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Children and Adolescents with Chronic Pain and Functional Disability: Use of a Behavioral Rehabilitation Approach

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Abstract Children and adolescents who present with various chronic pain experiences and associated functional disability often share common behavioral and clinical features. Caring for these patients is challenging to health care providers and expensive for the medical community. Given the complexity of interrelated medical, psychological, and environmental variables potentially involved, a biopsychosocial conceptualization of assessment and treatment is helpful. Recent research has been able to demonstrate the effectiveness of treating children and adolescents suffering from chronic pain within an interdisciplinary rehabilitation environment. An interdisciplinary inpatient behavioral rehabilitation approach is described in detail along with how it compares to related day-hospital pain programs and outpatient services.

Keywords Pediatric · Chronic pain · Functional disability · Interdisciplinary rehabilitation · Pain-associated disability · Behavioral approach

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Introduction

Over the last 25 years, there has been an increase in research focusing on children and adolescents with chronic pain. Pain that persist beyond 3 months and that does not remit with typical treatments for acute pain, such as rest, non-steroidal anti-inflammatory drugs, heat, or ice, is considered chronic [1]. King and colleagues [2] conducted a systematic review across epidemiological studies of pain in children and adolescents and concluded that chronic pain is prevalent in children and adolescents, with girls generally experiencing more pain than boys and prevalence rates increasing with age. Between 11 and 38 % of children and adolescents have chronic or recurrent pain [2, 3]. Severe chronic pain with high impairment occurs in children and adolescents with an estimated prevalence of 3–5 % [4••, 5]; review of other epidemiological studies across countries indicates that up to 30 % of children may have chronic or recurrent pain significant enough to impair functioning [6]. Zernikow et al. [7] conducted a 5-year retrospective study on 2,249 pediatric pain patients and found that in their sample, the most frequent pain locations were headache (69.0 %), abdominal pain (16.3 %), extremity/back pain (13.2 %), and other (e.g., whole-body, genital) (1.4 %).

When pain continues beyond what providers would consider a typical trajectory of the original injury or trauma and the child has not been able to return to age and

developmentally typical activities, health care professionals commonly refer to specialists such as neurologists, anesthesiologists, and psychiatrists. Zernikow et.al [7] noted that 40 % of their sample had a pain-related hospital admission prior to being seen at the tertiary pediatric pain clinic. By the time many of the patients reach a tertiary care pain center, they will have seen at least four physicians [8]. Initial evaluation of these patients often results in an extensive and costly diagnostic evaluation in an attempt to identify an underlying organic etiology [9]. This process of referrals and evaluations will take, on average, 4–6 months; all the while, these patients have significant alterations in their quality of life and lifestyle [8].

Chronic pain can be either recurrent or persistent and is a serious developmental health problem that can interfere significantly with daily functioning [2]. Chronic pain in children often results in significant impairments in quality of life including mood, sleep, relationships, academic performance, and social development, and may predispose the individual to the development of pain conditions later in life [10]. Severe functional disability that continues for 2 months or more has been adopted as one of the criteria used to define pain-associated disability syndrome (PADS) [6, 11]. PADS is used to describe a chronic pain condition with frequent and severe difficulties in functioning, regardless of the location or cause of the pain [11, 12]. Any child or adolescent, regardless of the specific etiology of the pain (e.g., juvenile rheumatoid arthritis, sickle cell disease, cancer, headaches, irritable bowel syndrome, etc.) can develop this syndrome [11]. Oftentimes, the original source of tissue damage or irritation initiating the pain disorder cannot be identified [11, 12]. Across studies from the USA [13], Europe [5, 14], and Canada [15], approximately 3 % of children and adolescents suffering from chronic pain demonstrate PADS.

Chronic or recurrent pain and disability in the absence of an identifiable physical cause are most often attributed to psychological factors [12]. Eccelston et al. [16••] conclude that psychological treatments are effective in reducing pain intensity for children and adolescents with headaches and that the benefit from therapy appears to be maintained. Psychological treatments improve pain and disability for children with non-headache pain as well [16••]. Psychological distress has been identified as one of the risk factors for pain chronicity. Bursch et al. [11] hypothesized that PADS develops when there is a physical trauma, illness or other life circumstance that becomes overwhelming to a vulnerable child who has poor coping skills and cannot regulate his or her emotions.

