Coping with Chronic Fatigue

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COPING WITH CHRONIC FATIGUE

Susan Lynne Jensen, Ph.D.
Western Michigan University, 2000

The purpose of this study was to examine sense of coherence in those individuals diagnosed with chronic fatigue syndrome (CFS), and to explore its relationship to age, gender, work status, duration of illness, fatigue and functional ability/disability in this population.

This study used a combined methods approach, using both qualitative and quantitative methods. A sample of thirty individuals diagnosed with chronic fatigue syndrome was surveyed by means of a self-administered questionnaire, including Antonovsky’s 13-item shortened Sense of Coherence (SOC) scale. A subset of 12 participants participated in the qualitative portion of the study, and answered specific questions regarding their experiences with chronic fatigue syndrome.

No relationship was found between sense of coherence and the CFS patient in terms of age, gender, employment status, duration of illness or fatigue. A significant difference was found between the SOC in the CFS patient and the SOC of other populations diagnosed with a chronic illness, which suggests that CFS may be different in its effects upon the individual than are other chronic illnesses. Qualitative data showed that the CFS individual found life increasingly chaotic, with little manageability, comprehensibility or meaningfulness. This individual experienced an
increase in general resistance deficits (GRDs) with fewer general resistance resources (GRRs) to mitigate the chronicity of his/her illness.

Sense of Coherence in the CFS individual is a concept that needs much additional research. Medical sociologists, as well as health care professionals need to further elucidate the concept of Sense of Coherence, and develop appropriate interventions to more effectively support those individuals diagnosed with chronic fatigue syndrome.
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Susan Lynne Jensen
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CHAPTER I

INTRODUCTION

This research examines the relationship between a dispositional orientation of the human personality, one's sense of coherence (SOC), and adjustment to a chronic and debilitating disease. It is hypothesized that one's SOC, characterized by an individual's global orientation to how manageable, comprehensible and meaningful one views the world to be, can have a major impact on how successfully that individual deals with life's ups and downs, and more specifically, how effectively he/she deals with a chronic illness. The disability that can result from a chronic illness is a serious public health and social issue all over the world. In the United States alone, approximately 35 million individuals experience some limitations in activity related to chronic health problems or impairments (NCHS Website, 2000). These chronic health problems result in very high health care costs as well as decreased productivity in the workplace.

Chronic fatigue syndrome, or CFS, is an enigmatic, chronic illness that afflicts many thousands of people in the United States alone and perhaps millions worldwide. The etiology, diagnosis, and treatment of this disease process are unclear. Most recover only partially, or do not recover at all, and become permanently disabled (Bombadier & Buchwald, 1995). Additionally, because of the lack of objective data validating the subjective complaints of the individual experiencing this
illness, many who have been diagnosed with CFS face a disbelieving health care system, as well as the eventual decreased support from family and friends. The CFS patient often reports feelings of stigma attached to this disease, similar in nature to the stigma an individual diagnosed with a mental disorder would feel. Therefore, increasing our understanding of the mysteries surrounding the experience of chronic fatigue syndrome is of vital importance to health care professionals and to those afflicted with this puzzling illness, as well as their friends and families.

Although CFS is a much-researched illness, it has not been studied in relation to sense of coherence. Sense of coherence, a concept developed by sociologist Aaron Antonovsky, attempts to explain a person’s response to illness by quantifying how manageable, comprehensible, and meaningful one views the world to be (Antonovsky, 1995; Antonovsky, 1996; Antonovsky & Sagy, 1986). How does one's sense of coherence affect those afflicted with chronic fatigue syndrome? Is there a relationship between sense of coherence and functional disability, age, gender, employment status, or duration of illness in those individuals diagnosed with CFS? Does the sense of coherence in the CFS population differ from that of other populations, and from that of individuals diagnosed with other chronic illnesses? If so, why does it differ? Understanding why an individual becomes ill with any disease process is of increasing importance to today's society in the face of a shrinking health care dollar and an aging population, many of which are riddled with chronic illnesses. Therefore, increasing our understanding of sense of coherence in the population of chronic fatigue syndrome patients will hopefully increase our awareness and improve
our ability to more effectively treat those individuals diagnosed with this debilitating illness.

**Chronic Fatigue Syndrome**

Chronic fatigue syndrome is a much researched and little understood debilitating disorder characterized by profound tiredness or fatigue lasting six months or longer. Individuals with chronic fatigue syndrome, or CFS, may become exhausted with only light physical exertion. These persons often must function at a level of activity substantially lower than their capacity before the onset of illness. Many do not recover, and become permanently disabled, unable to continue holding a job, attending school, or caring for family members. In addition to these key defining characteristics, those with CFS often report various nonspecific symptoms, including muscle aches and pains, weakness, malaise, fever, excessive sleep, sore throat, tender lymph nodes, impaired memory and/or mental concentration, insomnia, and depression (Joyce, Hotopf, & Wessely, 1990; Katon & Russo, 1992).

