Journal of Life Care Planning, Vol. 3, No. 4, (245-258)

Life Care Planning for Pediatric Chronic Pain Patients

Kenneth R. Goldschneider, M.D., F.A.A.P.
Wendy Ohme, M.N., R.N., C.R.R.N., C.L.C.P., C.C.M.

Introduction

The extent of the incidence of chronic pain in children and young adults has only just begun to be appreciated. In adults, the problem is significant, with back pain being one of the leading causes of disability and loss of work time (Spengler, et al., 1986). The problem in the pediatric age group has not been as well defined, but the few population-based studies that have been published suggest that problems such as headaches, abdominal pain, back pain, and extremity pain are very common (Abu-Arafeh, 1996; Borge, 1994; Kristjansdottir, 1997; Salminen, et al., 1995). For example, the prevalence of back pain in the mid-teenage years is almost as high as the prevalence among adults (Burton, et al.,, 1996). Although the etiologies of the pain may be different, the fact that back pain afflicts teenagers almost as often as it does adults seems astonishing.

Most pain is relatively transient and well treated by pediatricians and family practitioners, but chronic pain lasts more than 3 to 6 months. It is often very difficult to treat and beyond the capacity of primary care physicians alone. The pain itself, as well as the ineffectiveness of common treatments, is frustrating for patients and families. Health care providers, in turn, are frustrated by the difficulty of assessing chronic pain and the lack of clearly defined treatment protocols and outcome expectations. This frustration drives extensive and costly workups, which are very often unrevealing and not helpful.

Pain management services for these patients have existed only since the mid- 1980s, and currently fewer than two dozen multidisciplinary treatment clinics exist in the entire United States. Yet, chronic pain is fairly common, and the field of assessment and treatment can be expected to grow. The impact of pain on children is as profound and complex as any similar pain in adults. The personal issues are the same: Pain hurts, it impairs function, it can lead to disability, and it has an impact on family function (Hunfeld, 2002). Depression can coexist or be secondary to the pain. Extensive evaluations and misguided therapies can consume time, energy, and resources. The societal impact of chronic pain in children has not been fully defined, and the long-term ramifications of pain in early life are not yet known. Certainly, pediatric pain treatment seeks to prevent pain and disability from becoming lifelong problems. Early treatment outcomes research is beginning to suggest the impact on family and society

Reprinted with permission from Goldschnieder, K. & Ohme, W. (2004). Life Care Planning for Pediatric Chronic Pain Patients. In S. Riddick-Grisham (Ed.), *Pediatric Life Care Planning and Case Management Handbook* (pp. 577-591), CRC Press, LLC (800/272-7737).

can ultimately be addressed through multidisciplinary treatment programs (Chalkiadis, 2001; Tessman, et al., 2003).

Although worker's compensation is not an issue for children, school absenteeism represents the equivalent disability syndrome, and direct economic effects can be seen when parents miss work to attend physician visits or therapy sessions or stay home with a child who is in too much pain to go to school. At the extreme, we have seen parents who gave up their jobs altogether to be with their child and oversee the evaluation and treatment process. In the absence of experienced and organized treatment and evaluation, the work-up for pain in children can be extensive and costly to both families and third-party payers. Life care planning for these patients should include an organized strategy to help streamline care. Multiple therapies are often required for optimal benefit, and organizing them will help the patient, as well as conserve resources.

The general categories of pain seen in children and young adults are listed in Table 24.1. Headaches are often treated by primary care physicians. Neurologists see the recalcitrant cases or those with unusual presentations. Other pain conditions are often first seen in the primary care physician's office. Failing straightforward therapies, the patient is usually referred to the specialist in the relevant anatomic area. For instance, patients with limb and back pain are often sent to an orthopedic surgeon, and those with abdominal pain to a gastroenterologist. Pains that are refractory to treatments by either primary or secondary care providers or whose etiology is still unclear often find their way to specialized pain clinics. Many times, the referral is made because of suspicion that a psychosocial issue predominates. Unfortunately, this sometimes conveys the impression to the patient and family that the pain is thought to be "in the patient's head", thus creating a stigma that is difficult to erase.

