



Exploring Referral and Service Utilization Patterns Within an Outpatient Interdisciplinary Pediatric Chronic Pain Program

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Purpose: We examine referral sources and clinical characteristics for youth presenting to an outpatient interdisciplinary pediatric chronic pain program.

Patients and Methods: Referral data were extracted from the electronic health record. PROMIS Pediatric Anxiety and Pain Interference Scales were administered at an initial evaluation visit.

Results: The program received 1488 referrals between 2016 and 2019, representing 1338 patients, with increasing volume of referrals over time. Referrals were primarily from orthopedics (19.6%), physical medicine and rehabilitation (18.8%), neurology (14.4%), and rheumatology (12.6%). Patients referred were primarily female (75.4%), White (80.1%), English-speaking (98.4%) adolescents (median=15.0 years). Of those referred, 732 (54.7%) attended an interdisciplinary evaluation (ie, with ≥ 2 disciplines). Adolescent anxiety was within the expected range by self-report (N=327, $M_{T-score}=55.67$) and parent proxy-report (N=354, $M_{T-score}=57.70$). Pain interference was moderately elevated by self-report (N=323, $M_{T-score}=61.52$) and parent proxy-report (N=356, $M_{T-score}=64.02$). There were no differences between patients referred who attended versus did not attend an interdisciplinary evaluation based on age, sex, ethnicity, or language. A smaller than expected proportion of referred Black patients (44%, $P=0.02$) and patients referred from orthopedics (40%) or pulmonology (11%) attended an evaluation, whereas a larger than expected proportion of those referred from physical medicine and rehabilitation (78%) were evaluated ($P<0.001$).

Conclusion: Results highlight the demand for outpatient interdisciplinary pediatric chronic pain treatment. Findings can inform decisions related to staffing and service design for pediatric hospitals that aim to establish or grow outpatient pediatric chronic pain programs.

Keywords: chronic pain, interdisciplinary, pediatric, referral, treatment

Introduction

Pediatric chronic pain is associated with increased risk for a wide range of functional impairments, including social difficulties,¹ sleep problems,² frequent school absences and decreased academic performance,³⁻⁵ elevated anxiety and depressive symptoms,^{6,7} and reduced quality of life.⁸ Families of youth with chronic pain also experience negative effects including missed days of work and lost employment,⁹ caregiving stress,¹⁰ and impaired family functioning.¹¹ The financial burden of pediatric chronic pain on health-care systems is enormous, costing \$19.5 billion dollars annually within the United States alone.⁹ Youth with untreated or poorly managed chronic pain are likely to continue to experience chronic pain and related disability into adulthood.^{6,12-17} In turn, chronic pain in adults results in an estimated economic burden of more than \$600 billion each year because of health-care costs, lost work productivity, and disability programs.¹⁸

Comprehensive treatment for pediatric chronic pain involves interdisciplinary teams of health-care providers from various specialties, including but not limited to medicine, psychology, physical therapy, occupational therapy, psychiatry, nutrition, social work, and alternative or integrative medicine (eg, acupuncture, massage, and yoga).¹⁹ These providers work collaboratively with the patient and family to develop a treatment plan, often consisting of a combination of these services, with the ultimate goal of improving the youth's functioning. Research demonstrates the effectiveness of interdisciplinary chronic pain treatment approaches, including improvements in functioning and reductions in distress.^{20–22} Interdisciplinary outpatient clinics are also a cost-effective approach for treating pediatric chronic pain.²³

Unfortunately, interdisciplinary pediatric chronic pain treatment programs are limited in number, and emerging research suggests inequities in access to these services. According to childpain.org, there are only 90 interdisciplinary pediatric chronic pain treatment programs available worldwide. Across several studies, females were more likely than their male counterparts to be referred to chronic pain treatment programs.^{20,24,25} Additional predictors of referrals to pediatric chronic pain clinics include presence of generalized chronic pain, regional pain syndromes, mental health or musculoskeletal comorbidities, and recent hospitalization or surgery.²⁵ Lower income and socioeconomic status are associated with increased risk of chronic pain,²⁶ yet reduced access to and use of interdisciplinary chronic pain management services.^{27–29} Considering the high prevalence and substantial effects of pediatric chronic pain, additional interdisciplinary pediatric chronic pain treatment programs are urgently needed.³⁰

To guide program development in ways that optimize efficient and equitable access to care for the diverse population of youth who experience chronic pain, understanding the characteristics of youth currently served in this setting is essential. This study sought to build on the existing literature by examining referral sources as well as sociodemographic and clinical characteristics of youth referred to an outpatient interdisciplinary pediatric chronic pain treatment program over a 4-year period. To identify potential disparities in access to these services, we also compared patients who attended versus did not attend an interdisciplinary evaluation within the program based on referral sources and sociodemographic characteristics.

