Reflex Sympathetic Dystrophy awareness
by Judith Scott Nicoll

A thesis submitted in partial fulfillment Of the requirements for the degree of Master of Nursing
Montana State University

Abstract:
An estimated six million people in the United States have been diagnosed with Reflex Sympathetic Dystrophy, a poorly understood symptom complex. In the absence of early intervention, this disorder progresses rapidly to an irreversible, debilitating condition. There is a perceived lack of understanding among health care providers suggested by advocates for the disorder, people with the disorder, and pertinent literature. No published research was identified to validate the perceived lack of understanding.

The purpose of this study was to: a) describe the level of awareness about Reflex Sympathetic Dystrophy among Advanced Practice Registered Nurses in Montana, and b) identify key factors (e.g. education, years of practice, etc.) that are related to the awareness of Reflex Sympathetic Dystrophy. All Advanced Practice Nurses (N=317) were sent a mail questionnaire developed by the researcher.

The response rate was 70.9 percent. Seventy-seven percent of responders had a “poor” awareness about the syndrome. Associated factors in the study were: field of expertise, previous education on Reflex Sympathetic Dystrophy, and gender. The certified nurse anesthetists had the highest level of awareness regarding the disorder.

This study provided the first systematic validation that there is a lack of awareness about RSD among a group of health care providers.

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A thesis submitted in partial fulfillment
Of the requirements for the degree

of

Master of Nursing

MONTANA STATE UNIVERSITY-BOZEMAN
Bozeman, Montana

April 1999

APPROVAL

of a thesis submitted by

Judith Scott Nicoll

This thesis has been read by each member of the graduate committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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VITA

Judith Scott Nicoll, the daughter of George and May Nicholson, was born July 16th, 1962, in New Jersey. She received her secondary education from Collingswood High School in Collingswood, New Jersey. She graduated from Presbyterian University of Pennsylvania in 1981 with a Licensed Practical Nursing degree. The Montana bug bit her in 1984 and she began her journey west. She graduated from Montana State University with a Bachelor of Science in Nursing in 1987.

Employment included positions as a traveling nurse and staff nurse in rural hospitals in Montana, Wyoming, and Idaho. The majority of time spent in nursing was in small rural hospitals in Montana. One of her greatest achievements was developing a hospice program for a small rural town in Montana. A Master of Nursing degree from Montana State University was completed in August, 1999.

ACKNOWLEDGEMENTS

This opportunity is taken to thank the members of my committee, Dr. Clarann Weinert, Deborah Kern, and Dr. Vonna Koehler, for their guidance throughout this project. As a beginning researcher, Dr. Weinert's expertise in the field of research was especially appreciated.

The unconditional support from my husband, family, and friends provided the strength I needed to accomplish my goals. I thank my father and mother, George and May Nicholson, and mother-in-law, Marion Nicoll for their love and concern. To my husband, Steve, who helped me focus on my dream and offered endless love, patience and understanding throughout my endeavors. To my dogs, for their daily reminder that life is good.

Finally, I dedicate this thesis to my father-in-law, Dr. G.S. Nicoll. My personal experience with Reflex Sympathetic Dystrophy was successfully treated due to his early recognition of the condition. His dedication to the medical profession has been an inspiration and his love and understanding made the completion of this goal possible.

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ABSTRACT

An estimated six million people in the United States have been diagnosed with Reflex Sympathetic Dystrophy, a poorly understood symptom complex. In the absence of early intervention, this disorder progresses rapidly to an irreversible, debilitating condition. There is a perceived lack of understanding among health care providers suggested by advocates for the disorder, people with the disorder, and pertinent literature. No published research was identified to validate the perceived lack of understanding.

The purpose of this study was to: a) describe the level of awareness about Reflex Sympathetic Dystrophy among Advanced Practice Registered Nurses in Montana, and b) identify key factors (e.g. education, years of practice, etc.) that are related to the awareness of Reflex Sympathetic Dystrophy. All Advanced Practice Nurses (N=317) were sent a mail questionnaire developed by the researcher.

