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Protocol to Enhance Psychosocial Treatment Intervention for Clients with Reflex Sympathetic Dystrophy

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Protocol to Enhance Psychosocial Treatment Intervention for Clients with
Reflex Sympathetic Dystrophy

by

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Scholarly Project

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CHAPTER I

INTRODUCTION

Reflex Sympathetic Dystrophy (RSD) is a chronic condition characterized by burning pain and abnormalities in the sensory, motor, and autonomic nervous systems (Duffy, 1998). The prevalence of RSD has been estimated between 500,000 and six million cases at any given time within the United States (Hendler, 2000). Mild cases may resolve with no treatment and other cases may progress through various stages and become chronic, often displaying debilitating side effects (Duffy).

RSD is a painful disorder that can affect a person's ability to function in his or her daily life. Psychosocial aspects are often overlooked and not properly addressed during treatment of RSD. Frequently, the client's, their families and healthcare professionals poorly understand the psychosocial aspects involved with RSD. The goal of this scholarly project was to investigate the psychosocial features of RSD and develop a specialized treatment protocol focusing on these aspects using Cognitive-Behavioral Therapy.

Cognitive-behavioral therapy is an action-oriented form of psychosocial intervention that assumes maladaptive thinking patterns cause maladaptive behavior and "negative emotions". The treatment focuses on changing an individual's thoughts in order to change his or her behavior. It is a recommended treatment option for a number of disorders, including chronic pain disorders (Bruce & Borg, 2002). Cognitive-behavioral strategies for pain management may be implemented to reduce pain and improve function and overall quality of life by occupational therapists. Occupational therapists have a common commitment to person-centered care, the

promotion of health and well-being, and the prevention of long-term disability resulting from pain (Bruce & Borg, 2002).

Skilled occupational therapy services provide a holistic view and work with a variety of healthcare professions to meet the needs of those with RSD by addressing both the physical and psychosocial areas of concern. The combination of addressing the psychosocial aspects with an aggressive multidisciplinary rehabilitation focus will allow the patients to maximize their function in activities of daily living at home, work and in their social environments.

CHAPTER II

REVIEW OF LITERATURE

Reflex Sympathetic Dystrophy (RSD) is a dynamic and progressive illness and to date, more than 6 million people have RSD (Duffy, 1998). Although the exact incidence of new cases is unknown, estimates have ranged from 100,000 up to a million new cases a year. The prevalence of RSD has been estimated between 500,000 and six million cases at any given time within the United States (Hendler, 2000). RSD is a perplexing condition that has been relatively ignored by the medical community. Perhaps RSD is such a perplexing condition because of its wide range of definition and confusing names.

RSD Defined

Within the medical community, there is no precise definition of what constitutes the disorder of RSD. The Reflex Sympathetic Dystrophy Syndrome Association of America defines RSD as, “a multi-symptom, multi-system, syndrome usually affecting one or more extremities, but may affect virtually any part of the body” (Kirkpatrick, 1992, para.1). In 1864, nearly 125 years ago, surgeons Mitchell, Moorehouse and Kean first described the phenomenon of RSD. They noted a particular pain syndrome that developed in the hands and feet of wounded soldiers who filled their boots with water and wrapped their affected limbs with wet rags to ‘extinguish the fire’ (Duffy, 1998). In 1867, Dr. Mitchell named this condition Causalgia, from the Greek word *kausos* (heat) and *algos* (pain) (Levin, 1991).

The International Association for the Study of Pain in 1994 decided that Causalgia and RSD differed enough to be split into two disorders renaming RSD as Complex Regional Pain Syndrome Type I and Causalgia to Complex Regional Pain Syndrome Type II. The difference between these two conditions is that there is a definable nerve injury present in Complex Regional Pain Syndrome Type II (Simmons, 1998). Subsequently, RSD has been given more than 13 different names. A short list of other labels associated with RSD include: Sympathetically Mediated Pain Syndrome, Algodystrophy, Algodynia, Sudek's Atrophy, Shoulder-hand Syndrome and Neurovascular Dystrophy Syndrome (Werner, 2003). These terms will be phased in over the next few years. The term Reflex Sympathetic Dystrophy was coined to emphasize the complex interaction of somatic, psychological and behavioral factors and the regional distribution of symptoms. The International Association for the Study of Pain has recently attempted to develop criteria to improve the diagnosis of CRPS; however, these have not been fully validated and need further work (Simmons, 1998). The recent name change has had an adverse effect on patients making it more difficult for them to apply for Social Security disability benefits. At the current time, Reflex Sympathetic Dystrophy is the term more widely used in the literature and recognized by clinicians (Turner-Stokes, 2002), based on this, the term RSD will be used for this project. More than a century after its initial recognition as a disease, RSD is still poorly understood and often confusing.

Cause of RSD

Reflex Sympathetic Dystrophy is often initiated by major or minor trauma and may follow central nervous system damage such as stroke, tumor, or syrinx (Duffy, 1998). Approximately 95% of cases have some history of trauma or surgery (Turner-Stokes, 2002). The cause of RSD can range from accidentally striking the hand against the wall, to wearing tight nursing shoes, to twisting an ankle. Minor traumas, such as a sprain, dislocation, fracture, crush injury, contusions, cuts, pricks of the fingers or toes, casting of a limb etc., have also been known to cause RSD. RSD can follow other injuries such as iatronic injury (injury caused by a medical problem), some micro or macro trauma associated with certain occupations (such as repetitive movement disorder) and diseases such as myocardial infarction and neuralgic disorders (Hendler, 2000). A significant number of RSD cases resulted from the insertion of a needle into the median nerve while trying to set up an IV (Schaffer, 1991). There is little relationship between the severity of the condition and the original insult.