Materials and Methods

Procedures

The Nemours Children's Health Institutional Review Board reviewed this quality improvement study and determined that it did not require IRB oversight. Informed consent was not obtained, as the IRB concluded that this was not human subjects research. Referral orders placed for an interdisciplinary outpatient pediatric chronic pain treatment program within a mid-size children's hospital (195 inpatient beds) located in the Mid-Atlantic region of the United States between January 1, 2016, and December 31, 2019, and associated patient demographic data were extracted directly from the electronic health record (EHR). The hospital is located within a tri-state area (PA, NJ, DE), which serves families from rural, suburban, and urban communities. There are 27 locations associated with the hospital system, including those that offer primary care, specialty care, and emergency services. The health system accepts both private and public insurance, including Medicaid, and serves a diverse patient population (eg, approximately 53% White, 24% Black, 12% Hispanic, 2% multiracial; 48% female; see Phan et al³¹ for more information on sociodemographic characteristics of patients served by this health system). For each referral order placed during this period, manual review of the EHR was conducted to ensure data quality (eg, removing duplicate or cancelled referral orders) and record information on patient attendance at subsequent evaluation visits with medical, psychological, occupational therapy, and/or physical therapy providers within the interdisciplinary chronic pain program. Questionnaires assessing pain interference and anxiety were mailed to families or provided during the check-in process at the initial program evaluation visit. There were no exclusion or inclusion criteria; all youth presenting to the clinic and their caregivers were invited to complete questionnaires.

This interdisciplinary outpatient chronic pain treatment program offers individualized treatment plans including weekly cognitive-behavioral therapy sessions with a licensed pediatric pain psychologist or a pediatric psychology trainee supervised by the licensed psychologist, weekly or twice weekly physical and/or occupational therapy, medication management by a physician or advanced practice nurse, and/or integrative therapies (ie, healing touch, yoga, and

massage). Typical waitlist time for this treatment program is 4–6 weeks. Patient-reported data presented in this manuscript were collected prior to participation in the treatment program.

Measures

Demographics

Demographic characteristics for patients referred to the program, including age, sex, ethnicity, and race, were extracted directly from the EHR. Our hospital's EHR uses sex, ethnicity, and race categories conforming to the US Department of Health & Human Services and the Office of Management and Budget data collection standards. These include the following categories: sex (Male, Female), ethnicity (Hispanic or Latino, Not Hispanic or Latino, Information Not Available, Refused), and race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White, Some Other Race, Information Not Available, Refused). Patients or their parent/legal guardian can select one or more categories to describe their race; those who identified as more than one race were coded as "Multi-racial".

PROMIS Pediatric Pain Interference Scale (v2.0, Short Form 8a)

This eight-item questionnaire assesses the extent to which pain interferes with functioning (eg, emotional, academic, and physical) over the past 7 days by self-report and parent proxy-report.³² Items are rated from 1 (never) to 5 (almost always). Normative data are available, and raw scores are transformed into T-scores. Higher scores indicate greater pain interference. This instrument has demonstrated strong psychometric properties.³² Internal reliability was good in the current sample for both the adolescent self-report ($\alpha=0.85$) and parent proxy-report versions ($\alpha=0.86$).

PROMIS Pediatric Anxiety Scale (v2.0, Short Form 8a)

This eight-item survey assesses symptoms of anxiety experienced by adolescents during the past 7 days by self-report and parent proxy-report. Items are rated on a 5-point Likert scale from 1 (never) to 5 (almost always).³³ Raw scores are transformed into T-scores using normative data. Higher scores indicate greater anxiety. This questionnaire has demonstrated good psychometric properties,³⁴ including among youth with chronic pain.³⁵ Internal consistency was excellent in the current sample for both the adolescent self-report ($\alpha=0.94$) and parent proxy-report versions ($\alpha=0.93$).