Table 24.1 Non-Cancer, Chronic Pain Conditions in Children

Location	*Etiology*
Multiple	Fibromyalgia, myofascial pain syndromes, neuropathic pain conditions, syndrome-related pain, sickle cell disease
Abdomen	Recurrent abdominal pain/irritable bowel syndrome dysmotility, pan creatitis
Back pain	Low back pain, sciatica, scoliosis, myofascial pain, spondylolysis
Chest	Hyperventilation, cystic fibrosis-related, slipping rib syndrome
Extremity	Complex regional pain syndromes, rheumatologic diseases, post-ampu tation pain (phantom and stump pain), growing pain
Head	Migraine, tension, and rarer headache types, temporomandibular joint pain
Hip	Spasticity-related, avascular necrosis
Pelvis	Endometriosis

In order to help appreciate the aspects of life care planning that are required by pediatric chronic pain patients, the components of a classic multidisciplinary pain clinic are described here. Several adjunct therapies are mentioned, each of which has a role to play in the treatment of various pain conditions. It should be noted that this chapter does not discuss pain that occurs secondary to cancer. Cancer pain and palliative care are broad topics and resource intensive in

nature. For those patients who survive their diseases and have long-term pain issues, the discussion in this chapter is pertinent. For those patients who are not expected to survive, issues of life care planning are greatly modified from being structures designed for long-term chronic illnesses and become related more to death care planning or end-of-life care planning.

Components of a Multidisciplinary Pain Clinic

Physical Therapy

Physical therapy (PT) is a crucial component of both the evaluation and treatment of chronic pain in children. Pain affects the biomechanics and daily function of the body. The way a child walks, sits, or uses an extremity can change due to pain in a particular part of the body. The site of function can lose strength and range of motion. Patients can become deconditioned and require a conditioning program to regain lost stamina and strength. These changes not only affect the original pain site but also generate secondary pain problems that need to be addressed; therefore, pediatric pain clinics focus on function as well as pain. Importantly, some painful conditions benefit as much from PT as from any other therapy. For instance, myofascial pain requires stretching and range of motion exercises to improve. PT is the cornerstone for treating complex regional pain syndrome (CRPS), formerly referred to as reflex sympathetic dystrophy (RSD) (Stanton-Hicks, et al., 1998). The number of treatment sessions required for a particular diagnosis or patient will vary roughly between 2 and 20 sessions to bring patients to the point where they can pursue an independent PT program at home. The emphasis is, and should be, on establishment of a home exercise program. In our clinic, we emphasize self-reliance. The patients are told clearly, "The pain is not your fault, but taking care or your body is your responsibility."

Once established with a regimen at home, patients rarely need to return for a formal visit to their therapist unless their condition changes; however, it is too much to expect young children, or older ones in pain, to work aggressively at home without professional guidance. Often, special equipment is needed that might only be available in the physical therapists' work area. Examples of such equipment include exercise bicycles, parallel bars, weight-training apparatus, hot and cold packs, and ultrasound and electrical stimulation machines.

On occasion, chronic pain clinics will see patients with long-term needs, such as those recovering from severe trauma or who have lifelong conditions such as juvenile rheumatoid arthritis or cerebral palsy. These patients may need long-term PT programs in order to maximize their function as well as comfort.

Therapies provided under the rubric of PT are numerous. Stretching, strengthening, and reconditioning programs are staples of pain therapy. Aquatic therapy is important for those patients who are not weight bearing or have a limited range of motion or strength (Templeton, Booth, & O'Kelly, 1996). Range of motion exercises and endurance training are also important. Massage, heat, and cold therapies are helpful adjuncts to increase functioning and enhance other PT modalities. Transcutaneous electrical nerve stimulation (TENS) is a low-risk analgesic therapy that works by providing nonnoxious stimulation that competes for the "attention" of the spinal cord and reduces the amount of pain sensation the patient feels. TENS units are usually provided under the guidance of a physical therapist and are effective for a number of painful conditions (Rushton, 2002). Most insurance companies cover TENS units, although a trial period is usually followed by either a rental or purchase arrangement. Typical charges are shown in Table 24.2. While many of these therapies require specialized equipment,

those patients who are capable of pursuing a home program are given relevant instruction and support. Occupational and physical therapists can also guide the use of braces, orthotics, shoe inserts, TENS units, and prostheses.

Psychology

Pain is not just physical. It causes stress, suffering, family tension and dysfunction, anxiety, and depression. Pain can disrupt almost any aspect of a child's life. The family is always involved in the child's suffering because of the inherent bonds that start to form even in utero. Family and school problems can worsen a painful condition and dramatically reduce a patient's level of function. Additionally, pathways through the central nervous system function to suppress incoming nociception, and these pathways of descending inhibition can be stimulated by medications or certain psychological interventions. Many times, families recoil at the thought of seeing a psychologist, afraid that the pain is thought to be psychological and not real. We emphasize that pain is what the patient says it is, regardless of whether an obvious organic cause is identified. Suffering is subjective by definition.