The Centers for Disease Control (CDC) has estimated that at least 500,000 individuals in the United States alone are afflicted with CFS (Chronic Fatigue Syndrome Website, 2000). Millions worldwide may be affected with this disease. Dr. William Reeves, chief of the CDC branch responsible for researching CFS, stated that this disease process affects women and men of all racial and ethnic groups, as well as adolescents and children. However, because white women have the greatest risk for this disease, the CDC has concluded that CFS is a serious women’s public
health concern. In fact, a Caucasian woman has a much greater risk of becoming ill with CFS than she does of contracting HIV, AIDS, or lung cancer (CFS Website, 2000).

The etiology of this disease process has not yet been identified, and no specific diagnostic tests are available. Moreover, incapacitating fatigue can be associated with a wide range of well-defined illnesses, such as cancer, subacute infections, depression, auto-immune diseases, and hormonal disorders. Since many of these diseases are treatable, other causes of fatigue must be ruled out before a diagnosis of CFS can be made. A diagnosis can be reached only through this process of elimination. However, even with the lack of objective findings and difficulty with diagnosing, many clinicians believe that CFS is a genuine clinical condition whose etiology, diagnosis, and treatment is the focus of intense research (Bombardier & Buchwald, 1995; Clark et al., 1995; Lewis, Heitkemper, & Dirksen, 2000). On the other hand, there are still a large number of health care providers who, because of the lack of identifiable, objective data, do not believe that this disease exists or believe that it exists on a psychological (emotional) rather than physiological basis (CFS Website, 2000). Therefore, the individuals diagnosed with CFS must deal not only with an incapacitating disease, but also with a disbelieving public, who may regard the ill individual as a "slacker," "malingering," or one trying to avoid work or other responsibilities.
Medicalization of Deviance and the Sick Role

Because the individual diagnosed with CFS cannot verify the existence of his/her disease through the normal channels (by acknowledgement via the medical community, objective data, etc.), this individual is often thought of as exhibiting deviant behavior. If no objective data exists, then oftentimes, the symptoms the person is reporting is thought to be “in his/her head”, and not given much credibility by the public. Peter Conrad (1992) coined and initiated much discussion regarding the concept of ‘medicalization of deviance’ in today’s society. Subsequently, much has been written about this phenomenon.

It was clear that the medical model-focusing on individual organic pathology and positing physiological etiologies and biomedical interventions-was being applied to a wide range of human phenomena. Human life, some critics observed, was increasingly seen as a sickness-wellness continuum, with significant (if not obvious) social consequences (Conrad, 1997, p. 402).

Talcott Parsons first described the sick role, and is credited with assigning sickness as a form of deviance. Deviance in this context means non-normative behavior. According to Parsons, the sick individual in today’s society is expected to act the part, to not appear to enjoy his/her sickness, and is expected to do whatever is necessary to regain his/her health as soon as possible. Further, the ill individual is not to be blamed for the illness, is to be excused from normal day to day responsibilities and obligations for the duration of the illness, and is expected to seek whatever medical attention is necessary to make a speedy recovery (Cockerham, 1998; Conrad, 1997; Freund & McGuire, 1995; Heinonen, 1993). However, if a diagnosis cannot be made for whatever reason, the ill individual is not allowed to
enter the sick role and reap the benefits of that role. Human beings, however, do not just feel the effects of an illness physiologically, but also emotionally, spiritually and socially. Conrad and Kern (as cited in Heinonen, 1993) stated:

> When a veterinarian diagnoses a cow's condition as an illness, he does not merely by diagnosis change the cow's behavior, but when a physician diagnoses a human condition as an illness, he changes the man's behavior by diagnosis: A social state is added to a biophysiological state by assigning the meaning of illness to disease. (p. 33)

The real meaning of illness that is encompassed in the sick role, then, includes all that the individual experiences as a result of the disease, including the biophysical state as well as social expectations and interactions. Heinonen (1993) asserted:

> The most salient aspect of the sick role...is that since a person, when ill, is relieved of certain obligations, they are also spared the stigma that accompanies other possible outcomes, such as psychiatric diagnosis or the deviant designation of malingerer...In certain instances, some groups of people do not merely accept the sick role, but seek it precisely because of its power to destigmatize otherwise deviant behaviors. (p. 19)

It is in this vein, then, that some health care providers have decided (and this decision may have been a conscious one or an unconscious one) that individuals presenting with symptoms of CFS fall into the category of using an amorphous condition that cannot be verified by current diagnostic methods as a valid escape from perhaps overwhelming roles and expectations.