Data Analysis

All analyses were conducted in SPSS, version 27. PROMIS measures were scored using the HealthMeasures Scoring Service (www.assessmentcenter.net/ac_scoring-service), which utilizes response pattern scoring to handle missing item-level data; among the subset who completed PROMIS measures, 0.66% (self-report) and 1.58% (parent-report) of all Pain Interference and 0.42% (self-report) and 1.24% (parent-report) of all Anxiety item responses were missing. Descriptive statistics were used to summarize referral sources and demographic and clinical characteristics of the sample. An independent samples *t*-test was used to compare age for patients referred who attended versus did not attend an interdisciplinary evaluation (ie, visits with chronic pain program providers from two or more disciplines). Chi-square tests were utilized to examine differences between patients referred who attended versus did not attend an interdisciplinary evaluation based on sex, race, ethnicity, language, and referral source. Alpha was set to 0.05 for all analyses.

Results

Patients Referred to the Program

The program received 1488 referrals between January 2016 and December 2019 (M=372 referrals per calendar year; see [Figure 1](#)), representing 1338 unique patients. Referrals increased steadily over the study period, from 320 referrals in 2016 to 445 referrals in 2019. Referrals were primarily from orthopedics (19.6%), physical medicine and rehabilitation (18.8%), neurology (14.4%), rheumatology (12.6%), diagnostic medicine/consultative pediatrics (8.9%), psychology (7.5%), and gastroenterology (6.5%). Patients referred to the program were primarily female (75.4%), White (80.1%), non-Hispanic (92.7%), English-speaking (98.4%) adolescents (median age=15.0 years; see [Table 1](#) for complete demographic characteristics).

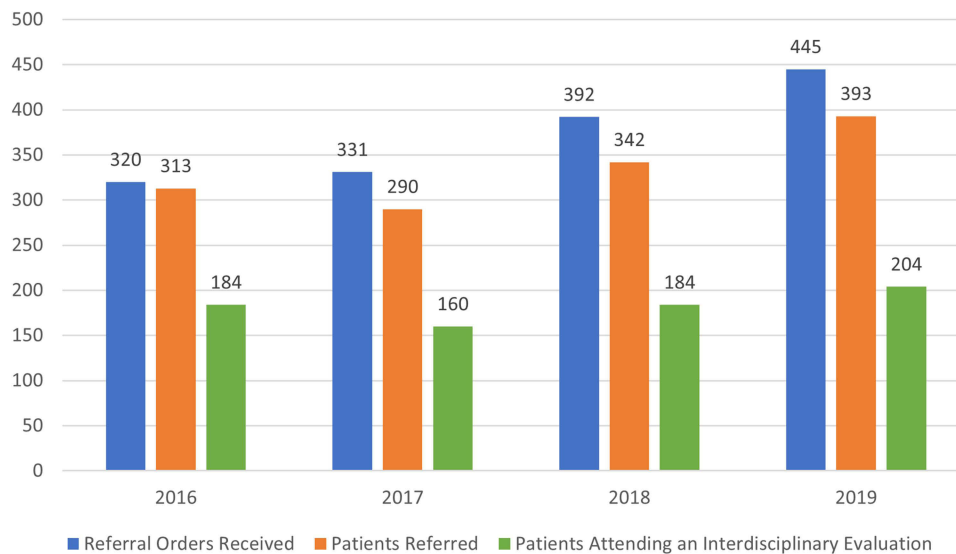


Figure 1 Referrals placed and patients evaluated within an interdisciplinary pediatric chronic pain treatment program between 2016 and 2019.

Notes: Some patients were referred to the program more than once within a given year. "Referral Orders Received" represents all referrals placed to the program, whereas "Patients Referred" represents unique patients referred to the program.