Symptoms

Reflex Sympathetic Dystrophy commonly involves one extremity; however, approximately 25% of all cases occur bilaterally (Galer, 2002). RSD is composed of five major features: pain, swelling, autonomic dysregulation, movement disorders and atrophy and dystrophy (Schwartzman & Popescu, 2002). The pain and symptoms of RSD may exceed both the magnitude and duration of symptoms expected from the normal healing process. Initially, RSD symptoms are generally localized to the site of injury; however, as time progresses, the pain and symptoms tend to become more

diffuse. Symptoms are classified as ranging from minor to severe (Schwartzman & Popescu).

The hallmark symptom of RSD is pain and mobility impairment. The first and primary complaint occurring in one or more extremities is described as severe, constant, burning and/or deep aching pain. There may also be spontaneous sharp jabs of pain in the affected region (Kirkpatrick, 1992). Patients with RSD have difficulty with experiencing pain upon moving.

Pitting or hard (brawny) edema is usually diffuse and localized to the painful and tender region. If the edema occurs sharply on the surface of the skin along a line, it is almost considered definite that the patient has RSD (Hord & Oaklander, 2003; Kirkpatrick, 1992). In addition, patients describe difficulty in initiating movement as though they have 'stiff' joints.

Skin changes may occur as well including shiny, dry or scaly skin. Hair may initially grow coarse and then thin. Nails in the affected extremity may be more brittle, grow faster and then slower. Faster growing nails is a common symptom associated with the illness and is often part of the differential diagnosis of RSD (Hord & Oaklander, 2003; Kirkpatrick, 1992).

Stages of RSD

Reflex Sympathetic Dystrophy may present in three stages. Stage I and II symptoms begin to appear within a year and in some cases, patients may not progress to Stage III. Furthermore, some of the early symptoms may fade as the disease progresses to Stage III (Kirkpatrick, 1992). Stage I, or the acute stage, lasts one to three months. Symptoms usually begin within days, weeks or even hours of the

incident. Stage I is characterized by severe and constant burning or aching pain at the injury site. There may be muscle spasms and limited mobility and often vasospasm is noted. The skin becomes red, warm and dry but may change to cold, cyanotic and sweaty (Kirkpatrick). It is important to note that RSD is most curable at this stage, so early diagnosis and treatment is critical (Miller, 2003).

Stage II or the dystrophic stage usually lasts three to six months and the pain becomes more diffuse and severe and is characterized by continuous burning. Swelling increases and atrophy begins to take place. The skin is shiny, nails are brittle and there is increased thickness in joints and more muscle wasting (Miller, 2003). It is important to remember at this point that all symptoms may not be seen with every patient and each stage may not be accompanied by all of the defined symptoms.

The last stage, Stage III or the atrophic stage, is characterized by marked tissue changes. The skin becomes smooth and glossy and the muscles become weak, have limited motion, and start to atrophy. Contractures of flexor tendons often develop at this stage as well. Pain becomes severe and spreads to the entire limb. The spread of RSD does not normally occur in most Stage III patients, but it may spread to involve the entire body. “Approximately 4% of RSD patients at the Stage III level will have RSD throughout their body,” (Schwartzman & Popescu, 2002, p. 167).

Over the last few years, the staging of RSD is a concept that has begun to lose favor. Current trends in the literature are beginning to move away from describing RSD in three different stages and are beginning to focus on a typical

progression analysis of the disease. However, when treating RSD, it is important to note what stage the individual is in as well as the progression rate of the disorder.

Therefore, the stages of RSD have been described to assist in the treatment process.

Mechanism of RSD

Kirkpatrick (1992) describes the process triggering RSD as the activation of the sympathetic nervous system following an injury as part of a fight or flight response to an emergency situation. This response is very important for survival. Ordinarily, the sympathetic nervous system shuts down within minutes to hours after an injury. For reasons not clearly understood, in individuals who develop RSD, the sympathetic nervous system appears to assume an abnormal function. Theoretically, this sympathetic activity at the site of injury could cause an inflammatory response causing blood vessels to spasm leading to more swelling and pain. The events could lead to more pain, which triggers another response, establishing a cycle of pain (Kirkpatrick).

Some predisposing factors have been reported in association with RSD. Patients with industrial injuries have a higher rate of RSD for procedures such as arthroscopy and one particular study reported high frequencies where 'worker's compensation' insurance was involved (Finsterbush, Frankl, & Mann, 1991). There is a strong association with inactivity (including jobless persons and bankrupt self-employed people). Patients with RSD report more significant life events in the year preceding onset, such as death or divorce (Rauis, 1999).

Diagnosis

Since the diagnostic criteria for RSD can vary according to different medical professions, it can be difficult to reach a conclusive diagnosis in the early stages of the disease. This can potentially create a problem since the long-term outlook for patients with this disorder is significantly better if he/she can begin treatment early before the disease progresses. The initial diagnosis relies on the presence of clinical features appropriate to the progression of the condition (Turner-Stokes, 2002).

Diagnosis can be confirmed with thermography, a test that measures blood flow and localized heat in the body, and X-rays or bone scans may be used to look for signs of osteoporosis at the site of injury (Werner, 2003). Magnetic Resonance Angiography (MRI) has more recently gained recognition in diagnosis, especially where radiology is contra-indicated (Turner-Stokes, 2002).

Treatment Options

Some patients may spontaneously recover from RSD although this is rare. There are many treatment options available for patients diagnosed with RSD; however, choosing the best treatment for a patient can be difficult. The single most important modality for treating patients with RSD is education (Kirkpatrick, 1992). The informed consent process should be the focus of education with the physician defining potential benefits, risks, alternatives and costs. From the beginning, goals must be defined and accepted by the patient (Kirkpatrick).

A randomized, controlled study demonstrated that physical and occupational therapies reduced pain and improved active mobility in patients with recent onset of RSD (Oerlemans, Oostendorp, & Goris, 1999). Acupuncture and transcutaneous

electrical stimulation (TENS) are another treatment option; however, currently there are no convincing data supporting acupuncture in the treatment of RSD (Turner-Stokes, 2002). TENS has been found to be effective in 50% to 90% of pediatric patients with RSD (Hord & Oaklander, 2003). Of the treatment approaches available, rehabilitation is more likely to have fewer negative consequences than other treatment approaches (Stanton-Hicks, Baron, Boas, & Gordh, 1998).