Psychologists experienced in pediatric pain management can provide a variety of assessment and therapeutic tools. Patients presenting to clinic are screened for depression, functioning, suicidal risk, coping skills, stressors, family issues, school issues, pain levels, past psychosocial history, and anxiety, among other factors. Usually about six treatment sessions follow the initial evaluation. Treatments are individualized and can include both individual and parent therapies. Relaxation training, biofeedback, coping skills training, and psychotherapy can be useful for the pain patient (Eccleston, 2003). Biofeedback is an interesting and useful modality that trains the patient to become more cognizant of his or her body and to gain a greater measure of control over it. Biofeedback is efficacious for a variety of painful conditions and is easily learned by children and young adults.

Table 24.2 Usual and Customary Fees for Several Common Pain Treatments

	Range of Charge ($)
Procedures	
Lumbar sympathetic catheter	260–400
Epidural catheter, lumbar	460–560
Trigger point injection	85–150
Fluoroscopic guidance	170–240
Intravenous regional blockade	150–190
Epidural steroid injection	460–560
Occipital nerve block	180–220
Epidural blood patch	380–450
Professional Fees	
Physical therapy visit evaluation	100–180
Physical therapy follow-up	100–140
Psychology visit	100–150
Acupuncture, per session	100–150
Physician visit, evaluation	100–340

Physician visit, follow-up	30–125

Equipment

Transcutaneous electrical nerve stimulation (TENS) unit	500–700

Note: Charges do not include medication, anesthesia, nursing, or pharmacy fees. Fees vary by geographical location, amount of medication used, time involved, and arrangements with third-party payers; therefore, they are only rough estimates.

Parents can benefit from coaching and parenting skills. Commonly, parents unwittingly feed into disability behaviors by providing secondary benefits to their child. Such benefits might include increased attention and time with a parent, avoidance of school or other stressful situations, extra presents, or exemption from chores. The parent or other caretaker plays a crucial role in the child's pain condition and its effects on child and family function. Parental therapies include teaching the parent strategies for behavioral interventions such as distraction, and pacing, guiding them in consistent discipline, training them in coaching skills and stress management, and involving them in family therapy.

Pediatric Pain Specialist

The pediatric pain specialist may have training in pediatrics, anesthesia, physiatry, or a combination of specialties; often, they have special training and certification in pain management. The role of the pain physician is to coordinate the evaluation and treatment program for the patient. An extensive evaluation is conducted upon first meeting the patient. During this session, detailed history and physical exams are conducted and background information is reviewed. Often, the patient has seen a number of physicians prior to coming to the clinic and has undergone a number of studies, such as computed tomography (CT), and magnetic resonance imaging (MRI) scans. Physicians look for red flags. These signs or symptoms of serious illness can include fever, weight loss, and neurological dysfunction, among others. For instance, a patient with back pain who also has signs of leg weakness or bladder dysfunction may have a tethered spinal cord. Once identified, surgery is usually required, and time should not be wasted on general efforts until the underlying condition is addressed.

Most of the time, no such red flags are found, and efforts are made to demedicalize the process. Often families are worried that something is being missed and insist that more studies be done. In this litigious era, physicians may pursue more testing than might be indicated strictly on medical grounds out of concern of being sued by such insistent families; however, pursuing unneeded tests not only uses resources but also diverts attention from treatment and potentially can delay recovery.

The number of pediatric pain specialists is limited, so most pediatric pain conditions are seen and treated by primary physicians. It is reasonable to expect that several visits will be necessary and some basic testing will be conducted. For example, back pain that radiates into the legs warrants a CT scan or MRI of the lumbar spine to rule out a bulging disc. Pain on extension might warrant spine x-rays to rule out spondylolysis or spondylolisthesis. Chronic headaches rarely warrant extensive testing unless symptoms are atypical or a red flag is raised. Patients who are non-verbal (e.g., due to severe mental retardation, cerebral palsy, or young age) may require more testing than average due to an inability to communicate their symptoms

with precision or at all. Areas of the country where resources are not centralized pose a particular planning problem. Several false starts into therapy can be expected if the primary physician does not have physical therapy, psychology, or other therapeutic options readily available.