PADS is the common term used for the phenomenon that the literature identifies as the downward spiral of increased disability and pain for which symptom-focused strategies did not lead to acceptable resolution. Children experiencing pain may experience negative effects across all aspects of their lives. They are often excused from normal activities and routines until the condition and related pain have subsided. If the child does not perceive that the pain is subsiding, then these reduced expectations and requirements for normative activities and responsibilities may be extended indefinitely. Thus, the physical symptoms may allow the child to avoid or escape the pain sensation, anticipation of pain or discomfort, and associated negative emotions. This conceptualization of chronic pain was first derived from the literature on operant psychology by Fordyce [17].

According to this operant conceptualization, a patient's overt behavioral responses to pain sensation constitute a significant part of clinical pain, and this pain behavior can be influenced by numerous social and environmental factors, in addition to being influenced by the actual tissue damage or irritation (see Fordyce and colleagues' work summarized in Sanders [18] and Slifer et al. [19]). Social and environmental consequences immediately following pain behavior influence the probability of the pain behavior occurring in the future. Therefore, pain behavior that first arose because of body damage or tissue irritation may come under control of consequences and conditioning that occur in the patient's social environment. Two general processes are involved in this type of operant conditioning: (1) positive reinforcement and (2) avoidance learning (negative reinforcement). In positive reinforcement, the occurrence of pain behavior will increase in frequency if followed by positive or preferred consequences. By definition, if a behavior increases in frequency after a specific consequence consistently follows it, then whatever that consequence was is said to be a positive reinforcer. Positive reinforcers of pain behavior may include contingent social attention (attempts to comfort and console), efforts by others to soothe the pain, and providing contingent pain medication. Avoidance learning of pain behavior is thought to occur when the frequency of a behavior increases after that behavior enabled the individual to escape or avoid aversive stimulation. In this avoidance-learning process, pain behaviors such as limping, bracing, or activity avoidance become associated with decreased or no pain sensation. Thus, these behaviors are negatively reinforced and are maintained or increase in frequency. In chronic pain patients this process may develop to the point that the mere anticipation of pain sensation functions as a conditioned aversive stimulus. Therefore, in the context of anticipated pain, if the patient engages in protective pain behaviors such as limping or bracing, or lying in the dark, and pain perception or its exacerbation does not occur, then the same protective behaviors are more likely to occur in the future (technically, they have been negatively reinforced). Fordyce also noted that once such avoidance

learning occurs, it requires little ongoing reinforcement to maintain it. If a behavior occurs because of anticipation of pain and motivation to avoid both the aversiveness of anticipating pain (anxiety, physiological arousal) and the painful sensation itself, the person will maintain the avoidance behavior even if the nociceptive stimulation is never again experienced [17–19].

In the context of behavior maintained by avoidance learning, the goal of operant treatment is to prompt and positively reinforce normative physical activity and arrange the environment such that the patient attempts typical physical activity with minimal self-protective pain behaviors and does not experience pain or experiences it at much lower intensity [18]. The way a child experiences and reacts to chronic pain is influenced by many interrelated factors. In addition to the social and environmental consequences that Fordyce highlighted, age, personality characteristics, ability to cope/mastery of coping skills, activity level, anxiety, and previous experiences with pain all have been found to be related to pain perception and functional disability.

With respect to children with PADS, when a child fails to develop positive coping strategies, an avoidant and dependent behavioral pattern such as Fordyce described may develop. In this pattern avoidance of stressful, effortful, or painful situations occurs along with increasing dependence on others, social withdrawal, avoidance of school and physical activity, and progression of functional disability. Simons et al. [20] and several other authors have hypothesized that numerous other variables contribute to a child's pain-related disability. These include pain intensity, emotional factors (e.g., anxiety and depression), cognitive factors (e.g., pain catastrophizing, pain-related fear), behavioral factors (e.g., motivation, coping responses, self-management skills), and social factors (e.g., context, parent response, peer influences).