There is a large list of pharmacological treatment that can be prescribed for patients with RSD. Medications are available for the early stages of RSD and the later, more complex, stages of RSD. Medications range from opioid drugs to topical treatment options (Hord & Oaklander, 2003). When choosing which medication would work best, it is important for the physician to consider the individual's symptoms and severity of the condition.

Treatment procedures used to intervene with RSD include local anesthetic blockade of sympathetic and somatic innervation and the use of an indwelling intrathecal and subcutaneous pump. The local anesthetic block provides temporary relief of pain to facilitate physical or occupational therapy. In a study conducted by Cepeda and Carr (2002), 1144 patients were evaluated on the effectiveness of the blockades. Results showed that 29% of patients had full response, 41% had partial response, and 32% showed no improvement in their pain. The subcutaneous pump was developed to improve the therapeutic ratio of medications by administering a higher concentration of medication near the spinal chord and less in the brain. The two most common medications that are used include morphine and baclofen (Hord & Oaklander, 2003).

Neurosurgical treatment procedures are the last resort in treating individuals with RSD. Patients who experience RSD symptoms soon after trauma may benefit from decompression of a compromised neural structure. Neurosurgical procedures provide pain relief that can exceed that obtained from medical treatment.

Neurosurgical procedures should only be considered when more conservative treatments fail (Thimineur & Saberski, 1996). Electrical stimulation of the dorsal columns of the spinal chord is another surgical intervention; it is minimally invasive and may temporarily relieve pain (Hord & Oaklander, 2003).

Psychosocial Aspects & Pain

While a variety of treatment options are available to treat physical symptoms, treatment of the psychological issues involved with RSD is rarely addressed. Patients with RSD frequently experience a complex and convoluted journey through their recovery stages. These patients may have significant financial, psychosocial, and environmental constraints secondary to their disability. Psychological and psychosocial issues can coexist in patients with RSD. For example, an individual may have classical symptoms associated with RSD and have a psychosocial disorder, such as depression.

According to the American Psychiatric Association in the Diagnostic and Statistical Manual for Mental Disorders Text Revision (2000), the category of “psychological factors affecting medical condition” can be used to describe disorders that have been referred to as psychosomatic or psychophysiologic. Common problems for patients having chronic pain disorders, such as RSD, are suppression of emotional expression and internalization of feelings (Aronoff & Livengood, 2003).

Patients, more often than not, will hide their feelings of pain and frustration, which may lead to the development of a psychological disorder, such as depression. In chronic pain syndromes such as RSD, there is often a complex interaction between physical and psychological factors. Aronoff and Livengood describe common characteristics of patients with chronic pain:

- Preoccupation with pain
- Feelings of isolation and loneliness
- Passivity
- Lack of insight into patterns of self-defeating behavior
- Inability to deal with anger and hostility
- Use of pain as a symbolic means of communication

Turner-Stokes (2002) also supports this finding by explaining that positive associations of these characteristics are notable in patients having RSD. This author goes on to explain that RSD is frequently reported in association with an exaggeration of the patient's disability and a preoccupation with pain.

Defined by the International Association for the Study of Pain, pain is "an unpleasant sensory and emotional experience with actual or potential tissue damage or described in terms of such damage," (Merskey, 1986, p. 730). Pain is a subjective experience and is often difficult to explain when dealing with a variety of patients. With pain being the primary symptom associated with RSD, it can create problems with performing daily tasks, such as bathing, grooming and caring for others. Pain is a symptom that is constantly on the individual's mind and can create discomfort when completing daily tasks.

RSD resulting from trauma, disease, or injury may have a considerable effect of patient's lives. Many individuals may have to give up work permanently, eliminate satisfying physical and social activities, and/or withdraw from contact with friends and family. In addition to the problems created for the patients themselves, RSD will likely alter traditional family roles and create distress for other family members. Several studies have attempted to improve understanding of the consequences of RSD on family life; however, it is extremely difficult to assess exactly what happens in a family when one member suffers from RSD (Jensen, 1993; Kemler & Furnee, 2002; Rowat, 1985).

RSD patients may be forced to re-develop their life around their disability. If the individual is able to remain in the work force, he or she may require adaptations (energy conservation techniques) to assist in completion of job tasks and/or may require specific arrangements to accommodate for their disability. In some cases, the person may need to find a different job that fits them and their disability.

Cognitive-Behavioral Theory Frame of Reference

Cognitive-behavioral theory is used not only in psychological contexts and settings, but in any intervention setting in which the goals are to broaden clients' knowledge, strengthen the application of knowledge in skill-building, or to improve an individual's ability to problem solve (Bruce & Borg, 2002). It is a frame of reference that assumes that a person's cognitive function and beliefs mediate or influence his or her affect and behavior. Cognitive-behavioral theory recommends that intervention include both verbal and behavioral strategies. The goal of intervention is to change the person's thoughts, which in turn will change the person's

behavior, ultimately improving the client's daily function and sense of self-efficacy. An important outcome of cognitive-behavioral intervention is increased self-knowledge and a heightened sense of self-efficacy, as clients view themselves as capable of handling new situations that may arise (Bruce & Borg).

Forms of Cognitive-Behavior Therapy

Three major forms of cognitive behavior therapy have been identified including, (1) Rational psychotherapies, (2) Coping skills therapies, and (3) Problem solving therapies. Occupational therapists use diverse cognitive and cognitive-behavioral strategies in occupational therapy intervention and prevention (Mahoney & Arnoff, 1974). Four major cognitive theories that are often cited in occupational therapy that contribute to intervention include, (1) Albert Ellis' rational emotive therapy, (2) Albert Bandura's social learning theory, (3) Donald Meichenbaum's cognitive behavior modification and, (4) Aaron Beck's cognitive therapy (Bruce & Borg, 2002). The following information will primarily focus on Beck's cognitive therapy and the application to patients diagnosed with RSD.

