

Pediatric Pain Rehabilitation Program (PPRC)



The Mayo Pediatric Pain Rehabilitation Program (PPRC) is an intensive 3-week outpatient program providing multidisciplinary rehabilitative therapy to adolescents with chronic pain and their families. The PPRC is part of the Mayo Clinic Comprehensive Pain Rehabilitation Center in Rochester, Minnesota, which has been offering multidisciplinary rehabilitative services to patients with persistent pain since 1974. This center was among the first pain rehabilitation programs and is now one of the largest pain rehabilitation programs in the nation.

The primary goal of the PPRC is to improve quality of life and facilitating a return to regular daily activities for adolescents experiencing chronic pain. Functional goals are the priority of the rehabilitation program and include return to school, discontinuation of all opioid analgesics, improved physical conditioning, improved mood/level of depression, decrease in medical utilization, and return to social/recreational/leisure activities. The core team of health-care professionals who care for patients in the PPRC include physicians, psychologists, nurses, physical therapists, occupational therapists, and biofeedback therapists.

The adolescent is involved in 40 hours a week of cognitive-behaviorally based treatment that includes physical reconditioning, relaxation training and biofeedback, stress management, pain management training (e.g. activity moderation, elimination of pain behaviors), chemical health education, occupational therapy and recreational therapy for school, leisure and home activities. Family involvement is critical to success in the self-management of chronic pain. Parents are involved in 15 to 20 hours of treatment a week focused upon cognitive-behavioral skills of parenting, assisting the child in moving out of the illness role, and resuming work and leisure activities for the parents. The program essentially focuses on helping teens and parents learn aspects of their pain and life they can control when a cure for the pain is not possible.

Goals

Important goals for participation in the PPRC include:

- Return to regular daily activities
- Return to school
- Increase physical strength, stamina and flexibility
- Reduce use of pain medications, including discontinuing analgesics
- Minimize pain behaviors
- Learn stress management techniques
- Resume leisure and recreational activities
- Improve interpersonal relationships
- Reduce reliance on health-care professionals, with improved ability to self-manage chronic pain

Chronic Pain and Rehabilitation

Chronic pain refers to pain that does not improve with time. It may affect a specific part of the body, as in low-back pain, headaches or facial pain. It can also involve many regions of the body at once, as in fibromyalgia. No longer is the pain just a symptom of a disease, illness or injury; it becomes an illness unto itself. Regardless of the location or cause of chronic pain, many patients develop difficulty functioning in daily activities. Some also experience depression, drug-related complications, anxiety, and diminished quality of life.

All too often, specific forms of pain treatment, such as medications, injections or surgery, do little to relieve the chronic pain itself or the long-term suffering and disability that can develop. Patients, their families and their doctors can become discouraged and frustrated. The PPRC offers hope and specific assistance in reversing the downward course of chronic pain.

Common Conditions

At the PPRC, patients often have a variety of chronic pain disorders. Headache (31%) and abdominal (25%) pain are the most frequent pain disorders, although a significant percentage (31%) of patients also have a diagnosis of postural-orthostatic-tachycardic syndrome (POTS) that contribute to a decrease in overall functioning. Additionally, some patients have no identifiable cause for the pain they are experiencing which can make the pain even more frustrating. The PPRC staff work with all types of chronic pain problems, individualizing treatment to the specific needs of each patient.

Core Treatment Components

Throughout the three-week program, various types of treatment and therapies are provided in an integrated program to help each patient achieve success in returning to an active and fulfilling life. The following are the core components of the multidisciplinary program:

Medication Management

The role of opioid medications in treating chronic pain is complex and sometimes controversial. Often long-term use of opioid medications do little to relieve chronic pain and may cause debilitating side effects that limit one's functioning and mobility even greater. When used appropriately, some medications can help to reduce pain with limited side effects for some people. Often other conditions can accompany chronic pain, such as depression and insomnia. Appropriate medication use can help manage these conditions.