Lagerwey & Markle (1994) discussed the sick role as portrayed by Edith Wharton in her novel Ethan Frome, which took place in the early 20th century. Whereas Parsons' sick role was dependant upon a purportedly objective medical diagnosis, Wharton's sick role existed and was legitimized in "intricate community and family negotiations" (p. 130). Because medical authority was fragmented and
weak at this time of American history, but desirous of obtaining true cultural authority, it was common for physicians of the day to give names to what they identified as common ailments. “An umbrella diagnosis such as hysteria was a convenient way to classify and dismiss any problematic symptoms for which medicine could find no specific organic etiology” (Lagerwey & Markle, 1994, p. 129). Once a label had been affixed, the individual was allowed to enter into the sick role. This role did not exist in a vacuum, but had rather extensive and serious ramifications. Middle and upper class women were regarded as fragile creatures who spent a good deal of their time attending to their various ailments. Lower class women, in an attempt to enjoy the attention those in the upper classes had, often tried to imitate the actions of the upper class women. “When circumstances permitted, rural and working class women could also find secondary gains of an invalid status very attractive – a relief from monotony and a means of avoiding the arduous demands of rural life” (Lagerwey & Markle, 1994, p. 129). Thus, a cycle was created in which a woman had some non-specific symptoms, went to her physician, who, not wanting to appear as if he did not know what was wrong, gave the woman a “label”, or a diagnosis, and in so doing, validated her symptoms. The female could then say “Look, I’m sick...now I need attention”, and receive whatever secondary gains were available in that situation. Wharton’s sick role, then, was less concerned with medical issues surrounding the taking on of the sick role, but instead, focused on the importance of social class, gender, and community in the definition and legitimization of this role.

Today, an individual with a chronic illness enters into the sick role only after
he/she exhibits symptoms and receives a medical diagnosis validating the individual's complaints. If no definitive diagnosis can be made because of the lack of objective data, then the ill individual is not allowed to enjoy whatever rewards that sick role may entail. Further, much as Wharton's novel depicted, the sick role of the CFS individual does not occur in a vacuum, but is dependent upon such factors as social class, gender, and how the community defines (gives credibility) to the diagnosis of CFS.

Salutogenesis

For many years, health researchers have asked why one person becomes ill, while another in a comparable environment, with a similar genetic makeup, remains vigorously healthy. Aaron Antonovsky's salutogenic paradigm is a relatively new construct in the field of health research that attempts to address this question. Antonovsky was the first sociologist to place an emphasis on the salutogenic, or the origins of health and wellness paradigm. He was interested in how people manage stress and stay well (Antonovsky, 1995; Antonovsky, 1996; Antonovsky & Sagy, 1986). The salutogenic model describes the interactional relationship between such factors as stressors, states of tension, coping ability of the organism, and outcomes in terms of tension management and health status. A major difference between salutogenesis and the current medical model of disease is that salutogenesis asks what is it that keeps an individual healthy, rather than what makes a person ill. Strumpfer (1990) has done much work in support of the salutogenic paradigm. He has proposed
that the concept of salutogenesis be broadened to include the origins of psychological strength in general. Strumpfer (1995) refers to this concept as fortigenesis, and asserts that "fortigenesis" is more embracing, more holistic, than "salutogenesis" (p. 82). Whether using salutogenesis or fortigenesis, understanding how and why people stay well is of fundamental importance in research and practice for those in the various fields of health sciences, whose primary concern are the maintenance and enhancement of wellness. Further, with the increased emphasis on medical cost containment, and the aging of the population, understanding how people stay well, and respond positively to the various stresses and obstacles in life, will become of increasing importance.

**Sense of Coherence**

Inherent in this salutogenic paradigm is a concept called 'Sense of Coherence'. This concept combines and synthesizes the earlier concepts of Frankl's 'will to meaning', Rotter's 'locus of control', Seligman's 'learned helplessness', and Kobasa's 'hardiness' into a more encompassing concept which researchers have found useful to determine how and why some individuals respond to illness and hardship with a strong determination to overcome, while other individuals become weaker and more disabled when faced with extreme circumstances (Strumpfer, 1990; Sullivan, 1993). Antonovsky defined sense of coherence as:

A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one
to meet the demands posed by these stimuli; and (3) the demands posed by these challenges, are worthy of investment and engagement (Antonovsky, 1996, p. 170).

A strong SOC is associated with successful tension management and lower stress, which places one toward the "health ease" end of the health status continuum. A weak SOC would be associated with less successful tension management, greater stress, and placement toward the "health dis-ease" end of the health status continuum (Coe, 1997, p. 5).

Essentially, an individual with a strong SOC views his/her world as more comprehensible, manageable and meaningful.

Sense of coherence is perhaps the most encompassing of the concepts developed in an attempt to explain an individual's response to illness. Theoretical developments which have assumed a prominent role in the study of coping, stress, and health include the identification of various 'stress buffers', several of which bear a strong resemblance to each other: Rotter's 'locus of control', and Kobassa's 'hardiness' are two such examples (Sullivan, 1993). However, none of the previously developed constructs of stress buffers use Antonovsky's salutogenic approach to health. "The SOC, then, is a perception of ability to cope which incorporates dimensions of comprehensibility, manageability and meaningfulness as part of the process of appraisal of stimuli, recognition of tension and appropriate choice of resources to meet the challenge" (Coe, Romeis, Tang & Wolinsky, 1990, p. 288). Individuals with a high SOC would, when under increasing duress in life, have the ability to draw from various positive coping mechanisms and select those coping devices most appropriate for the situation at hand. Antonovsky proposes then, that those individuals with a high SOC would be able to face various situations with a higher number of appropriate
responses, and therefore, suffer less from the side effects of prolonged stress, such as physical or mental disorder. In the population of CFS individuals, he would assert that those with a higher sense of coherence would exhibit decreased levels of fatigue, perhaps decreased illness duration, as well as decreased functional disability.