Medical Interventions

The types of medications used for pain in children vary greatly. Opioids are not often used, unless there is a specific indication for them, such as a long-term illness (e.g.. juvenile rheumatoid arthritis, lupus). We find muscle relaxants can be useful for myofascial pain. Tricyclic antidepressants are helpful for a variety of painful conditions and aid disturbed sleep as well (Kingery, 1997; McQuay, 1996). The newer antidepressants are useful when depression *per se* is a major problem. Anticonvulsants are useful for neuropathic pain, such as nerve injury or CRPS/RSD (Backonja, 2002). The newer ones are obviously more expensive but generally have fewer side effects or interactions with other medications than do older anticonvulsants. Non-steroidal antiinflammatory drugs (NSAIDs) are widely used both for their analgesic and antiinflammatory properties. Some migration to the use of the newer COX-2 inhibitors has occurred, as they have fewer side effects than the older NSAIDs, although they are generally more expensive (Peura, 2002). Recent articles suggest that the COX-2 inhibitors are more cost effective than older NSAIDs, especially when they are paired with agents designed to protect the gastrointestinal tract from damage from the NSAIDs themselves (Chancwellor, et al., 2001; McMurry & Hardy, 2002).

Injection therapies abound in adult pain treatment, but much less so in pediatric pain management because of differences in the causes of pain and the lower tolerance children have for being stuck with needles. Certain pain conditions, however, do require invasive therapy in order to maximize benefit. When a child requires such a therapy but cannot tolerate being injected, they need to be anesthetized. This obviously incurs greater expense and risk but is sometimes the only way to provide the child with the needed therapy. A good example is refractory CRPS/RSD. If the patient is not making progress with conservative therapy, then a sympathetic blockade is indicated (Stanton Hicks et al., 1998; Wilder et al., 1992). In adults, usually a series of injections into regions of the sympathetic nervous system would be performed. A child would almost never tolerate even a single injection, much less a series; therefore, a catheter (e.g., epidural or in the lumbar sympathetic region) is placed while the child is anesthetized. The patient is then admitted to the hospital for intensive therapy under the comfort of the catheter-guided infusion. The overall risks are reduced by having a single anesthetic and a single catheter placement, but benefits are offset by the costs of hospitalization. Fortunately, the results of intensive therapy such as this are usually quite good and may result in lower outpatient fees.

Other injection therapies include epidural steroid injection for herniated vertebral disks and trigger point injections for myofascial pain. The former procedure can be done under anesthesia for younger and/or developmentally delayed patients, whereas the second does not warrant the risk and expense. Herniated disks are not common in children, so only a limited number of these procedures are performed in pediatric pain clinics. Implanted devices such as spinal cord stimulators are rarely, if ever, indicated for pediatric patients who have non-cancer pain.

Adjunct Therapy

A number of non-traditional therapies can benefit individual patients. Massage, chiroprac-

tic, acupuncture, and hypnosis are a few of the modalities that patients may find helpful in managing their pain. Most are relatively short-term interventions, although several sessions are usually required to realize a benefit. Our clinic encourages a holistic approach to pain care but emphasizes that whatever the adjunct therapy chosen, it should serve the goals of independence and self-care.

Case Examples

Two case presentations follow. The first, back pain, profiles a fairly common problem. Back pain is the most common single reason for referral to the Chronic Pain Clinic at Cincinnati Children's Hospital Medical Center. It would be instructive to examine a typical scenario and clinical pathway for such a patient. Costs and effects on familial, social, and economic function will be highlighted. The clinical pathways for low back pain (with and without sciatica) are shown in Table 24.3. CRPS type I (formerly reflex sympathetic dystrophy) will be used to illustrate a more complex care path. Between the two entities, the reader should come away with a good feel for the levels of planning required for a range of pediatric pain problems.

Amy

Amy was a 15-year-old young lady with a 1-year history of low back pain. It was made worse by prolonged standing, sitting at a desk at school for long periods of time, and by stress. No radiating pains or signs of systemic illness were observed. No obvious trauma was noted. Amy had missed 22 days of school at the midpoint of the year, but her grades were only slightly worse than her usual. She no longer participated in cheerleading but would occasionally go out shopping with friends. Her mood had been sad, and she did not sleep well many nights. Her parents were divorced. X-rays and a spinal MRI were normal. A physical exam revealed a tender lumbar paraspinous region, with muscle banding and limitation in range of motion. The rest of the exam was normal.