The PPRC has a conservative approach to the management of medications. The PPRC team works with each patient individually to eliminate or reduce the use of analgesic medications as appropriate. Medications are gradually reduced through structured tapers tailored for individual patients. Factors such as medication efficacy, safety, drug interactions, and practical issues such as costs are taken into consideration when making medication adjustments. Medication reduction has been found to be a successful component of the program. A recent study of patients attending the PPRC program found that patients with severe and disabling pain at admission experienced significant improvement in physical and emotional functioning with decreased pain severity despite tapering these medications. Group classes equip patients and parents with medication information on the benefits and risks associated with the various classes of medications used in chronic pain conditions. Patients are encouraged to make informed decisions on medication use for both prescription products and dietary and herbal remedies.

Education and Group Sessions

Group sessions are an integral part of the PPRC program. When chronic pain intrudes on life, many find themselves overwhelmed by intense, often negative, emotions including panic, fear, grief and anger. Like the pain that causes them, these emotions affect the body, sapping energy and intensifying pain. As a result more time may be spent alone and less time with friends and family.

Group sessions are designed to help patients recognize and deal with negative changes and emotions, improve relationships and become more effective at managing their pain. Group sessions are a combination of informal discussions about how lives have been affected by chronic pain and formal lectures on how to effectively deal with pain. Many adolescents find talking with others whose lives and family have been negatively affected by chronic pain to be helpful – particularly when they also support making positive changes to lead a new life.

Group sessions are structured and will focus on a particular theme, pattern of behavior, or area of learning, such as:

- Stress Management
- Anger Management
- Assertive Communication
- Perfectionism and Unrealistic Expectations
- Cycle of Chronic Pain – learning to develop a new cycle
- Planning for a Difficult Day
- Personal Responsibility

Stress Management and Relaxation

Stress and pain have a pronounced effect on each other. When a person is in pain, the typical stress of daily life can become much more difficult, often turning common hassles into major obstacles. Stress can also impact pain. The physical reactions to stress such as increased muscle tension can significantly intensify pain. In short, pain causes stress and stress intensifies pain.

Stress management training provided in the PPRC program utilizes coping strategies to break the pain-stress cycle. Taking control of stressful situations can modify the bodies 'fight or flight' response to stress. Coping strategies are numerous and the stress management classes provide a comprehensive overview of these strategies.

One of the most common coping strategies for managing stress is relaxation. Relaxation reduces muscle tension, reduces anxiety, increases self-control and allows a person to feel refreshed and rejuvenated. The program presents a number of different forms of relaxation and encourages daily practice.

Physical Therapy

Physical therapy involves strengthening, stretching, and aerobic conditioning. The physical therapy staff also provides education on proper body mechanics, lifting techniques, proper posture, benefits of aerobic exercise and discussions of pain behaviors. While at the program, patients participate in range of motion exercises each morning and physical therapy sessions, which include strength training, stretches and aerobic conditioning, with the intention of increasing function. Most people have had some physical therapy before coming to the PPRC, usually focused on the site of pain. The PPRC physical therapy focuses on increasing stamina and functioning, and teaching more efficient ways of moving the body, so that daily tasks become easier and patients will be able to do more despite pain. The exercises are designed to help decrease fear of movement that can be more debilitating than the pain itself.

Occupational and Recreational Therapy

Recreational therapy is focused on restoring social and leisure activities that have been diminished due to chronic pain. Throughout the 3-week program, a variety of recreational activities are integrated into the program.

For many patients, pain is controlling the choice of activities done during the day. In the PPRC, the goal of occupational therapy is to create a balance between school, self-care, and social/leisure activities. In occupational therapy, the focus is on learning techniques that increase the control a person has over activities of daily living, as well as helping to increase independence when performing activities.

At times, it is helpful to have specific recommendations in creating a plan that will promote a successful return to school and home. Occupational therapy staff, as well as the nurse care coordinators, are available to assist with return to school issues.

Biofeedback

Biofeedback is a treatment that provides information about how physiological processes in the body can be negatively affected by chronic pain. A computerized instrument is used to measure and increase a patient's awareness of predominantly involuntary physiologic processes such as breathing rate and muscle tension. Biofeedback then aids the patient in learning how to increase control over these processes and strengthens the ability to maintain control while engaged in daily activities. This is just one more tool to increase control over life and pain. Strategies for incorporating these skills into the home environment are introduced and practiced in the PPRC.