Purpose

The purpose of this study is to examine sense of coherence in those individuals diagnosed with chronic fatigue syndrome, and to explore and describe the experience of the chronic fatigue syndrome individual. The study will address whether there is a relationship between age, gender, work status, duration of illness, fatigue, or functional ability/disability and sense of coherence in the CFS patient, and whether the sense of coherence in the CFS patient differs from the sense of coherence in individuals diagnosed with other chronic illnesses. By increasing our understanding of the relationship between sense of coherence and adjustment to CFS, the healthcare professional will have an increased understanding of how to better support the individual diagnosed with this potentially incapacitating illness.

Overview of the Study

This study is presented in six chapters. The first chapter introduces the problem, need for the study, and purpose of the study. In Chapter II, a review of the literature is presented. The method, data collection procedures, instruments utilized, reliability and validity, data analysis and interpretation, source of subjects and
protection of human rights are presented in Chapter III. The data analysis is presented in Chapter IV. A discussion of the experience of the CFS patient, which includes a presentation of qualitative data, is presented in Chapter V, and in Chapter VI, the results and interpretation of the study are discussed, as well as its limitations.
CHAPTER II

REVIEW OF THE LITERATURE

This research focuses on describing the experience of the CFS individual in relation to sense of coherence, fatigue, work, and functional ability. In this chapter, a review of the literature addresses the concepts of fatigue, chronic fatigue syndrome, salutogenesis, and sense of coherence. Sense of coherence will be reviewed across various other populations in order to provide a greater understanding of how SOC has been researched in the past. No literature was found regarding gender, work status or functional ability in relation to sense of coherence, however, these concepts will be addressed in Chapter III.

Fatigue

Unfortunately, there is a dearth of research on the concept of fatigue. In general, fatigue is a universally reported symptom in most disease processes. In fact, it may be one of the most prevalent symptoms reported in people suffering from physical or mental diseases. This fatigue may be induced in the ill individual by the disease process itself and, in part, by anxiety about the diagnosis (or lack of), treatment (or lack of), and by the resultant changes in lifestyle as a consequence of illness. Physiologically, the body's responses to this stress and apprehension lead to an increase in the amount of fatigue experienced due to the body's increased energy...
expenditures. Varrichio (1985, p. 122) defined fatigue as "a subjective sense of weariness or tiredness resulting from exertion or stress or as a condition of impaired efficiency resulting from prolonged mental and/or physical activity, or from an attitude of boredom or from disgust from monotonous work". Fatigue may be the result of an imbalance caused by psychological, physiological, or pathophysiological factors. Mitchell (1986) asserted that chronic fatigue is most often attributed to stress, may affect multiple body systems, and has manifestations similar to those of sleep deprivation. For the purpose of this dissertation, fatigue is defined as:

...acute, normative, or chronic...a subjective feeling existing at one point in time on a continuum from weariness to complete exhaustion, resulting from physical, mental, or emotional activity. Acute fatigue is most often caused by excessive physical or mental exertion and can be relieved by rest. Normative fatigue may be influenced by circadian rhythms and result from the activities of daily living, while chronic fatigue is most often the result of prolonged stress or tension on the body and is less likely to be relieved by rest alone (Jensen & Given, 1991, p. 182).

Individuals diagnosed with CFS would most likely assert that they are frequently at or near the "complete exhaustion" end of the continuum.

In medical terms, fatigue is not a distinct entity but refers to "a group of phenomena associated with the impairment or loss of efficiency or boredom" (McFarland, 1971, p. 1). According to McFarland, the kind of fatigue caused by hard muscular work is acute and results in a temporary loss of efficiency that can be relieved by rest. Chronic fatigue, however, is not relieved by sleep or rest and is cumulative in its effects. This kind of fatigue may have a psychological or psychiatric base characterized by loss of initiative, boredom, and progressive anxiety.

Jensen and Given (1991) studied fatigue in 248 caregivers of cancer patients
and found no relationship between severity of fatigue and caregiver age, employment status, the number of hours of daily caregiving, or the duration of the caregiving experience. A significant relationship was found between caregiver fatigue and the impact of care on the caregiver's schedule. This study contained a large sample size, and used multiple methods to ascertain findings. Recommendations for future research included a longitudinal study, from the onset of caregiving through the terminal phase, which would reveal critical points in the caregiving process at which interventions by health care professionals could be initiated. The authors concluded that increasing our understanding of the factors leading to caregiver stress and fatigue would contribute to better care and support of both the patient and the caregiver.

