid use discontinuation has been found in an adult population.³²

Improved physical strength and endurance are also important goals of the program. Most patients, regardless of type of pain, have a history of both decreased physical activity and deconditioning. Daily physical therapy and engagement in the program for 8 hours daily, without reclining or naps, were expected.

Another important goal of interdisciplinary pain rehabilitation is to help patients and parents change their perception of the patient as being sick and disabled to being capable of functioning despite pain or other chronic symptoms.^{33,34} Therapy is directed at discontinuing pain-related behaviors and using assistive devices for managing pain, as well as decreasing parental and patient focus on symptoms.³⁵ The extensive work with parents focused on assisting them in more effectively supporting their child's return to health and reintegration at school and with peers.^{24,36}

Viewed as essential to success in an interdisciplinary pain rehabilitation program was the assessment and management of comorbid psychological difficulties that contributed to the patient's poor functioning.^{37,38} Additionally, comorbid medical diagnoses that can contribute to poor functioning were assessed and managed.

Another goal of the program was to decrease medical utilization for chronic pain and chronic medical symptoms. Patients and families were encouraged to follow up with their primary care physician rather than seeking additional diagnoses and/or treatment from specialists for their chronic symptoms. Patients were asked to use the self-management tools taught in the program.

Another goal was to achieve decreased health care costs and patient/family financial burden, which has been accomplished in other rehabilitation programs.¹¹

PATIENTS AND METHODS

This study was approved by our institutional review board. As part of the program development, patients and parents were asked to complete several measures before starting and on discharge from the program as part of standard care. These data were used to guide the treatment plan and were shared with patients and parents at discharge. All patients included in this study provided written informed consent to have their clinical data used for research purposes.

Participants

The program accepted patients aged 9 to 24 years who presented with a variety of comorbid medical and psychological diagnoses. Although pediatric programs often do not include patients older than 18 or 21 years (depending on the site), the developers of this program opted to include young adults aged less than 25 years who were dependent on their caregivers because they functioned more like adolescents.

This article focuses on the first 1000 patients consecutively admitted to the program. A total of 96% (n=960) completed the 3-week program. Early discharges were related to incompatible goals for rehabilitation, need for other medical care, and need for primary psychiatric or chemical dependency care. Most patients completed the program during the full structured 3-week curriculum; some required a few extra days to complete all program goals. The program was designed to be flexible in meeting patients' needs. Demographic and descriptive data are presented for the entire sample. Clinical outcome data were not available for all 1000 patients, owing to early discharge from the program and missing data, especially from the program initiation point.

The participants described in this study were mostly female (74.5%) and Caucasian (96.1%). The average age was 15.9 (SD, 2.20) years. The most frequent types of pain were headache, abdominal pain, generalized pain, back pain, and lower extremity pain

(Table 1). Patients reported that the average length of time they had chronic pain before enrollment in the program was 38.0 months (SD, 33.6 months; range, 3-240 months).

Approximately 20% of patients treated in the program had postural orthostatic tachycardia syndrome (POTS), as defined by symptoms associated with excessive postural tachycardia on tilt-table testing. Adolescents with POTS frequently struggle with chronic pain in addition to symptoms of orthostatic intolerance, such as dizziness, light-headedness, tremulousness, and exercise intolerance.³⁹ POTS symptoms of light-headedness, dizziness, and fainting were targeted in the same manner as chronic pain or fatigue and responded to our operant and CBT strategies, which focused on improving functioning and decreasing psychological distress. Recent research has revealed promising results for patients treated in this interdisciplinary program with POTS on measures of functional status and psychological distress.^{40,41} Further, another 13% of patients admitted to the program had autonomic dysfunction with orthostatic intolerance but without excessive postural tachycardia.

All adolescents had at least one parent accompany them for the entire 3-week treatment course. At times, both parents participated in the program, as well as grandparents and siblings. Patients who participated in the program were geographically diverse, having been referred locally (2%), regionally (38%), nationally (59%), and internationally (1%).

Of the entire sample, 16% reported opioid use on admission for management of chronic pain. Of the young adults aged 19 to 24 years, 35% listed opioids as a medication they were

taking on admission. Of these patients, 98% were no longer taking opioids at the end of the program.