The response rate was 70.9 percent. Seventy-seven percent of responders had a "poor" awareness about the syndrome. Associated factors in the study were: field of expertise, previous education on Reflex Sympathetic Dystrophy, and gender. The certified nurse anesthetists had the highest level of awareness regarding the disorder. This study provided the first systematic validation that there is a lack of awareness about RSD among a group of health care providers.

CHAPTER 1

INTRODUCTION

Reflex Sympathetic Dystrophy (RSD) is a poorly understood symptom complex that affects the nerves, muscles, skin, bones, and in late stages, internal organs of the body. The effects of this disorder are both complicated and devastating, but it is the lack of knowledge among health care providers that may be of greater concern. Initial symptoms may be subtle and associated with injuries ranging from minor to severe. Misdiagnosis is common, and in the absence of crucial early intervention, this disorder progresses rapidly to an irreversible, debilitating condition.

Reflex Sympathetic Dystrophy is complicated by a number of factors including confusing and conflicting results about the etiology, pathophysiology, defining characteristics, and treatment plan (Fournier & Holder, 1998). To further confuse the issue, the name of the condition has changed repeatedly over the past 100 years (Walker, 1997). Despite the complicating factors, many researchers believe that the prevalence of this condition is much greater than presently acknowledged (Borg, 1996). An estimated six million people in the United States have been diagnosed with RSD (Hendler, 1996). In a recent study of patients diagnosed with the disorder between 1993

and 1996, only 46 states acknowledged having such cases. Montana was 1 of the 4 states without reported cases (Reflex Sympathetic Dystrophy Association, 1998); consequently there are no statistical data available to determine the incidence of the condition in Montana.

The lack of empirical information regarding the incidence of RSD in Montana is disturbing. A spokesperson for a pain clinic in the Gallatin Valley of Bozeman, Montana, reported an estimated 25 persons per year seek treatment for RSD at their clinic. A clinic representative stated, "These patients feel alone and believe their condition is poorly understood by the medical community" (J. C. Reese, personal communication, January 11, 1999).

Advanced Practice Registered Nurses (APRN) may be the first contact for persons with subtle symptoms associated with RSD. It is the role of a nurse practitioner to diagnose, treat, and manage a wide array of acute and chronic health conditions. Therefore, it is essential for nurse practitioners to recognize early signs of this syndrome and to assure a precise diagnosis, treatment, and/or referral to prevent an irreversible disability.

Purpose

The goal of this study was to determine if the awareness of Reflex Sympathetic Dystrophy displayed by Advanced Practice Registered Nurses in Montana is consistent with the perceived lack of understanding suggested by advocates for the disorder, people with the disorder, and pertinent literature.

The purpose of this research was to:

(1) Describe the level of awareness about Reflex Sympathetic Dystrophy among Advanced Practice Registered Nurses in Montana.

(2) Identify key factors (e.g. education, years of practice, etc.) that are related to the awareness of Reflex Sympathetic Dystrophy.

Significance of Study

Perceived Lack of Knowledge

No published research was identified to support a lack of knowledge about RSD among health care providers. Although, researchers and patient advocates often make reference to a perceived lack of knowledge about the disorder. This lack of knowledge is said to lead to overuse of pain medications and a delayed accurate diagnosis (Peck, 1998).

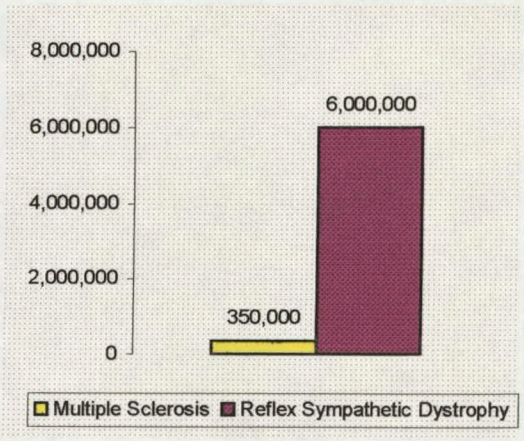
A variety of resources for those who have been diagnosed with RSD are available through literature, published information from the national RSD Association, and the Internet. The Internet is a primary source for the public to obtain information about the syndrome. Many support groups and independent web pages are filled with advice from persons afflicted with this condition. Several publications written by persons diagnosed with RSD suggested an "insensitivity" and "lack of knowledge" for their condition by health care providers. Several persons ultimately diagnosed with RSD described years of being shuttled between specialists without a diagnosis or effective