Outpatient Pain Clinic: Initial Evaluation and Choosing the Treatment Setting, Modalities, and Intensity

Our goal at the Pediatric Pain Rehabilitation Program at Kennedy Krieger Institute is to help children and adolescents more fully participate in daily activities and to develop coping skills that help them successfully return to school, home, and community life. In our institution, each patient referred to our pain program receives a comprehensive initial evaluation in our outpatient interdisciplinary pain clinic to assess the severity of pain and functional disability, history of treatment, and level of intervention indicated. Our interdisciplinary pain team is comprised of a pediatric anesthesiologist, physical therapist, and behavioral psychologist. As each provider meets with the child or adolescent and family independently, a diagnostic assessment is conducted, and treatment recommendations are formulated as to the type and level of services warranted (i.e., outpatient services, intensive day program, inpatient rehabilitation, or some sequence of all of these). The initial evaluation is comprised of a complete medical and pain history, including onset, location, intensity, quality, frequency, duration, variability, predictability, aggravating and alleviating factors, and results of prior treatment efforts. A detailed psychosocial assessment is conducted that comprehensively examines the child or adolescent's emotional and family functioning, current understanding and use of coping skills, trauma history, and the impact of pain on daily life (sleep, appetite, school, social, and physical activities). A physical therapy assessment of the child or adolescent's general appearance, posture, and gait is conducted focusing on what limitations there are on the child's activities of daily living (e.g., bathing, dressing, grooming), need for assistive devices for mobility (e.g., crutches, wheelchairs), and overall strength and endurance to complete such activities. Once the interdisciplinary team has provided recommendation(s), a proposed treatment plan is discussed with the family with consideration given to additional factors that may include insurance authorization, geographical limitations, and parental involvement.

Inpatient Rehabilitation Hospital Treatment

As noted previously, the pediatric chronic pain experience is complex, and it is helpful to conceptualize it within a biopsychosocial framework that accounts for physiological, psychological, and social factors that may be contributing to the pain-related outcomes [20, 21]. Eccleston et al. [22] have suggested that the optimal treatment for these patients should include emphasis on interdisciplinary cognitive behavioral therapy (ICBT), with child or adolescent and parent involvement that focuses on pain management and rehabilitation to normal activity rather than elimination of all pain symptoms. Given this, treatment for those pediatric patients who demonstrate severe suffering and extensive pain-related disability may benefit from the interdisciplinary multimodal inpatient treatment approach with a special focus on psychological intervention [23] and intensive daily therapy that addresses physical, daily living, medical, and educational goals. An inpatient admission may also be recommended if the child or adolescent has exhausted all medical interventions to date, has already received outpatient services (physical therapy, occupational therapy, and cognitive behavioral therapy), and is still not functioning at a developmentally appropriate level across most areas of daily living. Of note, careful screening is important in order to identify children and adolescents who have more severe psychiatric conditions (e.g., active suicidal ideation, engagement in high risk behaviors) that could impede

participation in a rehabilitation setting and in achieving therapy objectives. Additionally, this subgroup must also be considered carefully to ensure that they could be safely cared for in a pediatric rehabilitation hospital setting.

The German Pain Society defined multimodal inpatient treatment as a treatment provided by a minimum of three health care disciplines including medical, psychological, and physical therapy, which are provided concurrently, generally lasting for 3 weeks [24•]. At our institution, our interdisciplinary inpatient team is comprised of physicians (pediatricians or pediatric physiatrists), physical therapists, occupational therapists, behavioral psychologists, social workers, nurses, neuropsychologists, educators, therapeutic recreation, and child life specialists. Additionally, special services are provided on a consultation basis, as needed. These consultation services include pediatric pain management anesthesiology, psychiatry, nutrition, complementary and alternative therapies (e.g., massage, energy, acupuncture), and other medical diagnostic consultation (e.g., rheumatology, neurology, etc.).