Sleep Hygiene

Chronic pain has a significant impact on sleep. Sometimes managing pain by spending time in bed or on the couch taking naps can lead to insomnia. Becoming stressed about having difficulty falling asleep or doing too much activity before bed can also make insomnia worse. Because sleep plays an important role in how one manages daily activities, chronic pain and overall mood, the program emphasizes assessment and education of sleep hygiene techniques. Sleep hygiene sessions are designed to promote sleep efficiency, leading to a more restful night and an active day.

Lifestyle Management

The PPRC strongly believes that decisions and habits related to one's lifestyle are key in managing chronic pain and anxiety. Current information, assessment, and individual consultations with experts are offered to participants to promote healthy lifestyle changes in many areas, including nutrition, tobacco cessation, sleep, and chemical dependency. Additionally, pastoral care and vocational counseling can be arranged to further improve the overall quality of life and functioning.

Parent Program

Chronic pain affects the whole family, not just the person who is in pain. Family and friends often feel very helpless and frustrated when up against chronic pain. The PPRC offers programming for family or other loved ones to gain a better understanding of chronic pain and ways to respond more effectively. Parental participation indicates a willingness to learn how to assist your child toward better management of their chronic symptoms.

Parents, and other significant family members, are involved in 15 to 20 hours of treatment a week focused upon cognitive-behavioral skills of parenting, moving out of the illness role, and resuming work and leisure activities for the parents. During this group, families have an opportunity to look at better ways to respond to chronic pain as well as learning techniques to care for themselves. Also discussed is the benefit of using a neutral response to pain behaviors instead of an overly care-taking or punitive response. A positive outcome for family or loved ones would be to reclaim your life and minimize how chronic pain may have controlled you and your child.

Aftercare Program

The PPRC has a formal Aftercare program that is schedule a few months after a patient dismisses from the program. It is an intensive 2-day outpatient program tailored to the graduates of the teen program with the following goals:

- Promote continued use of concepts learned in the program
- Problem solve difficulties in generalizing the skills to the home environment
- Check on school progress or facilitate return to school full-time
- Promote staying off unnecessary medications
- Promote continued exercise and re-entry into normal activity with peers
- Relapse prevention and difficult day management
- Decrease medical utilization
- Parent and parent/teen sessions to reinforce gains and enhance continuation of health enhancing behavior change toward continued rehabilitation.

Parents meet separately and with their child in groups that enhance communication, encourage limit setting and decrease the focus on the pain and pain behaviors.

The staff of the PPRC also coordinate with the patient's home care providers and school staff, as well as provide necessary referrals to facilitate a successful transition home. Our goal is for every patient to continue with the strategies learned in their home environment.

Patient Descriptions

Patients come from across the United States. The average age of patients in the program is 15 years, with a range of 11 to 19 years old. The average patient reports missing approximately 10 days of school in the past month due to pain and other symptoms. Headache (31%) and abdominal (25%) pain are the most frequent primary pain disorders, although a significant percentage (31%) of patients also have a diagnosis of postural-orthostatic-tachycardic syndrome (POTS) that contributes to poor functioning upon admission. The duration of pain averages 35 months, with a range from 9 to 96 months. About twenty-five percent of the adolescents take opioids at the time of admission. From a mood standpoint, 72.5% endorse depressive symptoms and 18% have clinically elevated scores on assessment of anxiety upon admission.

Treatment Outcomes

Comprehensive pain management programs similar to the Mayo Pediatric Pain Rehabilitation Center program are consistently shown to be the most beneficial and cost-effective for persons with chronic pain in comparison to medications, surgeries, or implantable devices (Gatchel and Okifuji, 2006). The Mayo PRC and PPRC conducts ongoing treatment research to better understand how to help people with chronic pain and determine the level of improvement our patients achieve (Townsend et al, 2008).

Patient Satisfaction

Upon completion of the 3-week program, information regarding the usefulness of the program is gathered from the patients. When asked if they would recommend the program to a friend, 79% of parents indicated they “definitely would recommend” the PPRC. The majority of adolescents (82%) indicated they “strongly agreed” or “agreed” with the statement that PPRC was beneficial in helping to learn how to live well in spite of chronic pain.