Patients Attending an Initial Evaluation Visit

Of the patients referred to the pediatric chronic pain treatment program (N=1338), 934 (69.8%) were evaluated by at least one provider within the program (ie, medical, psychology, physical therapy, and/or occupational therapy). Of these, 732 patients (78.4%) attended an interdisciplinary evaluation visit (ie, evaluated by two or more disciplines) within the pediatric chronic pain treatment program. Patients who attended an interdisciplinary evaluation visit (N=732) were predominantly female (76.5%), White (81.4%), non-Hispanic (92.6%), English-speaking (98.8%) adolescents (median age=14.0 years; see Table 1). These patients were primarily referred from physical medicine and rehabilitation (28.1%), orthopedics (14.9%), rheumatology (13.7%), neurology (13.4%), diagnostic medicine/consultative pediatrics (7.9%),

Table 1 Demographic Characteristics of Patients Referred to an Interdisciplinary Pediatric Chronic Pain Program Between 2016 and 2019 (N=1338) and Those Who Attended an Evaluation (N=732)

Characteristic	Patients Referred to Program (N=1338) N (%)	Patients Attending an Evaluation (N=732) N (%)
Sex		
Female	1009 (75.4%)	560 (76.5%)
Male	329 (24.6%)	172 (23.5%)
Race		
White	1071 (80.1%)	596 (81.4%)
Black or African American	123 (9.2%)	54 (7.4%)
Some Other Race	76 (5.7%)	46 (6.3%)
Multiracial	38 (2.8%)	25 (3.4%)
Asian	17 (1.1%)	7 (0.9%)
Declined to Report	9 (0.7%)	2 (0.3%)
American Indian or Alaska Native	2 (0.1%)	2 (0.3%)
Hawaiian Native or Other Pacific Islander	1 (0.1%)	–

(Continued)

Table 1 (Continued).

Characteristic	Patients Referred to Program (N=1338) N (%)	Patients Attending an Evaluation (N=732) N (%)
Ethnicity		
Not Hispanic or Latino	1240 (92.7%)	678 (92.6%)
Hispanic or Latino	84 (6.3%)	46 (6.3%)
Declined to Report	14 (1.0%)	8 (1.1%)
Preferred Language		
English	1317 (98.4%)	723 (98.8%)
Spanish	16 (1.2%)	7 (1.0%)
Other or Unknown	4 (0.3%)	2 (0.2%)
American Sign	1 (0.1%)	–
Referring Department		
Orthopedics	273 (20.4%)	109 (14.9%)
Physical Medicine and Rehabilitation	263 (19.7%)	206 (28.1%)
Neurology	180 (13.5%)	98 (13.4%)
Rheumatology	174 (13.0%)	100 (13.7%)
Diagnostic Referral	116 (8.7%)	58 (7.9%)
Psychology	100 (7.5%)	55 (7.5%)
Gastroenterology	86 (6.4%)	41 (5.6%)
Inpatient Pediatrics	40 (3.0%)	21 (2.9%)
Urology	23 (1.7%)	9 (1.2%)
Hematology/Oncology	13 (1.0%)	5 (0.7%)
Neuropsychology	10 (0.7%)	4 (0.5%)
Pulmonology	9 (0.7%)	1 (0.1%)
Adolescent Medicine	8 (0.6%)	5 (0.7%)
Emergency Medicine	7 (0.5%)	3 (0.4%)
Primary Care	6 (0.4%)	4 (0.5%)
Infectious Disease	5 (0.4%)	2 (0.3%)
Otolaryngology	5 (0.4%)	3 (0.4%)
Genetics	4 (0.3%)	2 (0.3%)
Neurosurgery	3 (0.2%)	–
Palliative Care	3 (0.2%)	–
Nephrology	2 (0.1%)	–
Physical Therapy	2 (0.1%)	1 (0.1%)
Weight Management	2 (0.1%)	2 (0.3%)
Cardiology	1 (0.1%)	1 (0.1%)
Integrative Medicine	1 (0.1%)	–
Psychiatry	1 (0.1%)	1 (0.1%)
Surgery	1 (0.1%)	1 (0.1%)
Age (years)	Range (M, SD) 2–21 (13.92, 2.80)	Range (M, SD) 4–21 (13.90, 2.78)

Notes: Demographic data were extracted from the electronic health record. For patients who were referred more than once to the program, demographic data at the time of their initial referral are included here.

psychology (7.5%), and gastroenterology (5.6%; see Table 1 for complete list of referring departments). The proportion of patients referred to the program who attended an interdisciplinary evaluation declined slightly across the study period, from 58.8% in 2016 to 51.9% in 2019 (see Figure 1).