treatment. By the time the condition was properly diagnosed, it had advanced to a point where treatment was difficult, expensive, and ineffective. In a real-time computer chat room, anger and distrust towards the health care system were verbalized as persons diagnosed with RSD described their physical limitations, loss of income, and disruption of the family unit related to the poorly understood condition (F. Bauer, K. Haags, R. Hartley, J. Reid, & F. Schaeffers, personal communication, September 4, 1998).

Magnitude of the Disorder Nationally

It is difficult to understand the significance associated with the estimated six million people in the United States diagnosed with RSD. In order to illustrate the relevance of RSDs' perceived lack of awareness, a more recognizable condition was used for comparison. Although multiple sclerosis (MS) and RSD are not related, they have similar affects on the bodies ability to function; both can progress to irreversible, debilitating conditions. It is believed that MS has greater public awareness, but as can be seen from Figure 1, RSD has a significantly higher rate of prevalence nationally.

Figure 1. Estimated National Prevalence of Multiple Sclerosis vs. Reflex Sympathetic Dystrophy (RSDA, 1998; National Multiple Sclerosis Society, 1997).



An estimated 8,000 new cases of MS are reported every year in the United States. It is claimed that MS is the third most common cause of disabling illness in persons between the ages of 15 and 50 years (National Multiple Sclerosis Society, 1997). If this is the case, then RSD could be considered to be of epidemic proportions. This assumption, however, is complicated by the fact that it is so poorly understood, recognized, and researched.

Magnitude of the Disorder in Montana

Due to the lack of statistical information about the RSD in Montana, tentative assumptions were made based on the identification of approximately 25 persons with the diagnosis of RSD who seek care at one clinic in the state. Based on this finding, the probability that more cases exist throughout the state is conceivable. This study was the first step in the acquisition of information regarding the awareness of the disorder among a group of health care providers in the state.

CHAPTER 2

LITERATURE REVIEW

CINAHL and MEDLINE computer databases were used to identify relevant research. Both databases collectively yielded approximately 300 publications. Out of appropriate research publications, one nursing research study dealing with Reflex Sympathetic Dystrophy (RSD) in the pediatric patient was identified with the remainder being medical research exploring specific diagnostic issues and treatments.

History

The first documentation of RSD was by Weir Mitchell during the American Civil War (1861-1865). Mitchell and his associates identified this condition when it resulted from the trauma of gunshot injuries. The book Gunshot Wounds and Other Injuries of Nerves (Mitchell, Moorehouse, & Keen, 1864) contained an account of the signs and symptoms of peripheral nerve injuries as observed in soldiers at Turners Alne Hospital for Nervous Diseases in Philadelphia. An abbreviated quotation of their description follows:

> In our experience of nerve wounds, we met with a small number of men reporting 'red-hot rasping of the skin'. . . . The seat of burning pain is very various; but its favored site is the foot or hand. In these parts it is to be found most often wherethe nutritive skin-changes are met with; . . . . Its intensity varies from the most trivial burning to a state of torture, which can hardly be credited, but which reacts on the whole economy, until the general health is seriously affected. The part of itself is not alone subject to deep burning sensation, but becomes exquisitely hyperesthectic, so that touch or tap of the finger causes pain . . . . The sleep is restless, and the constitutional condition, reacting on the wounded limb, exasperates the hyperestic state so that the rattling of a newspaper, a breath of air, the step of another across the ward, the vibrations caused by military band, or the shock of the feet in walking, gives rise to an increase of pain (Mitchell et al., 1864, p. 289).