Ninety-four patients required hospitalization on an inpatient psychiatric unit⁴²; diagnoses for this group included major depression (32%), eating disorder (25%), and conversion disorder (9%). Further, a recent review of a subsample of 248 adolescents referred for an eating disorder evaluation from the interdisciplinary pain rehabilitation program found that 14% met criteria for a formal eating disorder diagnosis.⁴³

Exclusionary criteria included the following: any medical condition that would hinder full participation in the program (eg, recent surgical treatment that would not allow participation in physical therapy); active suicidal ideation; psychosis; and emotional or behavioral disorders that would hinder full participation in the program (eg, primary diagnoses of oppositional defiant disorder, chemical dependency, or an active eating disorder).

Measures

Patients completed measurements of functional status, depression, pain catastrophizing, and opioid use on admission to the program and again at discharge 3 weeks later. Functional status improvement was considered a primary treatment goal; pain catastrophizing and depression were considered to be factors that could affect treatment progress and/or improvement maintenance. Pain catastrophizing was measured for all patients at the time of admission as a predictor of important outcomes such as disability.⁴⁴ Pain catastrophizing is a heightened and negative mindset about pain.

Functional Status. The Functional Disability Inventory is a widely used self-report, 15-item measure of perceived limitation on physical and psychosocial functioning. Higher scores indicate greater self-perceived disability. The measure has been found to be both reliable and valid for children and adolescents⁴⁵ It has not been used in young adult populations. However, the items on this measure (eg, “walking upstairs,” “walking to the bathroom,” and “doing something with a friend”) appear logical to the patient instead of “face

TABLE 1. Percentage, by Location, of Patients Who Had Primary Pain

Location of pain	% of patients
Head	31.8
Abdomen	22.0
Generalized	13.5
Back	7.6
Lower extremity	6.4
Upper extremity	1.9
Chest	1.8
Face	1.2
Other	13.8

valid” and can be easily completed by patients aged 18 to 24 years.

Pain Catastrophizing. The Pain Catastrophizing Scale for Children was used to assess pain catastrophizing, a construct that appears to predict disability in children and adolescents.⁴⁶ It is a self-report questionnaire adapted from the adult version of the Pain Catastrophizing Scale.⁴⁴ Specifically, the child version is composed of the adult version with simplified wording and language adapted to be understood by a child as young as a fourth grader. Scores can range from 0 to 52, with higher scores suggesting more distress, and the measure has been found to be a reliable and valid instrument for children aged 8 to 16 years. Thus, use of this child version with patients aged 17 to 24 years seemed suitable. Dimensions of this scale include rumination, magnification, and helplessness. For this study, we examined total scores. Studies have revealed that pain catastrophizing predicts poor pain outcomes for adults and pediatric patients. For example, higher pain catastrophizing scores in pediatric patients predict higher pain-intensity ratings and lower school attendance rates.

Depression. The Center for Epidemiologic Studies Depression Scale for Children is a 20-item measure of depression originally adapted from the measure for adults and is designed to assess depressive symptoms in children and adolescents. Extensive data have revealed scale results to be reliable and valid

for adults. The child version is similarly reliable and valid for children aged 7 to 17 years, with scores ranging from 0 to 60.⁴⁷ Higher scores indicate more substantial depressive symptoms. A score of 15 or higher suggests risk of depression and requires further evaluation.⁴⁸

Opioid Use. Self-report of opioid use was obtained at the time of admission and discharge from the program. All patients admitted to the program who were taking opioids were given a detailed tapering schedule. All opioids were administered by parents according to the taper schedule after initial assessment by the medical team. Withdrawal symptoms were assessed daily by nursing staff, and taper schedules were modified by the medical director as needed. The goal was cessation of all opioid use by the end of the 3-week program.

RESULTS

The comparisons from admission to discharge of self-reported functional status, depression, and pain catastrophizing are presented in Table 2. The average Functional Disability Inventory score for the full sample at admission was 27.0 (SD, 10.7), which indicates a moderate level of perceived disability.³ Participants reported significant improvements in functioning from admission to discharge, with a large effect size ($d=1.9$).