Our interdisciplinary rehabilitation model is based on the operant behavioral and cognitive–behavioral conceptualization, which guides our interdisciplinary colleagues to maximize efficacy in their treatment. As introduced earlier in this article, the operant conceptual framework for understanding chronic pain is that consequences immediately following pain behavior may have a powerful influence on the probability of the pain behavior occurring again in the future. As a result of this behavior-consequence association, pain behavior that originated because of physical trauma or tissue irritation may come under control of consequences and conditioning that occurs in the patient's social environment [19]. In clinical practice, operant procedures are rarely, if ever, used in isolation, and research evidence supports the benefits of combining these strategies with related behavioral techniques such as task analysis, stimulus fading, and response shaping, as well as cognitive-behavioral techniques such as distraction, relaxation training, biofeedback, visual imagery, and cognitive- behavioral coping skills training [19]. The focus emphasizes shaping via differential reinforcement of successive approximations of effortful functional behavior, differential reinforcement of coping and wellness behavior, extinction of illness and pain behavior (minimal social attention, prevention of complete activity avoidance), and cognitive restructuring of pain catastrophizing and other maladaptive automatic thoughts. Behavioral interventions for pain also include modification of antecedent and consequent stimuli in order to strengthen wellness-oriented behaviors that are an alternative to, or incompatible with, pain–related behavior (e.g., avoidance, guarding, behavioral distress). Examples of positive alternative behaviors include participation in therapies or positive leisure activities, use of pain coping strategies (distraction, muscle relaxation, positive self-statements), increased physical and social activity, reduced use of narcotic pain medications, and return to role functioning (i.e., school or work) [19]. Psychological interventions are provided in the context of physical rehabilitation (e.g., co-treating with other disciplines) in order to strengthen child or adolescent and family coping skills through prompting and positive reinforcement and to similarly help modify interaction patterns that may be maintaining pain and illness behavior [12].

Within the interdisciplinary behavioral rehabilitation model, children and adolescents and their families are encouraged to accept pain as a symptom that they can learn to manage. Children and their families are encouraged to shift their focus away from total elimination of pain and emphasize reinforcing more independent functioning in age-appropriate activities of daily living, academics, and social and physical activities. Interdisciplinary rehabilitation therapies are provided to treat specific symptoms of anxiety, depression, avoidance behavior, diminished muscle strength, limited range of motion, and academic deficits, and to teach active coping skills to the child and family [19]. In conjunction with the child or adolescent's individual work during their admission, caretakers are strongly encouraged to become active participants throughout treatment for behavioral management training, parent training, coping skills training, and individual sessions with social work for resources and support. Parents are taught ways to encourage and support their child or adolescent's use of active coping strategies across academic, home, and community demands in order to promote increased levels of age-appropriate functional activity.

While optimal medical management and reduction in the experience of pain may be one goal of the medical rehabilitation team, rehabilitation treatment "success" is conceptualized as not dependent on the complete elimination of pain, which may not be possible. However, improvement in daily functioning in spite of ongoing pain is considered an important achievement; reduction in pain intensity may be modest or may occur over months or even years rather than days or weeks. To maximize success and coping, attainable goals are set for each day. As the child/adolescent becomes better able to manage and cope with his or her pain, we gradually increase physical demands. This gradual increase helps the child or adolescent learn to pace their daily tasks and activities, learn when and how to relax, and allows them to experience actual "success" with operationalized steps along the trajectory of their recovery. This approach offers the possibility of treating not only pain symptoms but also modifying behavioral and psychological variables that have previously served to maintain chronic pain and disability using behavioral, cognitive-behavioral, and alternative/complementary therapies.