Beck's Cognitive Therapy

Beck has been a key contributor to cognitive-behavioral therapy. He refers to his model as cognitive therapy (CT) and defines it as "an active, directive, time-limited, structured approach used to treat a variety of psychiatric disorders" (Bruce & Borg, 2002). Beck's approach has an underlying theoretical rationale that an individual's affect and behavior are largely determined by the way in which he or she thinks. He assumes that:

1. An individual's cognition influences how he or she perceives and experiences everyday events
2. One's cognition are based on internal and external stimuli as well as past and present experiences
3. Thoughts influence personal feelings and behavior
4. Therapy can heighten the individual's awareness of these cognitions and how they influence his or her feelings and behaviors.

Beck uses cognitive techniques such as grading task assignments, modeling, coaching, behavioral rehearsal, homework, stress inoculation, cognitive modeling, and scripting. These techniques are often used to help develop assertive beliefs.

Educational methods may be combined to increase client awareness and control of his or her thoughts to achieve change and client goals (Bruce & Borg).

Patients having RSD may be able to benefit from the opportunities that Beck's CT has to offer. As stated earlier, patients suffering from RSD may frequently experience psychosocial issues that may be resulting from distorted thinking or coping with their illness in general. Pain is the most common complaint associated with RSD and may cause patients to develop psychological factors, including preoccupation with pain, feelings of isolation and so forth (Aranoff & Livengood, 2003). Cognitive-behavioral approaches primarily seek to change these types of thoughts that are believed to result in or cause specific behaviors.

The treatment focus is based on the individual's philosophy of life. The role of the occupational therapist is to collaborate with the patient in mutual exploration and to use inductive methods while asking the patient to support or dispute beliefs. The

therapist and the patient collaborate to select treatment activities and the therapist uses tasks graded in difficulty for the nature of therapeutic activities (Bruce & Borg, 2002).

Occupational Therapy

Cognitive-behavioral approaches are congruent with the theoretical foundation of Occupational Therapy (OT) practice. Since the beginning of the profession, the principles of social learning, behavioral, and cognitive theories and approaches have been valued. Adolph Meyer suggested in his literature that clients adapt by changing their behavior, the environment, or their thoughts (Bruce & Borg, 2002). Cognitive-behavioral theory and occupational therapy theory share several characteristics:

- Valuing the person's perspective or phenomenological experience
- Recommending a collaboration between client and practitioner during the evaluation and intervention process
- Valuing cognitive awareness and the person's ability to problem solve
- Integration of activity or tasks into the intervention process
- Providing many opportunities for practice in contexts in order to increase generalization of function (Duncombe, 1998).

Cognitive-behavioral principles that are applied during interventions are compatible with the task-oriented groups. Occupational therapists design interventions to influence client behaviors and/or environments in order to enhance the person's meaningful participation in daily life. Whether the therapist has chosen to emphasize behavioral or cognitive approaches or combine the two, the occupational therapy

process focuses on meeting the client's needs and providing opportunities for skill development.

The therapist using cognitive behavior theory sees the person as someone who thinks, feels, and functions in multiple environments while providing a sense of safety, which allows for a person to explore and learn. This safe, consistent environment allows the person to gain the knowledge base that will shape his or her beliefs, future learning, and knowledge acquisition. The therapist as an educator-facilitator provides a vehicle for structured, experiential, or self-directed learning and carefully explains the rationale behind the approaches and assignments while giving specific and frequent feedback regarding the patient's thoughts, behaviors, and accomplishments. New possibilities are introduced for the patient, and the therapist strives to be flexible, to individualize learning experiences, and to adjust the intervention approach to the patient. Collaboration between the therapist and the patient allows identification of problems and helps to plan and implement learning activities while providing a non-judgmental attitude and a secure base. Communication of respect to the patient for his or her ability to learn and solve problems is also important to consider (Bruce & Borg, 2002).

Conclusion

Reflex Sympathetic Disorder is a complex and perplexing condition affecting many Americans. It is a multi-symptom, multi-system syndrome resulting from a traumatic injury. This syndrome can have debilitating effects on individuals and their ability to perform daily activities. Physical and psychosocial factors may also impede on an individual's daily life and roles. Many treatment options are available to treat

the physical aspects of RSD; however, the psychosocial factors are often over-looked by the medical community. The following chapter will describe the process of developing an occupational therapy treatment protocol based on the Cognitive Behavioral Frame of Reference. It is designed to address pain and the psychosocial issues associated with RSD, hopefully increasing an individual's ability to resume daily living tasks, increase productivity and function more independently.

CHAPTER III

ACTIVITIES & METHODOLOGY

Reflex Sympathetic Dystrophy (RSD) is an illness that occupational therapists typically see in physical dysfunction settings and patients receive therapy to treat the physical aspects associated with RSD. It is critical to treat the patient holistically and treat the psychosocial effects as well. The psychosocial aspects of RSD are often overlooked by occupational therapists and the patients may seek additional services from another discipline. Occupational therapists have the skills and the training to treat the psychosocial aspects resulting from pain in conjunction with the physical symptoms. An intervention approach combining both the physical rehabilitation and addressing the psychosocial aspects may be more cost effective than referral to another professional. Occupational therapists have the skills to treat individuals with psychological illnesses through creative and meaningful interventions. Based on the need for additional attention to the psychosocial aspects of RSD, a treatment protocol with guidelines for evaluation, treatment techniques and sample homework assignments was developed.

With the guidance of faculty advisors, a topic proposal was developed and approved by the University of North Dakota Graduate School. The proposal briefly summarized areas to be addressed in the literature review and included an outline of the contents of the project.