Amy's treatment plan followed the outline presented in Table 24.3. She required roughly six sessions of physical therapy, with return visits required in the event of future flare-ups. She needed either basic exercise and stretching equipment at home or access to local facilities (e.g., YMCA, gym) for such equipment. Aquatic therapy at a local pool facility could have been useful, depending on her tolerance for other types of exercise. A TENS unit was helpful, and she used it daily until her pain was better controlled and then used it as needed going forward. She had six sessions of muscle relaxation biofeedback and relaxation skill training. If other psychosocial issues had been identified that exacerbated her pain, further visits would have had to be scheduled. Finding such hidden issues is not unusual, and treating them is important to obtaining maximal therapeutic benefit. She was started on cyclobenzaprine at night for muscle relaxation and to aid sleep. Analgesics such as ibuprofen were used to help relieve pain. If a history of ulcers, gastroesophageal reflux, or bleeding disorder had been present, a COX-2 inhibitor would have been used. If the psychologist had found that depression and anxiety were primary problems and not secondary to the pain, then the pain physician may have prescribed an antidepressant of the selective serotonin reuptake inhibitor class.

Approximately two to four follow-up visits to the pain physician were planned for the year that followed, with the number depending on how well she did and how long she needed to remain on medication. She did not need a brace or injection therapy. Chiropractic intervention,

massage, or acupuncture could possibly have been useful. She was cautioned that these are passive therapies and are only adjuncts. Again, the goal of self-care and empowerment was stressed. Over a couple of months, Amy's prognosis was fairly good, but flares of pain were expected to occur in the future, and it was expected that she would need to revisit her care team to gain control over her pain. Fortunately, recurrences of pain are usually shorter lived and easier to control than the primary event. Finally, education and communication of family members and school workers were important to help maximize her function and reduce her stress level as she returned to normal functioning.

Table 24.3 Clinical Pathway for Low Back Pain

Initial Evaluation
Physician
Psychology
Physical therapy
Review all records, treatments, history, physical findings, labs, radiographs

Treatment of Low Back Pain without Sciatica
Medications
- Tricyclic antidepressants
- Muscle relaxants (e.g., cyclobenzaprine, baclofen)
- Non-steroidal anti-inflammatory (NSAID) of choice
- Cyclo-oxygenase, type 2 (COX-2) inhibitor, if indicated
- Trigger point injections

Behavioral medications
- Biofeedback, coping skills, and relaxation techniques

Physical therapy
- Back care program: postural rehabilitation, general reconditioning, lifting techniques, stretching
- Transcutaneous electrical nerve stimulation (TENS)
- Exercise program
- Home program

Other
- Acupuncture, chiropractic, massage, yoga, aquatic

Treatment of Low Back Pain, Including Sciatica (Confirmed by CT/MRI)
Medications
- Epidural steroid series, up to three injections spaced at 2- to 3-week intervals (may require sedation or anesthesia)
- NSAID of choice
- COX-2 inhibitors if gastrointestinal/bleeding indications
- Muscle relaxant as indicated (baclofen or cyclobenzaprine)
- Neuropathic medications, tricyclic antidepressants, gabapentin, etc.

Behavioral medicine
- Biofeedback, coping skills, and relaxation techniques

Physical therapy
- Stretching, back care program: postural rehab, general reconditioning, lifting techniques, home program

It should be noted that future injuries or changes in body biomechanics may occur with time and the aging process. These events are wild cards in the long-term follow-up period after treatment is initiated. Reassessment is important, and changes in the treatment plan may be indicated by new data gained over time. Transition to an adult pain clinic, on occasion, will be required for long-term pain problems.

Cost analyses for these patients are complex, as is true for patients with any chronic condition. Table 24.4 illustrates the components of a cost analysis for our example. The exact cost of each component will vary from location to location and so is not listed in dollar terms. This example presumes that Amy recovered over the period of a year, although this is a simplification. Home equipment and maintenance therapies (e.g., stretching and fitness programs) can be presumed to be lifelong, assuming proper compliance on the part of the patient.