Use of adaptive functional outcome measures in addition to subjective pain ratings is central to the behavioral

rehabilitation approach. In our experience, patients may demonstrate little variability in their pain rating during inpatient rehabilitation, continuing to give high ratings despite showing positive affect during active participation in therapy and leisure activities. In addition, patients may look as if they are only "in pain" when asked or when aware of being observed. However, it would be a mistake to conclude that their pain symptoms are being exaggerated. A more likely and charitable interpretation is that patients are less affected by pain symptoms when distracted by activities that compete with their focus on painful physical sensations. This is supported by basic research showing decreased cortical activation of pain circuitry when distraction is introduced during experimental pain [25, 26]. It is also supported by the research on the benefits of distraction during acute procedural pain [27].

Currently, there are few national and international programs located in pediatric hospitals and other centers that use the interdisciplinary rehabilitation model to treat children and adolescents with chronic pain. The recently increasing number of these programs can be attributed to accumulating evidence of their demonstrated effectiveness. Programs appear to vary in type of setting, length of stay, and various disciplines involved, and it appears that programs may differ regarding the type and level of psychological interventions used [12]. Yet such programs have similarities in their overall treatment approach including an interdisciplinary team view of chronic pain as a biopsychosocial phenomenon. Interdisciplinary treatment for chronic pain in children typically consists of some combination of medical (e.g., medication, nerve blocks), physical (e.g., physical therapy, occupational therapy), and psychological (e.g., cognitive behavioral therapy, biofeedback) treatments [20]. The common themes across inpatient rehabilitation programs include the promotion of positive change despite pain, graduated exposure to increasingly more challenging physical activities, restoring functional independence (e.g., decreasing level of medical and social care), and return to normal everyday activities [22] .

Over the last decade and especially in the last few years, there has been growing evidence for the effectiveness of this inpatient rehabilitation model [12, 22, 23, 28]. The Maynard et al. [12] study highlighted significant improvements among children and adolescents with pain-associated disability and distress across measures of functioning after completing the interdisciplinary inpatient intervention protocol as compared to their pre-admission functioning. Hechler et al. [23] describe the efficacy of an inpatient interdisciplinary approach for pain management and concluded that a rehabilitation approach is effective in reducing pain symptoms, disability, and emotional distress of highly impaired children with severe chronic pain. In addition, although specific outcome data on clinical outcomes and cost-effectiveness are limited in the pediatric population, a very strong argument has been made for these approaches to chronic pain in adults [8].

Outpatient Treatment

Children and adolescents with chronic pain and associated physical, emotional, social, educational, and functional deficits can be difficult to treat on an outpatient basis. Given the interdependence of aforementioned factors, at times one cannot simply treat one to the exclusion of the others [21]. That said, in our institution as in others, outpatient services may be recommended when further medical evaluations are warranted, when physical therapy or cognitive behavioral therapy services have not yet been initiated or attempted, and/or when the child or adolescent is engaging in a relatively high level of overall functioning (i.e., attending school, participating in some extracurricular activities, etc.). Simons and colleagues [20, 29] found that patients who had been seen in an outpatient pain clinic reported significantly fewer doctor visits and decreased pain, somatic complaints, and functional disability 3 months after their initial pain clinic evaluation. However, home adherence to treatment regimens and recommendations given in a pediatric outpatient pain clinic is often suboptimal and often a barrier to success [20]. For patients who continue to struggle with their pain symptoms coupled with their inability or reluctance to engage in recommended treatments, more intensive treatment approaches may be warranted [20].

Interdisciplinary Day Treatment Program

A day hospital model offers an alternative rehabilitative approach that can be less costly than inpatient rehabilitation but intensive enough to benefit many of those children who fail to progress with traditional outpatient treatments [30]. Intensive day treatment may be recommended when a child or adolescent has exhausted medical interventions to date and when they may benefit from short-term intensive rehabilitation to help them successfully and systematically reintegrate back into school and the community. It also may be recommended that they participate in a day treatment program following an inpatient rehabilitation pain admission in order to facilitate reintegration, generalize learned skills, and maximize functional gains in a school/community setting. In a day hospital program, including the one at our institution, patients typically receive a full day of treatments (physical therapy, occupational therapy, psychological support, educational services, etc.) 5 days a week, providing treatment intensity and frequency comparable with inpatient hospitalization and simulating a school week (e.g., returning home in the afternoons and on weekends). Upon discharge, patients transition back into

the neighborhood school system and other community-based programs.