An extensive literature review was the first step in the process for this project. The purpose of the literature review was to describe RSD and illustrate the relevance to occupational therapy. The literature review used a wide range of supporting

journal articles. Key concepts were identified and described to develop an understanding of this complex condition. Current research regarding treatment options and techniques were explored and defined within the review. An emphasis was placed on the frequently over-looked psychosocial aspects of RSD.

The literature review served as a guide for developing the Psychosocial Treatment Protocol for clients with RSD. This treatment protocol will be discussed in further detail in Chapter 4.

CHAPTER IV

PRODUCT

A psychosocial treatment protocol was developed as the product for this scholarly project (Refer to Appendix A). Cognitive-behavioral therapy was used in conjunction with occupational therapy intervention approaches. One of the goals of this protocol was to design a resource that can be used in assisting individuals with Reflex Sympathetic Dystrophy (RSD) change their thoughts and behavior through cognitive-behavioral techniques. A second goal was to maximize function and independence of clients with RSD in completing their typical activities of daily living.

A brief overview of RSD was provided in the beginning of the protocol. Included within the overview was an explanation of cognitive-behavioral therapy and how it can be used to treat chronic pain. In addition, the role of the occupational therapist was explained and described to support development and implementation of the protocol. The objectives were clearly explained to outline the purpose of the protocol and specific areas of focus, including areas to evaluate, specific assessment tools, and precautions and contraindications were explained. The treatment process and suggested interventions and techniques were discussed. The treatment interventions focused on describing three techniques: stress inoculation, distraction and behavioral homework assignments. Guidelines for initiating treatment were outlined for the initial treatment session, which included establishing rapport and completion of the initial evaluation. Techniques to determine effectiveness included

monitoring the responses to treatment and withdrawal trials. Lastly, the discharge preparation and criteria were defined.

Following the treatment protocol, there are supplemental materials to support the treatment protocol. These include: the initial evaluation form used, example of the daily log used in the homework assignment treatments, RSD organization information, and websites for additional information.

CHAPTER V

SUMMARY & CONCLUSION

Reflex Sympathetic Dystrophy (RSD) is a complex condition that affects many individuals. This syndrome can have debilitating effects on individuals and their ability to perform daily activities. Physical and psychosocial factors may impede an individual's ability to fulfill daily life tasks and roles. The physical factors are most often treated while the psychosocial factors are often ignored. The treatment protocol was aimed at addressing pain and the psychosocial issues associated with RSD, in conjunction with increasing an individual's ability to resume daily living tasks, increase productivity and function more independently.

One of the major limitations of the literature was the lack of resources documenting the role of occupational therapists in cognitive-behavioral therapy. More research is needed to provide support for this service and to document outcomes of implementation. In addition, more information is needed to document the outcomes of psychosocial intervention with clients diagnosed with RSD. There was a limited amount of information regarding the knowledge that occupational therapists have in relation to RSD and psychosocial treatment.

The significance of the project lies in providing an added resource to support individuals with RSD, allowing the intervention to be holistic and emphasizing the occupation-based intervention process. Cognitive-behavioral therapy has been shown to be very successful in the treatment of chronic pain; it is consistent with the occupational therapy approach and has promise in effectively addressing the psychosocial needs of individuals diagnosed with RSD.

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Appendix A

Occupational Therapy Psychosocial Treatment Protocol for Reflex Sympathetic Dystrophy (RSD)

Reflex Sympathetic Dystrophy (RSD) is a complex neurological condition demonstrated by: (a) pain and altered sensation; (b) motor disturbances and soft tissue change; (c) vasomotor and autonomic changes; and (d) psychosocial disturbance (Turner-Stokes, 2002). RSD is a malfunction of the autonomic nervous system in which nerves misfire, sending constant pain signals to the brain. It develops in response to an event the body perceives as traumatic, such as an accident, a fall, or surgery.

The most universal symptom of RSD is pain, usually described as burning or stinging in quality. The lightest touch (such as clothing, bed sheets, shower spray, a light breeze) is often perceived by the individual as intolerably painful. The pain is real and as a result, some patients may develop psychological difficulties when families, friends, or physicians do not understand their pain (Turner-Stokes, 2002).

Cognitive-behavioral therapy is an action-oriented form of psychosocial intervention that assumes that maladaptive thinking patterns cause maladaptive behavior and “negative emotions”. The treatment focuses on changing an individual’s thoughts in order to change his or her behavior. It is a recommended treatment option for a number of disorders, including chronic pain disorders (Bruce & Borg, 2002).

Cognitive-behavioral strategies for pain management may be implemented to reduce pain and improve function and overall quality of life by occupational therapists. Occupational therapists have a common commitment to person-centered care, the promotion of health and well-being, and the prevention of long-term disability resulting from pain (Bruce & Borg, 2002).

The first thing that an occupational therapist needs to do is educate themselves about the effectiveness and nature of cognitive-behavioral therapy. In order for this approach to work effectively with RSD patients, the therapist has to be fully aware of cognitive-behavioral therapy and research studies that have been conducted on the effectiveness of the therapy.

Goals/Objectives

1. To assist the patient having RSD in achieving maximal functional level of independence.
 - a. Patient will be able to identify how the pain from RSD is affecting their ability to complete activities of daily living (ADL’s) and instrumental activities of daily living (IADL’s).
 - b. Patient will be able to identify strategies to cope with pain and become more independent in completion of ADL’s.

2. To educate the patient and family regarding cognitive-behavioral therapy and how it will benefit them.
 - a. Patient will describe the process and benefits of cognitive-behavioral therapy.
 - b. Patient will describe three strategies for following through with cognitive-behavioral therapy.
3. To educate the patient about the psychosocial aspects associated with RSD, including pain.
 - a. Patient will describe the psychosocial aspect associated with RSD.
 - b. Patient will describe the impact that pain has on their level of function.
4. Provide education about pain and how he/she can more effectively cope with the pain and live functionally once discharged from therapy.
 - a. Patient will develop coping strategies to cope with pain.
 - b. Patient will demonstrate the ability to use coping strategies to manage pain.
5. To change any distorted perceptions that individuals may have due to chronic pain resulting from RSD.
 - a. Patient will describe distorted perceptions that he/she is experiencing.
 - b. Patient will identify ways to change perceptions due to the pain.