Zoe

Zoe presented to her doctors with a 2-month history of pain in her left ankle and foot. It started after she twisted her ankle during gymnastics practice. It hurt to touch, turned blue, was swollen at times, and felt very cold. She slept poorly, because every time the blanket touched her leg, the pain woke her. The discoloration rose to the level of her knee, and the pain was like a sock around her foot and ankle. She was a good student and had not missed much school. On first assessment, no overt psychosocial issues were noted. She had tried several over-the-counter medications that had not relieved her pain. She had spent two weeks in a splint and felt worse when it came off. X-rays were negative. Her doctor ordered a bone scan and an MRI. Some blood work was done but did not show anything. On exam, her leg was mottled, cool to touch, swollen, slightly sweaty, and allodynic (light touch was painful), and she had trouble moving it. The rest of her exam was unremarkable. The diagnosis of CRPS type I was made.

Zoe followed the outpatient treatment program delineated in Table 24.5. After educating the parents and patient about CRPS I, a multidisciplinary program was started. The MRI and bone scan were cancelled. (CRPS I is a clinical diagnosis, and these tests are useful only if other potential diagnoses cloud the picture; otherwise, they are costly and only delay treatment.) Zoe was placed on medications (e.g., gabapentin and amitriptyline) for help with pain and sleep. She participated in physical therapy twice a week for several weeks, then gradually reduced the frequency of her appointments as she got better. She had a home regimen, with which her parents helped. The psychologist saw her six times for relaxation and coping skills training. If things had gone well, she would have completed her therapy successfully in 4 to 8 weeks.

Table 24.4 Cost Components of Pediatric Pain Evaluation and Treatment for Back Pain

	Physician (no. of visits)	*Physical Therapist (no. of visits)*	*Psychologist (no. of visits)*
Evaluation visits	1	1	1
Follow-up visits	2–4	4–10	6
	Muscle Relaxant (months)	*Analgesic (months)*	*Antidepressant (months)*
Medications	1–3	1–3	3–12

Equipment	Transcutaneous electrical nerve stimulation (TENS), home fitness equipment, local gym/pool membership
Adjunct therapies	Chiropractic, acupuncture, massage, aquatic therapy, yoga

Zoe did not do well. She had too much pain to perform the physical therapy, and after 2 or 3 weeks she was no better; in fact, she thought she was worse. The psychologist uncovered the fact that her parents were having marital difficulties, and Zoe felt trapped in the middle with her siblings. The patient agreed to have an intravenous regional blockade done under anesthesia (it is too painful to be done awake) as an outpatient surgical procedure. This procedure involved infusing a combination of medications into a vein in the affected limb and allowing the medicines to soak into the tissues directly. Although this works for other patients, Zoe did not benefit. The revised treatment plan then followed the inpatient structure shown in Table 24.5.

Zoe was admitted to the hospital. Under anesthesia, a lumbar sympathetic blockade (LSB) catheter was placed along her lumbar spine with fluoroscopic guidance. An epidural catheter was placed simultaneously. When Zoe awoke, an infusion of local anesthetic was run through the LSB catheter, which relieved her pain. Her foot became warm, and it did not hurt to touch. The epidural catheter was capped off, dressed in sterile fashion, and held in reserve, in case the LSB catheter pulled out. (This can easily happen and having the epidural already in place saved her another anesthetic and trip to the operating suite.) An intensive physical therapy program was begun, with structured sessions twice a day. She was limited to half an hour of television per day. She could only be in bed to sleep at night. School sessions were built into the daily schedule, and the psychologist worked with her 3 times a week. After 5 days, the infusion was discontinued, and she continued to feel well, with no pain or swelling. She was discharged from the hospital, followed-up with physical therapy and psychology weekly for a few weeks, and met a couple of times with the pain physician. She was weaned from the medication over a few months and discharged from the clinic.

In this case example, the patient did well. Even so, she was at risk for relapses and could require resumption of therapies for brief times in the future. For some patients, CRPS I is refractory to even maximal treatment, and long-term therapy will be needed. Table 24.6 illustrates the cost components for CRPS I evaluation and treatment for the whole range of therapeutic involvement.

Table 24.5 Clinical Pathway for Complex Regional Pain Syndrome, Type I

Initial Evaluation
Physician
Psychology
Physical therapy
Review all records, treatments, history, physical findings, labs, radiographs
Outpatient Treatment Program
Education
    Limit unnecessary testing
Medications
    Tricyclic antidepressants
    Anticonvulsants
    α-Adrenergic antagonists

Adjunct medications (e.g., tizanidine, non-steroidal anti-inflammatories)
Behavioral medications
Biofeedback, coping skills, and relaxation techniques
Physical therapy
Desensitization, range of motion, strength, contrast baths, strength
Transcutaneous electrical nerve stimulation (TENS)
Home program