Simons et al. [20] evaluated clinical outcomes among children with significant pain-related disability who participated in a day hospital pain rehabilitation program and provided a comparison with patients who engaged in multidisciplinary outpatient treatment alone. While improvements were found for both treatment modalities, patients that participated in the more intensive day program had significantly greater improvements in functioning as well as other outcomes (e.g., pain-related fear, readiness to change), and their caregivers showed similar improvements. Logan and colleagues [30] published a longitudinal case series of 56 children and adolescents ages 8–18 years with complex regional pain syndrome (CRPS) who failed to progress sufficiently with a previous outpatient and/or inpatient treatment and subsequently participated in a day hospital pain program. Their outcomes demonstrated clinically and statistically significant improvements from admission to discharge in pain intensity, functional disability, subjective report of limb function, timed running, occupational performance, medication use, use of assistive devices, and emotional functioning. Functional gains were reported to be maintained or further improved during follow-up visits.

A primary contraindication for either traditional outpatient or day hospital treatment is that the child or adolescent may be so debilitated that they are unable to tolerate a daily commute and outpatient program demands, and/or their family caregivers are unable to reliably get them to leave home to participate on a daily basis (e.g., secondary to difficulty with morning awakenings given severely disrupted sleep and pain). A more impaired child or adolescent, as well as the caregivers, may need more intensive environmental support and intervention that includes slow and gradual desensitization and shaping throughout the day, evening, and weekend, as well as additional services (e.g., nutrition, therapeutic recreation, etc.). This may also be the case during aggressive pain medication weaning that may occur simultaneously with increasing physical/rehabilitation demands, when increased medical and nursing monitoring is necessary, and increased psychological support may be warranted. Such individuals require more comprehensive interdisciplinary inpatient pain rehabilitation in order to make functional gains.

Conclusion

Progress has been made in the last several years in the management of acute and chronic pain in children and adolescents. There is greater appreciation for the social and psychological variables that contribute to the experience and perpetuation of pain states. Numerous studies with children and adolescents have adopted the biopsychosocial model of chronic pain and demonstrated how social and behavioral factors can influence pain and pain-associated disability. Interdisciplinary rehabilitation models view chronic pain as a biopsychosocial phenomenon best treated through integrated physical, psychological, and medical approaches, typically with an emphasis on gradual restoration of function. An inpatient interdisciplinary rehabilitation setting may be ideal for implementing systematic behavioral intervention to shape functional behavior and reinforce its generalization across settings and situations [28, 31].

For children and adolescents, there are only a few interdisciplinary inpatient rehabilitation programs worldwide that have been described and evaluated in terms of their effectiveness. Research to date is scarce, and there are limited publications on the effectiveness of an inpatient rehabilitation treatment approach within the pediatric population; however, the existing studies are promising as they report positive results and point to clinically significant improvements across functional and emotional domains. Results suggest that an inpatient interdisciplinary rehabilitation approach may lead to decreased overall use of medical resources, reduce long-term medical costs, and more importantly may disrupt the vicious cycle of ongoing pain and pain disability in the long-term. In addition, outcomes for interdisciplinary day hospital and day rehabilitation programs are similarly promising. More research is warranted on long-term outcomes of interdisciplinary pain rehabilitation interventions using consistent standardized measures. Studies are also needed comparing results related to using differing treatment settings, intensities, durations, combinations of specific modalities, and follow-up care plans.

Compliance with Ethics Guidelines

Conflict of Interest X. Celedon declares no conflicts of interest. A. Amari declares no conflicts of interest. C. Ward declares no conflicts of interest. S. Prestwich declares no conflicts of interest. K. Slifer declares no conflicts of interest.

Human and Animal Rights and Informed Consent All studies by Keith J. Slifer, Cynthia M. Ward, and Adrianna Amari involving human subjects were performed after approval by the appropriate institutional review board.

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