Areas to Evaluate

1. Patient's medical history, past medical issues, and presenting medical issues.
2. Cognitive Status
3. Living Situation – support, adaptive equipment needs
4. Psychosocial rehabilitation potential
5. Interest/pursuits – leisure activities/hobbies
6. Life stresses and coping ability in dealing with stress
7. Psychological adjustment to life role change due to RSD –what impact does the level of pain they are experiencing have on fulfilling daily roles and responsibilities.
8. Assessment will be administered when needed; for example, a stress management questionnaire will be administered when focusing on stress inoculation techniques. Assessments are administered to obtain information about the patient that will assist and guide the therapy process. Determination of the assessment solely depends on the patient and their needs.

Assessments will include:

- The Canadian Occupational Performance Measure (COPM) will be used in initial treatment along with the initial evaluation. This will be used to measure the patient's perception of his/her occupational performance in the areas of self-care, productivity, and leisure activities. The therapist should also ask the patient which area he/she feels is most impeded by their current pain level (Law et al. 1998).
- The McGill Pain Questionnaire will be used to assess pain experience. This assessment provides consistent methods of measuring subjective pain experience. It is designed to help the patient describe their pain and to study

the effects of pain management techniques on the quality and intensity of pain (Melzack, 1983).

- Stress Management Questionnaire will be administered to identify stressors in the client's daily life and to also address the client's perception of stress in daily life (Stein, Bentley, & Natz, 1999).

Treatment Precautions/Contraindications

Cognitive-behavioral therapy may not be suitable for some patients. Those who do not want to focus and address pain issues associated with their condition may be better served using a different treatment approach. Patients must also be willing to take a very active role in the treatment process. The occupational therapist needs to monitor the patient and be aware of signs of fatigue, increased stress, etc.

Cognitive-behavioral therapy will be used in conjunction with other treatments for RSD, including treating the physical symptoms. Therefore, it is critical that the occupational therapist document progress in order for insurance agencies to see functional outcomes and improvement in the patient receiving cognitive-behavioral therapy.

Treatment Process/Suggested Treatment

A number of different techniques may be employed in cognitive-behavioral therapy to help patients uncover and examine their thoughts and change their behaviors. The techniques that will be discussed in this protocol will include:

1. Stress Inoculation
2. Distraction
3. Behavioral homework assignments
4. Suggestions for additional treatment session include – coping skills development, problem solving techniques, and stress management techniques (Supplemental handouts are attached).

Goal: To change patients thoughts and behavior through these techniques in order to maximize function and independence within their contexts.

The roles and responsibilities of the occupational therapist include:

1. Assessment of the impact of pain on occupational performance in the areas of self-care, work, interests and leisure pursuits, habits and routines, and family relationship.
2. Collaboration with the patient to develop a client-centered treatment program to promote optimal function despite pain.
3. Liaison and referral within an interdisciplinary team.

Cognitive Behavioral Techniques

Initial Treatment Sessions

Initial treatment sessions are typically spent explaining the basic view of cognitive-behavioral therapy to the patient and establishing a positive-working relationship between therapist and patient. This is an important process because the therapy empowers the patient by providing an active role in therapy. A therapeutic rapport is beginning to develop and a comfortable environment is established.

An initial evaluation will be completed during the first treatment session (Refer to Appendix B). The purpose of the initial evaluation is to become familiar with the patient, assess what he/she wants to get out of therapy and to provide baseline information to guide the treatment process. Following the initial evaluation, the therapist and the patient will collaborate and develop a treatment plan with emphasis on the following cognitive-behavioral techniques.

Stress Inoculation

Cognitive-behavioral therapy states that our conscious thoughts about stressors determine the intensity of our emotional and behavioral reaction. Stress Inoculation Training (SIT) emerged out of an attempt to integrate the research on the role of cognitive and affective factors in coping processes. SIT has been employed on a treatment basis to help individuals cope with the aftermath of exposure to stressful events and on a preventative basis “inoculate” individuals to future and ongoing stressors. Stressors can cause and/or increase pain in individuals with RSD. SIT typically consist of a three-phase set up (Meichenbaum, 1996).

In the first stage, a collaborative relationship is established between the clients and the occupational therapist. Patients are educated on the nature and impact of stress and the role they are required to fulfill during treatment. They will also be educated on the role that stress can play in comparison with pain, for example, when stress rises, so does the current pain level. Clients are taught how to breakdown stressors into specific coping goals (Meichenbaum, 1996).

The second phase of SIT focuses on skill acquisition. Coping skills are taught and practiced primarily in the clinic or training setting and then are gradually rehearsed in vivo and are customized to the specific stressors that clients may have to deal with. Specific coping skills may include emotional self-regulation, self-soothing and acceptance, relaxation training, self-instructional training and problem solving (Meichenbaum, 1996).

The final phase of application and follow through provides opportunities for clients to apply a variety of coping skills across increasing levels of stressors. Such

techniques as imagery and behavioral rehearsal, role playing and modeling are employed (Meichenbaum, 1996).

SIT recognizes stress, as an individual experiences it, is widespread and unavoidable. As a result, SIT has often helped clients to alter environmental settings and work with significant others in altering environmental stressors. It is also necessary to go beyond individual and group interventions to decrease stress in each individual's life (Haggerty, 1995).