The subset of patients who attended an initial interdisciplinary evaluation visit within the program and completed PROMIS measures demonstrated anxiety within the expected range for the general population by both self-report

($N=327$, $M_{T\text{-score}}=55.67$, $SD=13.01$) and parent proxy-report ($N=354$, $M_{T\text{-score}}=57.70$, $SD=11.95$) and moderately elevated pain interference by self-report ($N=323$, $M_{T\text{-score}}=61.52$, $SD=8.44$) and parent proxy-report ($N=356$, $M_{T\text{-score}}=64.02$, 6.83).

There were no differences between patients referred who attended ($N=732$) versus did not attend an interdisciplinary evaluation ($N=606$) based on age ($t(1336)=.36$, $P=0.72$), sex ($X^2(1)=1.04$, $p=0.31$), ethnicity ($X^2(1)<.001$, $P=0.99$), or language ($X^2(4)=3.38$, $P=0.50$). There were significant differences based on race, with a smaller proportion of referred Black or African American patients attending an evaluation visit (44%) than expected ($X^2(4)=12.27$, $P=0.02$, Cramer's $V=0.096$). There were also differences based on referring departments, with a smaller than expected proportion of patients referred from orthopedics ($n=109$, 40%) and from pulmonology ($n=1$, 11%) and a greater than expected proportion of patients referred from physical medicine and rehabilitation ($n=206$, 78%) attending an initial evaluation visit ($X^2(26)=114.57$, $P<0.001$, Cramer's $V=0.29$).

Discussion

This study examined referral sources, demographic information, and clinical characteristics of youth referred and presenting to an outpatient interdisciplinary pediatric chronic pain program. Results highlight the high demand for outpatient interdisciplinary pediatric chronic pain treatment, with steadily increasing referrals placed over the 4-year period from a wide variety of specialists within the hospital system. This study can serve as a model for examining potential disparities in referral and access to pediatric chronic pain programs in other clinical settings through use of data that are readily available in most EHRs. Findings can inform decisions related to staffing and service design for other pediatric hospitals that aim to establish or grow outpatient pediatric chronic pain programs, with an emphasis on health equity.

On average, our interdisciplinary outpatient pediatric chronic pain program received 372 referrals per year, with a trend of increasing volume of referrals over time. There is a paucity of published data on the number of referrals placed and patients served by outpatient interdisciplinary pain programs within the United States. In one study examining outpatient chronic pain clinic referrals at a large Midwestern children's hospital over a 5-year period, 778 adolescents were identified as potentially eligible for a referral because of a chronic pain diagnosis, yet only 96 (12%) were subsequently referred to the clinic.²⁵ An outpatient interdisciplinary pain clinic within a large West Coast children's hospital reported serving approximately 350 patients annually.²³ Given that this study was conducted in a comparatively smaller children's hospital, our high referral volume is notable. Additional research is needed to examine referral patterns for interdisciplinary pain programs, including the potential influence of contextual factors such as hospital size and catchment area, pain management approaches provided through other services, and variation between individual providers.

Interestingly, we found several differences in attendance at the initial interdisciplinary pain program evaluation by referral source. Specifically, a lower than expected proportion of patients referred by pulmonology and orthopedics underwent an interdisciplinary program evaluation. Conversely, a greater than expected proportion of patients referred by physical medicine and rehabilitation (PMR) completed an interdisciplinary evaluation visit. Given that very few patients were referred by pulmonology during the study period, this finding may represent statistical error. On the other hand, orthopedics and PMR were two of the largest referral sources to the program within our hospital. Despite referring a similar number of patients (orthopedics: $n=273$, PMR: $n=263$), only 40% of those referred from orthopedics participated in an interdisciplinary evaluation versus 78% of those referred from PMR. At our hospital, one physician within PMR also provides services through the interdisciplinary pain program and is active in educating PMR colleagues and trainees on chronic pain. As such, it may be that enhanced education around chronic pain for both PMR health-care providers and youth and families seen by this service facilitates more appropriate referrals to the program and/or allows for greater follow-through with attending an interdisciplinary program evaluation. In addition, youth referred by orthopedics may be more likely to have experienced an injury resulting in acute rather than persistent pain. Additional research is needed to examine how pain education and management approaches within medical subspecialties may influence the referral process to pediatric chronic pain programs.