Reported Functioning

While participating in the Pediatric Pain Rehabilitation Center program, patients complete assessments of mood and overall functioning. Comparing results from admission to dismissal, adolescent patients show significant improvements in physical and social functioning, as well as an improvement in overall general health perception. These patients also report a decrease in depressive and anxious symptoms, and a decrease in pain catastrophizing.

References

Townsend, C., Kerkvliet, J., Bruce, B., Rome, J, Hooten, W., Luedtke, C., Hodgson, J. (2008). A longitudinal study of the efficacy of a comprehensive pain rehabilitation program with opioid withdrawal: Comparison of treatment outcomes based on opioid use status at admission. *Pain*, 140, 177-189.

Gatchel, R. & Okifuji, A. (2006). Evidence-based scientific data documenting the treatment and cost-effectiveness of comprehensive pain programs for chronic nonmalignant pain. *Journal of Pain*, 7, 779-793.

Making the Decision to Participate in the PPRC Program

Pain rehabilitation is a challenging process that requires a serious commitment. As you and your family consider admission to the PPRC, please ask yourself these questions:

- Is my life focused on pain and what I am not able to do, rather than what I am able to do in spite of the pain?
- Am I missing school and social events due to my pain?
- Are my doctors telling me there is nothing further they can do to relieve the pain? Do they tell me that I need to learn to get on with my life?
- Am I truly concerned about the long-term effects of taking pain medications?
- Is my family's well-being affected because of my chronic pain?
- Is my recovery from injury or illness taking much longer than my doctors or I expected?
- Am I not able to commit to social events with family or friends because my pain may be higher that day?

If you answered yes to one or more of these questions, PPRC may be appropriate.

Information for Patients

Insurance

After completing the initial evaluation to determine if you are a candidate for the program, you will be scheduled for one of the PPRC sessions, which are offered on a quarterly basis. A representative from Mayo Clinic's Patient Financial Services will contact your insurance carrier, as many health insurance plans require approval prior to admission to the PRC. Patient Financial Services will contact you if full approval for the program cannot be obtained. If the financial representatives are able to determine that insurance will not cover the program, a pre-service deposit will be required prior to entering the program. Questions regarding your benefits or the status of your approval, can be addressed to your insurance carrier, or if you need further assistance, a financial representative is available to speak with you about insurance issues at (507) 284-3980.

Parking

A patient/visitor parking ramp is available on the Saint Marys Hospital campus adjacent to the Generose Building. The daily charge is modest, and weekly passes can be purchased at a discount from the parking attendant. Many hotels and motels provide shuttle bus service to Saint Marys Hospital.

Lodging

Patients make their own arrangements for lodging. A brochure is available at the Pain Rehabilitation Center front desk, or patients can visit the Mayo Clinic lodging website at <http://www.mayoclinic.org/travel-rst/lodging.html> for a list of options in the area. Mayo Clinic staff are available to assist with general questions about accommodations, but arrangements are the responsibility of the patient.

Meals

Meals are not provided as part of the program. Patients are responsible for bringing or purchasing lunch, and an hour will be provided for lunch each day. A hot, cold and vegetarian choice will be available for purchase or patients may also bring their own lunch. The Saint Mary's Hospital patient cafeteria and the Generose Express also have many items available for purchase.

Dress

Clothing should be comfortable and casual, so that it can be worn for exercise and for the more active portions of the day. Due to variable Minnesota weather, many patients choose layered clothing for comfort. Tennis shoes or good walking shoes are recommended.

What to Bring

Patients are asked to bring a personal CD-player for use in their hotel room in the evenings. Relaxation CDs will be provided to use in the evenings. Patients should also arrive at the PRC with all medications taken on a regular basis. A nurse case manager and pharmacist will review medications at this time and make a plan for continued use.

Referrals

Patients who experience chronic pain that adversely affects daily life, mood or functioning are candidates for the Pain Rehabilitation Center programs. Referrals can be made by calling (507) 255-1791.

For more information, please visit our website at
www.mayoclinic.org/pain-rehabilitation-center-rst/



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