The term "causalgia" was given to this condition from the Greek words kausis (heat) and algos (pain) (Hooshmand, 1993). The term causalgia came from a combination of Weir Mitchell's (1864) work as well as that of Sir James Paget. Paget (1864) described the "glossy fingers, which are usually tapering, smooth, hairless, almost void of wrinkles, pink . . . always associated with distressing and hardly manageable pain and disability" (Bonica, 1979, p. 162). Mitchell's early contributions were recognized when his work was reprinted by the American Academy of Neurology in 1965 (Hooshmand, 1993). In 1943 the term "reflex dystrophy" was first used to describe painful changes in upper extremity tissue produced by "circulatory and neural disturbances provoked by trauma" (Bonica, 1979, p.162). Throughout the years researchers have utilized other terms, such as traumatic dystrophy, minor causalgia, algoneurodystrophy, shoulder-hand syndrome, and Sudecks atrophy, to describe RSD (Bonica, 1979). The most recent term used to define the condition is Complex Regional Pain Syndromes (CRPS) I and II (Stanton-Hicks, Janig, Hassenbusch, Haddox, Boas, & Wilson, 1995).

Pathophysiology.

While research on RSD is limited (Greipp, 1990), it is known that it affects all age groups, all races, and both genders at similar rates (Campbell, Meyer, & Raja, 1992). It seems to be triggered by either minor or major trauma. According to Schwartzmann (1993), the majority of cases are secondary to fractures, sprains, and soft tissue crushing injuries. While some cases are associated with an identifiable nerve injury, many are not. There are extremely rare cases of the syndrome related to head injury, stroke, polio, amyotrophic lateral sclerosis, myocardial infarction, operative procedures, and prolonged bed rest (Schwartzmann, 1993).

No single hypothesis explains all the features of RSD. Schwartzmann (1993) stated that a common mechanism might be injury to either central or peripheral neural tissue. Roberts (1986) proposed that sympathetic-maintained pain resulted from tonic activity in myelinated mechanoreceptor afferents. The input causes tonic firing in neurons that are part of a nociceptive pathway. Campbell et al. (1992) proposed a hypothesis which places the primary abnormality in the peripheral nervous system. Hardy & Hardy (1997) described RSD as an unsolved "puzzle", whereby they took all the pieces of the mechanism puzzle and categorized them into peripheral, spinal, and supraspinal (Hardy & Hardy, 1997).

Clinical Signs and Symptoms.

The clinical signs are often ambiguous and create a difficult task for an accurate diagnosis. There are no recognized criteria for diagnosing RSD (Pittman & Belgrade, 1997). Lankford (1990) described the key signs and symptoms as: (a) edema and skin discoloration, (b) demineralization and osteoporosis, (c) pseudomotor changes, (d) vasomotor instability, and (e) burning pain and stiffness.

Edema and skin discoloration are usually one of the earliest findings. Edema may involve the entire extremity, and the discoloration may vary from intensely red to cyanotic, pale, purple, or gray (Lankford, 1990). Demineralization and osteoporosis are among the most "classic" findings and are both late findings (Schwartzmann, 1993). Pseudomotor changes vary from hyperhidrosis to dryness; temperature differences between affected and unaffected extremities may be noted. Vasomotor instability is most commonly manifested as decreased capillary refill, and the skin may develop a glossy, shiny appearance. In the late stages of the condition, trophic changes may involve a decrease in subcutaneous tissue (Lankford, 1990).

Symptoms include pain and stiffness. Pain is intense and burning, is out of proportion to the injury, and may affect the entire extremity. There is pain with light touch termed "allodynia." Movement frequently, but not always, aggravates pain. Sufferers describe exacerbations with cold, and many feel worse when a low-pressure weather front is noted. Airplane ascent and descent can be painful. A predisposing personality of depression was suggested in much of the RSD literature. While a majority of persons with the disorder are depressed, other studies have demonstrated that they are depressed because of their pain (Peck, 1998).