Inpatient Treatment Program
Admit to hospital
Structured program, with daily schedule posted in patient's room
Lumbar sympathetic blockade (LSB) and epidural catheters placed under anesthesia, with x-ray guidance
Infusion of local anesthetic through LSB catheter
Epidural if LSB catheter ceases to function
Intensive physical therapy program
Psychology (three times a week or as indicated)
Continuation of outpatient medications
Evaluation after 5 to 7 days
If symptoms have resolved, discharge to home on medications and schedule follow-up visits for all disciplines
If symptoms have not resolved, continue therapy and re-evaluate every few days
Discharge — if better, follow up with all disciplines; if not better, arrange after-care conference

The examples given here outline the basic multidisciplinary approach to pain care in pediatric patients. The complexity of the treatment plans will vary greatly. Some conditions require reassurance and a short course of physical therapy. Other conditions require invasive treatments, extensive behavioral interventions, and/or prolonged physical therapy. Patients are referred to pain clinics because either the pain condition is too complex for primary caretakers to treat or are refractory to standards treatments. Short-changing the multidisciplinary plan defeats the purpose of such clinics and reduces the chances of success to those of the simple strategies that failed in the first place. As data are collected, it is becoming clearer that investment in the sometimes complex treatment pathways results in overall clinical benefit and increased productivity for both patient and parent.

Table 24.6 Cost Components of Pediatric Pain Evaluation and Treatment (Complex Regional Pain Syndrome, Type I)

	Outpatient Plan		
	Physician (no. of visits)	*Physical Therapist (no. of visits)*	*Psychologist (no. of visits)*
Evaluation visits	1	1	1
Follow-up visits	2–4	8–20	6
	Anticonvulsant (months)	*Antidepressant (months)*	*Other (months)*

Medications	1–3	3–12	—
Special	Intravenous regional blockade (outpatient surgery, 45 minutes of operating room time, medications, anesthesia charges, physician charges, recovery room)		
Equipment	Transcutaneous electrical nerve stimulation (TENS), home fitness equipment, fleece and other tactile stimuli, local gym/pool membership		

Inpatient Plan (5 to 14 days)

Medications	As above		
Hospital services	Hospital room charges, nursing, food, nursing, in-hospital school/tutor		
Special	Lumbar sympathetic blockade (LSB) and epidural catheters (1/2- to 1-hour operating room time, fluoroscopy charges, anesthesia and pharmacy charges, catheter kits, physician charges), infusion (similar to an epidural infusion run post-operatively)		
	Physician	*Physical Therapist*	*Psychologist*
Frequency of visits	Daily	Twice daily	3 times per week

Conclusion

Chronic pain in children has become increasingly recognized as a widespread problem. Multidisciplinary treatment centers are more common than 10 years ago but still lag behind clinical need. Out of necessity, treatment plans can be enacted or supervised by primary care physicians, if they have knowledge of such treatments and the proper resources available to them. As with adults, maximizing function and comfort are the goals of therapy. The pain can not always be made to go away, although this is the optimal goal. With proper treatment, patients can learn to raise their level of function to one that allows the most enjoyment out of life, with the greatest chances for reaching their potential for school, work, personal growth, and productivity. In pediatric pain care, helping the parents to resume their productive lives and the family to function normally are important secondary goals. Another difference from adult pain treatment is in the outcome period. The plan of care for pediatric pain patients must account for the next 50 to 70 years of growth, productivity, and personal fulfillment. Not enough time has elapsed since treatment programs were established to know the long-term effects of treatment; however, we certainly see the short-term effects of diminished pain, increased school attendance, normalized family dynamics, and better controlled depression and anxiety. The investment of pediatric pain treatment, therefore, is not large, given the long list of benefits and the prolonged period over which returns on investment can be seen. As the field of pediatric pain management grows, more detailed and accurate care plans will be created that will allow for more precise life care planning. For now, reasonable estimates can be made, allowing for changes in needs based on reassessment over time.

References

Abu-Arafeh, I. & Russell, G. (1996). Recurrent limb pain in school children. Archives of *Disease in Childhood*, 74, 336–339.

Attansio, V., Andrasik, F., & Burke, E. (1985). Clinical issues in utilizing biofeedback in children. *Clinical Biofeedback and Health*, 8, 134–141.

Backonja, M. (2002). Use of anticonvulsants for treatment of neuropathic pain, *Neurology*, 59, S14–S17.