Role of the occupational therapist

- Therapeutic Relationship - The occupational therapist providing SIT should be knowledgeable on the process of SIT and the importance of what it can accomplish. The therapist develops a collaborative relationship with the client through therapeutic use of self-techniques, including warmth, empathy, honesty, etc. Once rapport between the client and the therapist is achieved, a comfortable environment can be established which will assist in providing a successful treatment session.
- Communication – An open communication relationship should be established to allow for the patient to fully participate during treatment sessions.
- Evaluation – The therapist should evaluate the client at different stages during therapy to ensure that the client is benefiting from SIT. The therapist could evaluate client satisfaction and/or reduction of stressors in their life.
- Evaluate the patient's environment and provide suggestions for alterations to reduce environmental stressors.
- Assessment - The therapist will administer the Stress Management Questionnaire to the patient. This is a self-assessment to identify stressors and address the client's perceptions of stress in daily life. This assessment would provide the therapist with a baseline of how the patient is experiencing stress and how they deal with it.

Distraction

Distraction, also known as cognitive refocusing, is a cognitive-behavioral strategy that directs a person's attention and concentration towards other stimuli, thereby shielding them from their pain. Stimuli may be internal or external, it includes involvement in any activity to "take their mind off" of the pain. Stimuli may be self-initiated, such as making phone calls, or passive, as with listening to music or humor. The most effective distraction techniques are those that are unique and changing, those that require input from most or all of the senses including seeing, hearing, tasting, touching and smelling, and those that are interesting to and appropriate for the person practicing them. In some cases, awareness of the pain, as well as fatigue and irritability, increases when the distraction ends. Therefore, it is important for the client to develop a wide variety of distraction techniques to try at different times.

Role of the occupational therapist

- Mediator – The therapist will allow for the client to develop distraction techniques on his or her own. The therapist will act as a guide throughout the process, providing suggestions and opportunities to expand on the techniques developed.
- The therapist and the patient can practice these techniques within the setting and then allow the client to try the techniques on his or her own. Examples of distraction techniques include: watching television, listening to music, talking on the telephone, singing in a choir or engaging in a particular hobby.

Behavioral Homework Assignments

Cognitive-behavioral therapy often involves the patient completing homework assignments between therapy sessions. These may consist of real-life behavioral experiments where patients are encouraged to try out new responses to situations discussed in therapy sessions. Homework assignments allow the patient to continue working on managing their pain while they are in their natural setting. Homework assignments also allow for the patient to develop and visually see what is causing them stress and how the stress impacts their pain.

Examples of homework assignments include:

- Coping Skill Strategies: SIT treatment involves the patient developing coping skill strategies within the setting and then applying them outside of treatment. The occupational therapist could ask that the client develop a list of coping skills that they think would help them cope with their stressors in daily life. The patient would complete this assignment and would review it with the therapist.
- Reflective journal: Patient would be asked to keep a detailed journal recounting his or her thoughts, feelings, pain levels and so on. This will be used as a tool for the patient to increase his or her own insight regarding pain. The journal also helps to make the patient aware of his or her maladaptive thoughts, track negative and positive thoughts regarding pain and accomplishments during therapy. The therapist will not directly view the reflective journal; it is for the patient's reference only.
- Daily log: Patient would be asked to track daily thoughts, negative and positive (Refer to Appendix C). This would allow for the patient to once again visualize seeing his or her thoughts and identify ways to modify them into more healthy productive thoughts. The patient will develop skills in evaluating their thoughts and develop strategies to more effectively deal with them (acknowledge positive things they have done, keep an accomplishment list, positive affirmations, etc.)
- Home Program: The therapist and the patient could collaborate and develop a home program that would benefit the patient. Examples of activities within the home program could include: exercise program, paraffin baths, and relaxation techniques.

Role of the occupational therapist

- The occupational therapist and the patient will collaborate with one another to develop appropriate homework assignments that the patient would enjoy completing.
- Monitor completion of the assignments and communicate with the patient about the assignment.
- Problem solve ways to challenge negative thinking and develop more effective coping strategies.

Determining Effectiveness of Treatment

- 1) **Monitor Responses to Treatment:** The occupational therapist has to evaluate the nature of the response to each treatment. Patients with chronic pain have difficulty remembering things; therefore, keeping a diary that documents the magnitude and duration of the effect of each treatment can measure responses to each treatment session.
- 2) **Withdrawal Trials:** Withdrawing the patient from time with the therapist can also provide the occupational therapist with feedback regarding treatment effectiveness. After the therapist feels that the patient has accomplished his/her goals, they can withdraw from treatment for a certain period of time and the therapist will keep in contact regarding the patient's self-initiated pain management and effectiveness of the techniques learned in therapy.

Preparation/Criteria for Discharge

- 1) Re-evaluate patient's pain status at discharge throughout the course of treatment.
- 2) Patient will be able to identify the impact of pain on his/her ability to complete valued occupations.
- 3) Patient will be able to determine the effects of cognitive-behavioral therapy on his/her ability to cope and function.
- 4) Prepare patient for discharge to appropriate setting.
- 5) Encourage patient to follow through with any recommendations (relaxation training, stress management techniques, etc.)
- 6) Complete discharge summary and recommendations

The patient will be discharged from occupational therapy under the following conditions:

- 1) Patient has met program objectives and goals.
- 2) After the patient has a withdrawal from treatment and is continuing to manage their pain successfully without further treatment.
- 3) Patient not willing to continue to work with the process.