Throughout the years researchers have attempted to put the signs and symptoms in a recognizable order by utilizing stages of the disease process. These stages are primarily for communication among health care providers and insurance companies. Ordinarily, patients do not clearly pass from one stage to the next at a specific time. Each patient has different symptoms and different intensities of symptoms at different times. It is rare to see a patient exhibiting all of the symptoms in each stage. The only common denominator in all patients is pain. The recognized three stages identified by the RSD

Association include: (a) stage 1-the acute stage, (b) stage 2-the dystrophic stage, and (c) stage 3-the atrophic stage. All stages have distinguishing characteristics with the duration of stage 1 lasting approximately three months and stage 2 lasting from three to six months. It is believed that once stage 3 has been reached RSD becomes a progressive chronic condition (Reflex Sympathetic Dystrophy Association, 1996) (see Table 1).

Table 1. Stages of Reflex Sympathetic Dystrophy.

Stage 1 (Acute)	Stage 2 (Dystrophic)	Stage 3 (Atrophic)
1. Onset of severe burning pain limited to the site of injury	1. Pain intensifies and diffuses	1. Pain may involve entire limb
2. Localized edema	2. Edema spreads	2. Irreversible trophic changes
3. Hyperesthesia	3. Hair becomes scant, nails become brittle	3. Contractions and subluxations may occur
4. Muscle spasm	4. Initial signs of osteoporosis	4. Severe and diffuse osteoporosis
5. Stiffness and limited mobility	5. Atrophy of the muscle begins	5. Severe atrophy of the muscles
6. Hyperhidrosis		
7. Vasospasms: at onset skin warm, red, and dry quickly changing to cyanotic, cold, and sweaty		

The signs and symptoms of RSD may often alert the practitioner to another disease process. Patients with nerve entrapment syndromes or other neurological

conditions have been incorrectly diagnosed with RSD (Reflex Sympathetic Dystrophy Association, 1996). The fact that there are no specific tests that will unequivocally confirm the diagnosis of RSD often leads to misdiagnosis (Schwartzmann, 1993). Hendler (1993) noted the best way to differentiate a patient with RSD and one suffering from other nerve syndromes involves testing the affected limb for sensitivity to temperature. The majority of RSD patients experience extreme sensitivity to heat or cold (Hendler, 1993).

Diagnostic Studies and Treatments.

Several researchers have examined the different diagnostic techniques and subsequent treatments available. For the purpose of this study, the work of Hendler (1993) will be used to describe the recommendations regarding available resources to assist in the diagnosis and treatment of RSD. Hendler (1993) reiterated the importance of early diagnosis and treatment to provide a cure for RSD. He stated that "any delay in treatment will result in a disorder that is markedly resistant to treatment and can become permanent" (Hendler, 1993, p. 12). Keeping in mind the goals of the study, a brief review of available resources will be provided. Accepted diagnostic procedures include thermography, bone scan, intravenous phentolamine injection, drop and swipe test, sympathetic block, epidural block, peripheral nerve block, three dimensional computed tomography (3D CT), and electromyogram (EMG) nerve conduction (Hendler, 1993).

Accepted treatment regimens include steroids and intense exercise for early stages. Hareau (1996) studied 120 women, aged 35 to 75 years, and 30 men, aged 30 to

60 years. These patients were diagnosed with RSD three months after the onset of symptoms. Prompt diagnoses and range-of-motion exercises resulted in an 85% success rate and cure. Sympathetic blocks serve as a diagnostic tool as well as treatment. According to Hendler (1993) a patient should require no more than 12 blocks. If the symptoms return after the medication from the blocks wears off, a sympathectomy may be necessary. The success rate of a sympathectomy, the removal of a part of the chain of sympathetic ganglia, ranges anywhere from 12% to 92%. This spread in results is directly related to misdiagnosis and abuse of the treatment mode, the skill of the surgeon, and the reliability of a patient's response to treatment. Other treatment options include epidural electrical stimulation, morphine pumps and other pain medications, or amputation in extreme cases (Hendler, 1993).

Attempt to Clarify the Disorder.