Patients referred to this outpatient chronic pain program were largely White, non-Hispanic, English-speaking, adolescent females. It is also notable that a smaller than expected proportion of Black or African American patients who were referred to the program attended an interdisciplinary evaluation. These findings are consistent with prior research, which suggests that patients who are referred and served by interdisciplinary pediatric chronic pain clinics are primarily White, female adolescents.^{22,25,36} A robust body of work highlights the role of implicit bias, prejudice, and systemic racism in perpetuating disparities in pain management.^{37–39} For example, pediatricians with high implicit pro-White bias are less likely to recommend opioids for Black children.⁴⁰ In addition, a significant subset of medical trainees endorses implicit attitudes that Black people feel less pain³⁸ or are more pain-tolerant than White people.⁴¹ In instances of high clinical or diagnostic uncertainty (eg, chronic pain), these biases may be especially likely to be activated⁴⁰ and influence treatment recommendations, including referral to specialized pain care services, and the ways in which these recommendations are communicated to patients and families. In addition, barriers to accessing healthcare (eg, inadequate insurance coverage, limited transportation, inflexible employment, and inadequate language translation services) that disproportionately impact marginalized communities may result in disparities in receiving interdisciplinary pain care even when referrals are made.^{27–29}

Several potential clinical implications can be drawn from these findings. Inadequate pain education for health-care providers has been widely recognized as a leading contributor to poorly managed pain,¹⁸ with 96% of medical schools in the United States and United Kingdom lacking compulsory pain medicine courses.⁴² Similar deficiencies in pain education have also been identified across other health sciences programs.^{43,44} When pain is incorporated into curricula for health-care providers, physiological systems and pharmacological treatments are prioritized,⁴² despite decades of evidence supporting the biopsychosocial model and interdisciplinary approaches to pain management.⁴⁵ Improving pain education for health-care providers (eg, mandatory curricula and interprofessional education opportunities) may enhance referrals to interdisciplinary chronic pain treatment programs by both ensuring that the patients who would most benefit from these programs are identified and that accurate information is provided to families receiving these referrals. However, these changes must go beyond addressing inadequate or outdated knowledge and include strategies for health-care providers to identify and actively dismantle their own biases to prevent harm to oppressed and historically marginalized groups experiencing pain. Moreover, changes at the health-care systems level are necessary, such as implementing standardized chronic pain prognostic screening tools to help guide referral decisions, EHR workflows that automate referrals based on pre-specified criteria, and incorporating social determinants of health data that are increasingly available in the EHR into the scheduling process for chronic pain clinics (eg, offering social work supports in instances where insurance or transportation challenges have been identified) and may help to ensure more efficient and equitable access to interdisciplinary pain care services.

Limitations of this work should be considered when interpreting our findings. First, sociodemographic characteristics were extracted from the EHR and may not always accurately reflect how youth identify their gender, racial, or ethnic background. We also were not able to collect or analyze detailed information regarding patients' medical histories, chronic pain diagnoses, or health insurance coverage. Future research should explore associations between these variables and interdisciplinary chronic pain program referrals and service utilization. We were also unable to calculate average time from referral to initial evaluation in this sample, as date of evaluation was not extracted during our manual review of EHRs. This is a high priority area for further investigation, as lengthy waitlists may have negative impacts on quality of life for adults with chronic pain,⁴⁶ and wait times appear highly variable for pediatric chronic pain treatment programs.^{47,48} This study was conducted within one Mid-Atlantic pediatric hospital in the United States; multisite collaborative research is needed to examine referrals and access to interdisciplinary treatment programs at broader regional, national, or international levels, which may highlight contextual factors driving potential disparities in referral and access to care for youth with chronic pain. Additional research is also needed to more closely examine how patients, families, and clinicians make decisions regarding referral to specialized chronic pain programs and specific barriers to participating in interdisciplinary pain care services.

Conclusion

This study documented referral sources, demographic information, and clinical characteristics of youth referred to and evaluated by an outpatient interdisciplinary pediatric chronic pain program. Findings underline the demand for outpatient interdisciplinary pain clinics and may help guide program design and development in other pediatric health-care settings that aim to expand their capacity to effectively serve youth experiencing chronic pain. In addition, this study highlights how standardized tracking of referrals and service uptake can inform targeted strategies to ensure equity in access to and utilization of interdisciplinary pain care services.

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Disclosure

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