Borge, A.I., et al. (1994). Prevalence and persistence of stomach ache and headache among children: Follow-up of a cohort of Norwegian children from 4 to 10 years of age. *Acta Paediatrica*, 83, 433–437.

Burton, A.K., et al. (1996). The natural history of low back pain in adolescents. *Spine*, 21, 2323–2328.

Chalkiadis, G.A. (2001). Management of chronic pain in children [comment]. *Medical Journal of Australia*, 175, 476–479.

Chancellor, J.V., et al. (2001). Economic evaluation of celecoxib, a new cyclo-oxygenase 2 specific inhibitor, in Switzerland. *Pharmacoeconomics*, 19 (suppl. 1), 59–75.

Eccleston, C., et al. (2003). Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews*, CD003968.

Hunfeld, JA., et al. (2002). Stability of pain parameters and pain-related quality of life in adolescents with persistent pain: A three-year follow-up. *Clinical Journal of Pain*, 18, 99–106.

Kingery, W.S. (1997). A critical review of controlled clinical trials for peripheral neuropathic pain and complex regional pain syndromes. *Pain* , 73, 123–139.

Kristjansdottir, G. (1997). Prevalence of pain combinations and overall pain: A study of headache, stomach pain and back pain among school children. *Scandinavian Journal of Social Medicine*, 25, 58–63.

McMurray, R.W. & Hardy, K.J. (2002). Cox-2 inhibitors: Today and tomorrow. American *Journal of the Medical Sciences*, 323, 181–189.

McQuay, H.J. (1996). A systematic review of antidepressants in neuropathic pain [see comments]. *Pain*, 68, 217–227.

Peura, D.A. (2002). Gastrointestinal safety and tolerability of nonselective nonsteroidal antiinflammatory agents and cyclooxygenase-2-selective inhibitors. *Cleveland Clinic Journal of Medicine*, 69(suppl. 1), S131–S139.

Rushton, D.N. (2002). Electrical stimulation in the treatment of pain. *Disability and Rehabilitation*, 24, 407–415.

Spengler, D.M., et al. (1986). Back injuries in industry: A retrospective study. I. Overview and cost analysis. *Spine*, 11, 241–245.

Salminen, J.J., et al. (1995). Low back pain in the young: A prospective three-year follow-up study of subjects with and without low back pain. *Spine*, 20, 2101–2107 (discussion, 2108).

Stanton-Hicks, M., et al. (1998). Complex regional pain syndromes: Guidelines for therapy [review with 74 refs.]. *Clinical Journal of Pain*, 14, 155–166.

Templeton, M.S., Booth, D.L., & O'Kelly, W.D. (1996). Effects of aquatic therapy on joint flexibility and functional ability in subjects with rheumatic disease. *Journal of Orthopaedic and Sports Physical Therapy*, 23, 376–381.

Tessman, C., et al. (2003). Changes in healthcare utilization after treatment in a pediatric chronic pain program [abstract]. *Journal of Pain*, 4, 31.

Wilder, R.T., et al. (1992). Reflex dystrophy in children: Clinical characteristics and follow-up of seventy patients. *Journal of Bone and Joint Surgery*, 74A, 910–919.

About the Authors

Kenneth R. Goldschneider, M.D., F.A.A.P., is Associate Professor of Anesthesia and Pediatrics and Director of the Division of Pain Management at the Cincinnati Children's Hospital Medical Center (CCHMC). He coordinates the acute pain service for inpatients who have medical and surgical sources of pain. In addition, he directs the multidisciplinary outpatient clinic for children and young adults who have chronic pain. He is also involved in providing pain care for CCHMC's Starshine hospice program for children. Dr. Goldschneider conducts research on treatment outcomes for chronic pediatric pain, as well as on the aspects of acute pain treatment. He makes frequent presentations at regional and national meetings related to pediatric anesthesia and pain management.

Wendy Ohme, M.N., R.N., C.R.R.N., C.L.C.P., C.C.M. is certified in rehabilitation nursing, life care planning, and case management. Her practice, in Spokane, Washington, specializes in life care planning and case management, and forensic consultation. She is licensed to practice nursing in the states of Washington, Idaho, Oregon, Montana, and Alaska and holds adjunct faculty position at the Intercollegiate College of Nursing in Spokane. Ms. Ohme has provided direct patient care, taught at both the associate and bachelor of science nursing programs, and owned a Medicare-certified home health agency that provided skilled intermittent visits, private duty services, and infusion therapies.