The average pain catastrophizing score was 26.5 (SD, 11.5) at admission, which is considered to be significantly elevated. A paired-samples *t* test revealed a significant decrease

TABLE 2. Comparisons From Program Admission to Discharge for the Full Sample and Age-Group Subsamples

Dependent variable (No.)	Mean (SD)		Paired-samples <i>t</i> test	<i>P</i> value
	Admission	Discharge		
Full sample (ages 9-24 y)				
Functional disability (761)	27.0 (10.7)	9.4 (8.2)	46.5	<.001
Depression symptoms (765)	27.9 (12.7)	14.4 (10.7)	30.1	<.001
Pain catastrophizing (764)	26.5 (11.6)	13.6 (10.8)	27.7	<.001
Teen subsample (ages 12-18 y)				
Functional disability (668)	26.9 (10.7)	9.5 (8.4)	43.3	<.001
Depression symptoms (671)	27.7 (12.7)	14.3 (10.7)	28.2	<.001
Pain catastrophizing (671)	26.5 (11.6)	13.6 (10.9)	26.3	<.001
Young adult subsample (ages 19-24 y)				
Functional disability (81)	28.5 (11.1)	8.5 (6.3)	16.3	<.001
Depression symptoms (82)	30.1 (12.4)	15.6 (10.6)	10.8	<.001
Pain catastrophizing (81)	27.1 (11.1)	13.7 (10.5)	8.6	<.001

in pain catastrophizing (from admission to discharge), which is a large effect size ($d=1.2$).

Many patients reported a significant level of depressive symptoms at the time of admission; the average score on the Center for Epidemiologic Studies of Depression Scale for Children in our sample was 27.9 (SD, 12.7), which is above the cutoff score that indicates clinical depression.⁴⁸ Patients reported significant improvements in depressive symptoms at admission compared to post-treatment, with a large effect size ($d=1.2$).

When examined separately, the 19.7% of the sample who were aged 19 to 24 years also had significant reduction of functional disability, pain catastrophizing, and depression symptoms (Table 2). Patients who had POTS achieved similar improvements in functioning and reduction of depression symptoms and catastrophizing.

Of patients who were taking opioids at admission, 98% were successfully tapered off all opioids during the 3-week program. Four patients who graduated from the program were taking opioids at discharge. Three of these patients were continuing complex opioid tapering schedules at home after the program, and one had a diagnosis of osteogenesis imperfecta, with a history of more than 70 fractures. The treatment team assisted this patient in reducing his dose of opioids but felt that cessation of opioid use was not an appropriate goal.

DISCUSSION

This interdisciplinary program treated debilitating pain and associated symptoms in more than 1000 adolescents and young adults; significant improvements were documented in functioning, depression symptoms, and pain catastrophizing in a large proportion of that sample. This is a preliminary program evaluation and not a controlled research study. As such, it may have involved confounding factors that contributed to the positive results. The structured program incorporated the following: strategies of behavioral activation; differential reinforcement for healthy, age-appropriate behavior with removal of reinforcement for illness behavior; shifting patient and parent perception of patients as severely ill or incapacitated, yielding changes in self-efficacy and self-esteem; exposure therapy to

increase patient activity, including exercise, and improved social interaction and peer support to achieve the primary goals of improved functioning and decreased psychological distress.

Lessons Learned

Lessons learned include what factors were successful in adapting the adult program structure for adolescents and young adults and what challenges remain.

Mixing Diagnoses Worked. We learned that treating young patients who had differing primary pain issues was not problematic for patients or staff. Our data reveal that patients with various pain diagnoses can benefit from a broadly targeted rehabilitation program, consistent with previous research.³⁵

Group Structure Is Helpful. As in many group processes, the whole was greater than the sum of its parts. Being part of a relatively large, cohesive group was particularly powerful for the adolescent patients who had felt ostracized because of their limited functioning. This structure, which included rolling admissions, allowed new patients to see successful patients graduating. In addition, parents learned from the more experienced parents.

Age Did Matter. Combining age groups made it difficult for the staff to address important developmental issues. Although the younger children (aged 9-11 years) loved spending time with older adolescents, the adolescents felt that having a serious group discussion was difficult with younger children present. However, young adult patients (aged 19-24 years) could successfully receive interdisciplinary treatment with the adolescents. In an evaluation of separate age groups of younger children and young adults, results remained significant, despite the smaller samples.

Parents Are Key. Extensive parental involvement was required in this program and was considered by staff to be critical to interdisciplinary pain rehabilitative success for all ages and diagnoses. Research is ongoing regarding parenting style, the anxiety and depression of parents, and the role of these variables in program outcomes. We anticipate that changes in

parenting style and decreased parental distress will predict success for their children.

High Staff Expectations Are Important. Robust staff expectations for full and active functioning seemed to be critical to success. We expected patients to return to full-time school the day after completing the 3-week program. We did not have a tapered return to school schedule, nor did we support alternative schooling or online schooling. We believed that returning these patients to an environment with healthy peers and expectations would assist them in returning to a normal level of functioning.