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Appendix B

Department of Occupational Therapy
Initial Evaluation for RSD

Patient Name _____ Age _____ DOB _____ Sex _____
Date of Screen _____ Diagnosis _____ Other Diagnosis _____
Reason for Referral _____
Chief Complaint _____
Past Medical History _____
Surgical History _____

Current ADL Status (based on FIM Scores)

Dressing

Shirt/blouse/dress: Min. Assist ___ Mod. Assist ___ Max. Assist _____
Buttons/Fasteners: Min. Assist ___ Mod. Assist ___ Max. Assist _____
Pants/Undergarments: Min. Assist ___ Mod. Assist ___ Max. Assist _____
Socks/Nylons: Min. Assist ___ Mod. Assist ___ Max. Assist _____

Bathing

Tub Bath: Min. Assist ___ Mod. Assist ___ Max. Assist _____
Shower: Min. Assist ___ Mod. Assist ___ Max. Assist _____

Grooming

Brushing Teeth: Min. Assist ___ Mod. Assist ___ Max. Assist _____
Combing Hair: Min. Assist ___ Mod. Assist ___ Max. Assist _____
Washing Face: Min. Assist ___ Mod. Assist ___ Max. Assist _____

Comments: _____

Mental Status/Cognition

Oriented to: Person ___ Place ___ Time ___ Comments _____

Problem Solving: Intact ___ Impaired ___ Further Assessment Needed _____

Safety Awareness: Intact ___ Impaired ___ Further Assessment Needed _____

General Observations: _____

Pain Assessment

Current Pain Level: (1 being lowest, 10 being highest)

1 2 3 4 5 6 7 8 9 10

Performance Areas Affected: Scale of 1-5; 1 not affected at all, 5 affected greatly

Activities of Daily Living

___ Grooming ___ Dressing ___ Bathing ___ Toileting

___ Fulfilling roles (mother, father, husband, wife, etc.)

___ Work

___ Leisure activities

___ Social environment

Comments

Living Situation

Patient Lives: Alone ___ With Family ___ Spouse ___ Other _____

Patient lives in a: House ___ Apartment ___ Assisted Living ___ Other _____

Rehabilitation Potential

Physical: Excellent ___ Good ___ Fair ___ Poor _____

Psychosocial: Excellent ___ Good ___ Fair ___ Poor _____

Comments _____

Patient's Discharge Plans

Return to home: Alone ___ Home with Spouse ___ Relatives Home ___ Other _____

Patient's Individual Goals

Additional Comments

Therapist Signature: _____ Date: _____

Appendix C

Thought Log

Directions: Daily, you are to write down your thoughts, as well as your pain level that day. It is important for you to challenge your negative thoughts and develop more positive ways of coping. Negative thoughts impact pain levels and your ability to cope and function with daily tasks. We will discuss this during therapy and we will identify ways to modify the negative thoughts into healthy productive thoughts.

Date	Pain Level	Thoughts	Evaluation Positive/Negative	Ways to challenge negative thoughts and develop more positive strategies

Appendix D

Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA)

Membership Information

The Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA) is a national not-for-profit organization, headquartered in Milford, Connecticut, that promotes greater public and professional awareness of RSD.

Mission Statement

“Our mission is to promote public and professional awareness of Reflex Sympathetic Dystrophy Syndrome (RSD) and to educate those afflicted with the syndrome, their families, friends, insurance and healthcare providers, on the disabling pain it causes. We encourage individuals with RSD to offer each other emotional support within affiliate groups. And finally, we are committed to raising funds for research into the cause and cure of RSD” (www.rsds.org).

People who join RSDSA are not content to be victims of RSD, but take role in achieving their goals and education, awareness and research. Members include patients, family and friends, healthcare professionals, attorneys and business people who understand RSD and are dedicated to helping people live more functioning lives.

Become A Member

For \$15.00, you will receive:

- RSDSA Review – Quarterly Newsletter
- Pen Pal Service – Patient support program exclusively for RSDSA members
- Additional Benefits – Special mailings announcing timely news about RSD and discounts on RSDSA literature and conferences.
- In addition, your membership provides RSDSA with additional lobbying power in its on-going efforts to increase public and professional awareness of RSD and to find a cause and a cure.

For RSDSA membership application or other information, write to:

RSDSA

*P.O. Box 502
Milford, CT 06460*

RSDS Website: www.rds.org

Email comments to: newsletter@rds.org

Provided to you by your occupational therapist: _____

Appendix E

Additional RSD Websites

Raising Awareness and General Information

The American RSDHope Group www.rsdhope.org

AwareRSD, for information, support, friendship

<http://aware-rsd.com>; [online support group](#)

Canadian RSDNetwork <http://www.canadianrsd.com>

For Grace www.forgrace.org

Promoting Awareness of RSD in Canada <http://people.becon.org/~rsdinfo>

RSD Alert <http://www.rsdalert.co.uk/>

RSDSA-Calif. <http://www.rsdca.org>

RSDCare <http://www.rsdcare.org>

The RSD Awareness Coalition www.rsdaware.org

RSD On-line <http://home.ptd.net/~paulbarb/rsdweb.htm>

SCRSDA On-Line <http://www.homestead.com/scrsda>

RSD Friends, a California-based support and education group <http://rsdfriends.org/>

Children With RSD/CRPS

Aya's No Pain Zone <http://www.nopainzone.com>

RSDParents Group <http://groups.yahoo.com/group/RSDParents>

RSD Escape www.RSDEscape.com

Supporting Kids in Pain. <http://shsskip.swan.ac.uk> Based in the UK.

Research

International Research Foundation for RSD/CRPS www.rsdfoundation.org

Support and Chat Groups

Providing support for RSD/CRPS patients and their families [RSD-CRPSofAmerica](#)
[Intrathecal Pump Users Support Group](#) for people using or considering using
intrathecal pump therapy

Pain Pal's Medical Links & RSD Support
<http://www.angelfire.com/me2/rsdpainpals/links.html>

RSD Pen Pal Buddies www.angelfire.com/realms2/rsdpenpalbuddies/

Pregnancy Pals Support Network Bulletin Board <http://www.jd-dch.com/phpBB2/index.php>

RSD Retreat <http://www.RSD-retreat.com>

Additional Links

Stress Management Techniques: www.twu.edu
www.intelihealth.com

Pain Management: www.painsupport.co.uk
www.painmanagement.org.uk
www.tenresolutions.org
www.paincare.org
www.aapainmanage.org

Provided to you by your occupational therapist: _____