The most recent term used to define RSD is CRPS I and II. A special interest group of the International Association for the Study of Pain believes this term will aid in the diagnosis of RSD and avoid misdiagnosis. It is their belief that the terms "causalgia" and "reflex sympathetic dystrophy" independently describe this condition and, therefore, need to be differentiated (Colton & Fallat, 1996). The overall term, CRPS, requires the presence of regional pain and sensory changes following a destructive event. Other findings, such as abnormal skin color, temperature change, abnormal pseudomotor activity, or edema, are assessed and compared to the expected course of the injury. If the degree of the findings exceeds the expected findings, a diagnosis of CRPS should be

considered. CRPS type I (RSD) is said to be lacking the distinguishing characteristic of a nerve lesion. CRPS type II (causalgia) has the distinction of a definable nerve lesion. The term "sympathetically-maintained pain" (SMP) is also recognized as a separate component to this group of conditions (Stanton-Hicks et al., 1995). A text utilized by students and health care providers, (1998 Current Medical Diagnosis and Treatment), continues to recognize the term RSD and not CRPS.

Nursing Literature on Reflex Sympathetic Dystrophy

Nursing literature about RSD is seriously limited. Greipp (1990) conducted a research study and has published three articles relative to that study. Her research was a retrospective pain study in a pediatric sample. The researcher identified discrepancies between what appears in the literature and what is evidenced in clinical practice. The sample included 27 participants, ranging from the ages of 6-19 years. This sample was chosen from a random list of 165 clients registered with the RSD Association as having been diagnosed with RSD by physicians. Diagnoses were made on the basis of physical examination and clinical findings, including the clients' complaints of constant burning pain, hypalgesia, localized edema, vasospasm, and hyperhydrosis. The author suggested that RSD was not as rare in children and young adults as the literature reviews had revealed (Greipp, 1990). Greipp also recognized that by 1990 the disorder was not classified with an international classification of disease code (ICD). The author also endorsed documentation of all cases of RSD to provide a better perspective of this disease process (Greipp, 1990).

Subsequent to Greipp's work RSD was given an ICD code. There are actually four categories--each with a different ICD code--to demarcate the characteristics. The four categories include: (a) unspecified site, (b) other specified site, (c) upper extremity, and (d) lower extremity (Reflex Sympathetic Dystrophy Association, 1998).

Other Pertinent Nursing Literature

Identifying the role in which nursing should embrace this poorly understood disorder requires an understanding of certain aspects of the discipline. The role of the Advanced Practice Registered Nurse (APRN) is discussed along with the responsibility the discipline of nursing has to contribute to the further study of this confusing phenomena.

The APRN works independently as well as in collaboration with a variety of individuals to diagnose and manage clients' health care problems. The general scope of services provided by APRNs has three main categories: assessment of health status, diagnosis, and case management. The role is characterized by an emphasis on health promotion and disease prevention; in addition, it involves the diagnosis and management of common acute illnesses/injuries and stable chronic diseases. In the provision of these services, APRNs may order, conduct, and interpret appropriate diagnostic and laboratory tests and prescribe pharmacological agents, treatments, and nonpharmacologic therapies (Sherwood, Brown, Fay, & Wardell, 1997).

Controversies surrounding RSD have made it difficult to educate the health care community. This is compounded by the well-documented challenge for rural nurses to maintain proficiency in multiple areas of nursing (Bushy, 1991). The challenge of rural nurses to access professional development is compounded by geographical and professional isolation (Berry & Seavey, 1994).

McCarthy and Hegney (1998) conducted a literature review exploring issues related to evidence-based practice and rural nursing. The authors stated, "It is important that nurses' awareness and understanding of evidence-based practice be enhanced and that strategies for fostering the development of clinically relevant programs of nursing research be identified for rural health services" (McCarthy & Hegney, 1998, p. 97). Traditional needs assessment for continuing education reflect personal interests and perceptions of learning needs rather than an actual knowledge deficit (Maloney & Kane, 1995). The need for an increase in awareness and synthesis of nursing knowledge development is consistent with nursing's holistic focus (Copnell, 1998).

Theoretical Perspective

As a pioneer in the research of describing the level of awareness regarding RSD, certain assumptions where made to rationalize outcomes. Due to the complexity of RSD, a diverse selection of perspectives were used to understand the problem.