Barbara Piper has done much work developing a conceptual framework upon which to study the experience of fatigue. Her proposed framework permits multidisciplinary perspectives and identifies strategies for developing nursing theory related to the fatigue reported among cancer patients. Piper, Lindsay and Dodd (1984) developed a visual analogue fatigue scale by which to measure subjective dimensions of fatigue. Piper tested the fatigue scale on 50 newly diagnosed breast and lung cancer patients and noted that the scale effectively measured the temporal, affective, intensity/severity, and sensory dimensions of fatigue (Piper, 1985).

**Chronic Fatigue Syndrome**

Chronic fatigue syndrome (CFS) is an illness characterized by prolonged, debilitating fatigue and multiple nonspecific symptoms such as headache, recurrent
sore throats, muscle and joint pains, and cognitive complaints. Profound fatigue, the hallmark of the disorder, can come on suddenly or gradually and persists or recurs throughout the period of illness. Unlike the short term disability of an acute infection, CFS symptoms by definition, linger for at least six months and often for years (Bombardier & Buchwald, 1995; Clark et al., 1995; Joyce et al., 1997; Katon & Russo, 1992).

Although CFS is currently being extensively researched, few studies have been published investigating the psychosocial impact of this illness. Vercoulen et al. (1996) studied 246 patients diagnosed with chronic fatigue syndrome over an 18 month interval and found that 3% of patients reported a complete recovery, and 17% reported improvement. The overwhelming majority of 80%, however, showed no improvement in symptoms. Socio-demographic variables, a change or improvement in life circumstances, or treatment by alternative practitioners or specialists did not predict improvement.

In another longitudinal study over a 4-year period, Wilson et al. (1994) studied 103 persons diagnosed with CFS and found that 65 had improved, but only 6 reported no current symptoms. There was no relationship between outcome and age of illness onset, duration of illness, premorbid psychiatric diagnoses, neuroticism, or cell-mediated immune function. Overall, these researchers found that although most patients with CFS improve somewhat, a substantial proportion remain functionally impaired. Further, psychological factors such as illness attitudes and coping style appear to be more important predictors of long term outcome than demographics or
Poteliakhoff (1998) asserted that there is some clinical evidence that connective tissue disorders (many of which are regarded as autoimmune disorders) may be linked to CFS. These illnesses occur approximately one year after the onset of prolonged or chronic fatigue, with the implication that fatigue is not merely a symptom of these diseases, but precedes them. Poteliakhoff states that changes in the immune systems of CFS patients could be conducive to the subsequent development of various autoimmune disorders such as lupus, rheumatoid arthritis, and multiple sclerosis. He hypothesized that the cortisol insufficiency often seen in CFS patients allowed the immune system to become overactive, resulting in the increased frequency of autoimmune disorders seen in CFS patients. He discusses the proposed etiology of rheumatoid arthritis (RA) as viral or bacterial infections and psychosocial stress as being the initiating agents in genetically susceptible subjects (the same factors as are thought to initiate CFS). Mild cortisol insufficiency and the immune changes found in CFS could usher in the advent of RA. He asserts that the diminuation of corticosteroids, such as cortisol, found in CFS patients, could cause other autoimmune dysfunction such as lupus, multiple sclerosis, and RA.

Hartz, Kuhn, and Levine (1998) investigated fatigued persons with symptoms associated with CFS. They found that these fatigued patients experienced the following symptoms much of the time: impaired short term memory or concentration, sore throat, headache, tender lymph nodes, muscle aches and joint pain, unrefreshing sleep, post-exertional fatigue over 24 hours, sudden onset fatigue and fatigue that
interferes with work, family and social life. They also found frequent sinus or respiratory infections associated with CFS.

Despite multi-disciplinary investigations into the causes of CFS, its etiology remains unknown. Similarly, no specific diagnostic tests or therapies for CFS exist. A supportive program of patient management—including symptom based treatment, education about the disease, and regular follow up visits to rule out alternative diagnoses can offer reassurance and help individuals and their families adjust to living with this chronic illness.

Epidemiology of Chronic Fatigue Syndrome

Most CFS cases are sporadic. No published data indicate that CFS is contagious, that it can be transmitted through intimate or casual contact or by blood transfusions, or that people with CFS need to be isolated in any way. CFS is diagnosed two to four times more often in females than in males, which may be the result of biological, psychological, and social influences. The Center for Disease Control (CDC) estimates the minimum prevalence rate of CFS in the United States is 4 to 10 cases per 100,000 adults 18 years of age or older. Although the typical patient seeking medical care for CFS is a Caucasian woman between her mid 20s and late 40s, patients of both sexes across a wide range of ages, races, and socioeconomic groups have been affected. The demographics of the population currently diagnosed with CFS may be biased by cultural differences and access to medical care (Vercoulen et al., 1996; Wilson et al., 1994).
The diagnosis of CFS is primarily one of exclusion. CFS symptoms overlap with those of fibromyalgia, Lyme borreliosis, Lupus, early or mid multiple sclerosis, depression, and numerous other well recognized disorders. CFS and fibromyalgia, closely related illnesses, commonly coexist in the same patient. The diagnosis of fibromyalgia, however, unlike that of CFS, requires the detection of discrete tender points. Because CFS is so difficult to diagnose, it is estimated that most CFS patients see between 5 and 10 physicians before a concrete diagnosis is made (Clark et al., 1995).