Preliminary Findings

As indicated in Table 2, patients report significant improvements across all domains of functioning including functional disability, depressive symptoms, and pain catastrophizing. Coming into the program, patients were fearful of their pain and symptoms, felt little control over managing symptoms, and were losing hope of recovering their normal lives. Through functional restoration over 3 weeks, patients gained skills that likely improved not only their ability to do more daily tasks but also their mood and confidence in managing their symptoms. The outcomes are consistent with robust findings of improvement after interdisciplinary treatment in adults. A recent review of pediatric interdisciplinary programs found promising outcomes as well.³⁵ More detailed, longer-term outcomes were reported from this program separately and confirmed that improvement is maintained at 3-month follow-up evaluation.⁴⁹

Financial Impact

In the era of managed care, providing effective treatment may not be enough to keep a program running.^{11,50-53} Rather, clinicians increasingly are encouraged to focus on the financial bottom line and develop innovative models that deliver care at low cost. The pain rehabilitation program described in this article has been financially viable from its inception. The program is built on a group model of treatment with 16 or more patients attending the program at any one time. In comparison, many interdisciplinary programs that have been developed to treat adolescents

who have chronic pain treat only small groups or 1 to 2 patients at a time.

All patients have their insurance certified before admission to ensure that families have insurance coverage for the program. Staff focused on issues relating to documentation, diagnostic requirements, billing and coding, and insurance requirements in a proactive approach to educate insurance companies about the structure and success of our interdisciplinary approach. The cost of medical care for adolescents who have chronic pain and associated physical symptoms is substantial.⁵⁴

The program has achieved a 92% rate of insurance approval for participation and has been deemed, along with its adult counterpart, a “flagship program” for Blue Cross/Blue Shield of Minnesota. This designation, which allows patients to be admitted without a need for insurance precertification, was prompted by a meeting with their medical director at which we presented our outcome data. Medicare also approves this program without requiring precertification. Minnesota Medical Assistance (Medicaid) is currently considering funding patient participation. Program leadership appeals insurance denials and works closely with the precertification department to educate insurance companies by sending research articles that support intensive pain rehabilitation programs for adolescents and conducting peer-to-peer review phone calls to explain the medical necessity of such programs.

Future Directions

Research aimed at understanding and addressing barriers to participation in an interdisciplinary pain rehabilitation program is an important next step in the treatment of chronic pain in the pediatric population. Travel and accommodation expenses may be barriers, and families may need flexibility in program structure to be able to participate while maintaining employment or managing other family obligations. Three years ago, we developed a 2-day interdisciplinary treatment program for adolescents who had less disabling symptoms. A parent is still required to participate with the patient for 2 full days, but the burden of parental involvement is greatly reduced. Cognitive behavioral therapy

strategies are used to address chronic symptoms, with brief introductions to other strategies via physical and occupational therapy. Other models of interdisciplinary care are needed to address the diverse needs of families of children who have pain.

Limitations

Because this is not a controlled research study, confounding factors may have substantially influenced the results. Future research aimed at controlling potential biasing factors such as selection, measurement, the experimenter, and time in the program is important to determine the effectiveness of pediatric interdisciplinary programs for pain rehabilitation. Although promising large effect sizes were found across measures, better controls are needed, and these changes are not necessarily the result of the treatment program. Only one randomized controlled trial, with promising results, has been conducted on a pediatric interdisciplinary program.¹⁶

The generalizability of our findings poses a concern. Not all adolescents and young adults are able to participate in a program that is expensive and far from home. Further research is needed to expand the generalizability of these results to adolescents who have fewer parental supports and cannot attend a program that is 3 weeks long.

In addition, research is needed to determine the long-term success and durability of intensive interdisciplinary treatment for a pediatric population, particularly given the cost and burden of such treatment on patients and their families. Further exploration of factors associated with positive outcomes is also important as interdisciplinary programs are developed.

CONCLUSION

The development of the interdisciplinary pediatric pain rehabilitation program described in this article has been very successful. This program is unique in the size of treatment groups and inclusion of patients with psychiatric and medical comorbidities. Improved functioning and return to school as well as decreased psychological distress and discontinuation of opioid use are considered to be important health outcomes. The program has been found to be financially viable. Further research is

needed to establish the effectiveness of such interdisciplinary programs in a controlled randomized design.

Abbreviations and Acronyms: CBT = cognitive behavioral therapy; POTS = postural orthostatic tachycardia syndrome

Potential Competing Interests: The authors report no competing interests.

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