The research instrumental in the publication of From Novice to Expert by Patricia Benner provides assistance in explaining possible explanations for why some participants

in this study have a greater awareness of RSD than others. Patricia Benner explained that as nurses pass through levels of proficiency there is a "shift from reliance on analytical, rule-based thinking to intuition." For example, the expert nurse learns to recognize subtle physiological changes more effortlessly than the novice nurse does (Benner, 1984). As stated by Benner (1984), "The skills acquired through nursing experience and the perceptual awareness expert nurses develop as decision makers . . . lead them to follow their hunches as they search for evidence to confirm the subtle changes they observe in patients" (p.165).

The skill of the nurse and professional "intuition" will lead to a questioning of unexplained symptoms. Intuition has been an essential component of nursing clinical judgment for over 20 years. It is characteristic of a nurse to acquire "gut" feelings about a patient. These feelings may simply be that the nurse believes there is a deviation from the norm. This form of awareness is recognized as relevant and has been termed as "intuitive knowing" (King & Appleton, 1997).

Woods (1998) suggested that when the discipline of nursing develops a "passion" for a particular phenomenon a number of events take place. A desire to learn more about a particular population or disease process generates knowledge that is more sensitive to the individuals, families, and populations that are studied. This sensitive knowledge stems from the exploration of individual experiences and perceptions regarding the phenomena under study. Once an increase in knowledge is obtained, collaboration with

other disciplines--excluding geographic boundaries--is encouraged. The final event that occurs involves personal satisfaction towards the discipline of nursing for engaging in knowledge development (Woods, 1998).

Implementing interventions based on the knowledge gained is where nursing turns to Milio's framework for prevention. An upstream view encourages health-promoting choices and recommends that society be responsible to provide resources needed to promote healthy choices (Milio, 1976).

Summary

Reflex Sympathetic Dystrophy is a complex, multisymptom pain condition that was described during the early 1700s and is still poorly understood. The consequence of the obscurity of this disease is the presence of an underserved population; a population that feels isolated and misunderstood. Although controversy surrounds the pathophysiology, diagnosis, and treatment of RSD, researchers are in agreement that early recognition of the subtle, early symptoms is crucial for an appropriate treatment plan (Peck, 1998).

The underserved population in Montana is of great concern. In the study performed by the national RSD Association between 1993 and 1996, it was identified that Montana was 1 of 4 states without reported cases of RSD, and the only 4 states that do not have a local RSD association. The RSD associations in the 46 states collected the

data necessary for the study. One may argue that Montana does not have an association because there are no cases in the state; conversely, confirmation that there are persons with RSD in Montana was obtained from one clinic in one county of Montana. There are no documented statistics for persons with RSD in Montana although estimations could be cited following a review of national statistics.

Nursing research regarding this disorder is greatly lacking. However, nursing theory provides standards of care to facilitate appropriate actions for all conditions. APRNs have the ability if adequately trained to diagnose and treat RSD. Implementing preventive, holistic care for persons diagnosed with the condition is crucial. Becoming advocates for an underserved population will be possible with a better understanding of this complicating problem.

CHAPTER 3

METHODS

An exploratory, descriptive design utilizing the survey method was used in this study. This study was designed to elicit information regarding the level of awareness about a complex, poorly understood disorder and factors influencing that level of awareness. The need for education regarding the condition was also explored.

Research Methodology

The research was conducted using a questionnaire mailed to a target population. Survey research is the most common type of research, and the questionnaire was an easy-to-use and relatively inexpensive method for collecting data from a large sample. The questionnaire consisted of 27 fixed-choice questions developed by the researcher with a few questions requiring explanation of the choice selected. The self-administered questionnaire was descriptive in design and included demographic information. The estimated time for completion of the questionnaire was 10 minutes.

The majority of the questionnaires were sent to the participants' home addresses with a few sent to business addresses. It was important to assure a nonthreatening environment in which to complete the questionnaire considering the potential apprehension by the Advanced Practice Registered Nurses (APRN) related to answering questions about an unfamiliar subject.