CFS has also been reported in children as young as 2 years old, and is increasingly being diagnosed in the adolescent population (Dobbins et al., 1997; Jordan, Kolak, & Jason, 1997). In a four city surveillance, CDC researchers found a prevalence rate of 8.7 per 100,000 for chronic fatigue, and 2.7 per 100,000 for CFS in children ages 12-17. In the San Francisco study, a prevalence of 71.9 per 100,000 for chronic fatigue was found in ages 2-11, but no actual diagnoses of CFS were reported in this age group (Dobbins et al., 1997; Jordan et al., 1997). It is thought that CFS is under-reported in the younger child and adolescent population because physicians are not looking for this disease process in children. However, referrals from school nurses in Wichita, KS, and Reno, NV, showed prevalences of 52.9 per 100,000 for chronic fatigue, and 24.0 for CFS in the age group 12-17 year olds. The course of CFS in the pediatric and adolescent client remains unknown. It has been suggested that at least 50 percent of children and adolescents diagnosed with CFS greatly improve or recover completely, while others appear to have a prolonged course, with
significant fatigue and activity limitations. It is also not known how these individuals will fare once they enter adulthood, and whether their functional disability will continue, perhaps worsening with time.

Clinical Manifestations of Chronic Fatigue Syndrome

CFS often begins abruptly, but the onset may also be gradual. In about one-third of cases, the sudden onset follows a respiratory, gastrointestinal, or other acute infection with flu-like symptoms, including mononucleosis. Other cases develop after emotional or physical traumas such as bereavement or surgery. Besides a debilitating fatigue unrestored by rest, common symptoms of CFS include more intense or changed patterns of headaches, reduced short term memory or concentration, recurrent sore throats, tender lymph nodes, muscle discomfort or pain, joint pain without joint swelling or redness, insomnia, anxiety and depression. Although CFS can persist for many years, longitudinal and follow up studies indicate that CFS generally is not a progressive illness. The symptoms are usually the most severe in the first year or two. Some patients partially recover, some fully recover, while others gradually worsen and eventually, become permanently disabled. Currently, an individual's course of illness cannot be predicted. The long-term health risks of individuals with CFS, such as an increased risk of cancer, are currently unknown (Bombardier & Buchwald, 1995; Clark et al., 1995).
The Medicalization of Chronic Fatigue Syndrome

Heinonen (1993), in discussing how CFS became “medicalized”, stated: “The concept of disease has, in the past one-hundred or so years, become so amorphous a term and so ambiguous as to make it unclear what actually falls within the realm of disease and what does not” (p. 35). By blurring the boundaries of what has been defined in the past as ‘disease’, the medical profession, by virtue of their ‘cultural authority’ (as discussed in Conrad & Schneider, 1980; Friedson, 1970; and Starr, 1982) can “create” new diseases, or “medicalize” non-normative behavior now defined as “deviant”. Over time, any behaviors defined by various kinds of medical professionals as “deviant” would be given new labels as disease processes worthy of treatment.

CFS does not appear to be a new illness; it was described in medical literature in the 1930s, and has existed under various guises for at least 150 years. In fact, case reports of comparable illnesses date back several centuries, some of which are possibly linked to bacterial, viral, or protozoal infections. Heinonen (1993) notes that during the last century there have been multiple disease processes that have been “medicalized” for a brief time which bear a striking resemblance to CFS. Asthenia, neurasthenia, nervous exhaustion, neuromyasthenia, the vapors, hysteria, hypochondrium, and total allergy syndrome all have been defined by vague symptomology similar to CFS. Most recently, in 1988, the illness then called ‘the Epstein-Barr virus syndrome’, was renamed chronic fatigue syndrome, and given a working case definition to improve comparability and reproducibility of clinical research and epidemiological
studies (Holmes et al., 1998). Since the renaming of this disease entity, there have been 'outbreaks' in Huron County, Michigan in 1992 (Fukuda et al., 1997) and in northern California in 1993 (Shefer et al., 1993), which the CDC investigated as potential CFS disease 'clusters'. Although a higher number of individuals were found to have a 'fatiguing disorder', there was no significant difference between ill individuals and the control group (those without CFS) in either locale. However, members of the Air Force deployed to the Gulf War also reported a significantly higher number of generalized fatiguing symptoms, similar to those experienced by CFS individuals, that were not associated with specific Gulf War exposures (currently referred to a “Gulf War Syndrome”). Most of these individuals report continuing chronic illness to this day (Fukuda et al., 1998). Nevertheless, in spite of similar chronic, debilitating ailments reported from all parts of the country and the world, much controversy remains as to whether or not CFS is a true medical condition, or one that has multiple psychological overtones.

Salutogenesis

Because the pathogenic approach to understanding health and illness has met with only a limited amount of success, sociologist Aaron Antonovsky proposed a different framework from which to delve into the mysteries of the human existence in relation to health and illness. He coined the term "salutogenesis" in 1978. Salutogenesis, according to Antonovsky (1996), makes:

a fundamentally different philosophical assertion about the world than does pathogenesis. It directs us to study the mystery of health in the face of a
microbiological and psychosocial entropic reality, a world in which risk factors, stressors or bugs are endemic and highly sophisticated (p. 171).

Antonovsky (1995) states:

This alternative paradigm enjoins us to confront the question of the origins of health, the movement toward the health end of what I call the health ease/dis ease continuum... Salutogenesis focuses on the strengths, on the mystery of movement toward health. It is the spirit of the more general scientific problem of 'order out of chaos' (p. 6).

Therefore, Antonovsky would maintain that complexity in our world results in stress and/or conflict which we, as human beings both singularly or collectively, deal with by either exhibiting a system's breakdown, resulting in chaos, or moving towards coherence represented by meaningfulness, comprehensibility and manageability of the particular stress or conflict (Antonovsky, 1993).

As conceptualized within the Salutogenic Model, an individual’s health is measured along a continuum between a salutary end (health-ease) and breakdown (dis-ease) at the opposite end (Antonovsky, 1979; 1987). The interplay of opposing forces of environmental threats (also known as general resistance deficits [GRDs], discussion to follow) and the individual’s resistance (known as general resistance resources [GRRs]) will determine one’s position and movement along the continuum.

Environmental threats are the stressors of everyday life. According to Antonovsky, an encounter with a stressor causes a state of tension in an individual. In order to manage this tension successfully, one must use effective coping behaviors. However, when tension is not managed effectively, when the demand for action exceeds the individual’s resources, the tension may lead to stress and to movement towards the disease end of the continuum (Antonovsky, 1993; Sullivan, 1993).
Strumpfer (1990) examined five constructs of salutogenesis (Korbasa's 'hardiness', Ben-Sira's 'potency', Thomas's and Colerick's 'stamina', Rosenbaum's 'learned resourcefulness', and Antonovsky's 'sense of coherence') and concluded that because of the similarities and because of their emergence from different disciplines, that a new paradigm was forthcoming – one that emphasizes the origins of health (salutogenesis), instead of merely focusing on the traditional pathogenic paradigm. In 1993, Strumpfer argued that the concept of salutogenesis should be broadened to include the origins of psychological strength as well. He termed this new concept 'fortigenesis'.

To assist the individual with coping behaviors, Antonovsky (1979) stated that there are broad categories of resources that promote successful tension management when one is under stress. He called these factors “Generalized Resistance Resources” (GRRs). According to Antonovsky, GRRs include such factors as knowledge and intelligence, material resources, social support systems, ego strength, cultural stability, a stable value/belief system, and genetic strength.

At the opposite end of the continuum from the GRRs are GRDs (Generalized Resistance Deficits), chronic stressors which can be defined as “characteristics that introduce entropy into the system” (Antonovsky, 1987, p. 28). A chronic stressor is defined as “some life situation, condition, or characteristic that is crucially descriptive of a person's life” (Antonovsky, 1987, p. 28). Therefore, having a chronic and debilitating illness would be a GRD. Antonovsky believed that GRRs-GRDs were one unified concept to be considered as a continuum of available resources/deficits.
The more GRRs an individual possessed, the stronger his/her sense of coherence. Conversely, the fewer GRRs a person has, when exposed to the many chronic and ubiquitous stressors that exist in day to day living, the weaker the sense of coherence.

Sullivan (1989) evaluated the Salutogenic Model and its potential usefulness as a nursing paradigm, and asserted that this model is suitable for adaptation to nursing. Nursing has long been dissatisfied with the pathogenic orientation to health, but has not adopted an alternative conceptual framework from which to further develop nursing theory. Sullivan found Antonovsky’s model to be explicit, comprehensible, logically congruent, socially significant, and to have utility. Sullivan (1989) states:

...to the extent that the nurse promotes effective tension management, helps to mobilize other GRRs, and strengthens the client against subsequent stressors, nursing can be viewed as a GRR. As a caregiver providing help with a particular problem, the nurse is a specific resistance resource. The concept of nursing is thus implicit in the Salutogenic Model (p. 337).

Sense of Coherence

Antonovsky's Sense of Coherence, the central concept in his salutogenic model, has drawn increasing attention from health care researchers. A salutogenic approach focuses on the factors that allow a person to maintain a level of health, or move a person towards the health-end of the ease/dis-ease continuum. According to Antonovsky (1990, p. 79), the SOC directly influences health in that “it leads one to engage in behaviors ...which promote health”. Thus, an individual with a strong SOC is more likely to adapt his/her responses to the demands of a specific situation rather than routinely responding in a rigid manner to every situation, as well as
choosing coping responses (GRRs) that are either neutral or health promoting (e.g., engaging in an exercise program instead of using alcohol to reduce tension).

In order to begin to quantify salutogenesis, Antonovsky developed the Sense of Coherence construct and a corresponding Sense of Coherence scale, in which there are 3 components: (1) comprehensibility, (2) manageability, and (3) meaningfulness. The first component, comprehensibility, which Antonovsky refers to as the cognitive aspect of the sense of coherence construct, is the extent of the belief that the problem (from the world as a whole to a given current issue) is clear. The second component, manageability, is the extent of the belief that not only did one understand the problem, but that one also possesses the required resources to cope successfully with the problem. The third dimension of sense of coherence, and the one that is considered most important, is meaningfulness, which is the extent of the belief that coping "makes sense" and that one is motivated to cope (Antonovsky, 1996). Antonovsky believed that sense of coherence might be the deciding factor in one’s ability to shape and maintain order out of chaos in the human internal and external environment.

Also inherent in Antonovsky’s sense of coherence construct is the concept of individual boundaries. Antonovsky maintained that every individual sets boundaries— for some, the scope is very broad while for others, very narrow.

What goes on outside these (boundaries), whether comprehensible, manageable, and meaningful or not, simply doesn’t matter much, is not of importance to us...The boundary notion suggests that one need not necessarily feel that all of life is highly comprehensible, manageable, and meaningful in order to have a strong SOC (Antonovsky, 1987, p. 22).

He maintained, however, that there were four spheres that could not be
ignored in boundary setting if one were to have a strong SOC. The first sphere is the individual’s own feelings, the second is immediate interpersonal relationships, the third is one’s major sphere of activity, and the fourth is existential issues of death, failures, shortcomings, conflict and isolation. Further, Antonovsky expressed the opinion that flexibility about those life areas included within the boundaries may be an effective way of maintaining a coherent view of one’s world by temporarily or permanently contracting from an area where demands are becoming less comprehensible or manageable or by expanding to include new areas within the boundaries (DeBruyn & Wagenfeld, 1994, p. 22).

Antonovsky felt then that one’s boundaries were fluid and reactive to life’s situations, and sense of coherence could be maintained by changing (contracting or expanding) one’s boundaries as necessary in order to maintain comprehensibility and manageability (Antonovsky, 1987; DeBruyn & Wagenfeld, 1994; Strumpfer, 1990). In the case of a chronically ill individual, the boundary of ‘major sphere of activity’ or work may need to contract, but the boundary of ‘immediate interpersonal relationships’, for example, may expand because the individual now has more time to devote to these relationships. Therefore, the sense of coherence in this individual may not change, but his/her boundaries might be temporarily or permanently altered.

Development of the Sense of Coherence Scale

Antonovsky (1993) discussed the development, construction, and uses of the Sense of Coherence scale. The original scale, a 29 item scale with proven reliability and validity, has been used in 20 or more countries, within all social classes, genders, various races, and with children as young as 10, as well as the elderly population.
This scale, considered to be the core of a complex theoretical model of salutogenesis, refers to a global orientation to one's location and movement on the health ease/disease continuum. A shortened sense of coherence scale with 13 items has a smaller alpha of internal consistency, but is still within an acceptable range (Cronbach's alpha of .91 with SOC-29 versus a Cronbach's alpha of .88 for SOC-13).

Various researchers have utilized the sense of coherence scale and found it to be both reliable and valid (Antonovsky, 1993; Callahan & Pincus, 1995). In general, researchers have found that sense of coherence is positively correlated to increased self-care, increased ability to perform Activities of Daily Living (ADLs), increased well-being, and decreased disability (Baker, 1994; Callahan & Pincus, 1995; Schnyder, Buchi, Morgeli, Sensky, & Klaghofer, 1999). High SOC was negatively correlated with neuroticism, anxiety, life stress, psychological distress and increased disability (Flannery & Flannery, 1990; Gibson & Cook, 1996; Rena, Moshe & Abraham, 1996). Initially, Antonovsky felt that sense of coherence was firmly established by age 30, and, for most individuals, stayed fairly constant over their lifetime. He originally viewed sense of coherence as stable and fundamental to an individual's personality (1979), but later recognized that the dynamic nature of life's experiences play an important role in shaping, and perhaps, re-shaping, one's sense of coherence (Antonovsky, 1987; Post-White et al., 1996). Therefore, Antonovsky's views on the establishment of SOC changed over time. Further, Antonovsky believed that there was entropy inherent in the human system, and that, over time, sense of coherence could erode in any individual through the various life challenges,
and this erosion might be especially prevalent in the chronically highly stressed individual. "A stressor, in sum, can be defined as a characteristic that introduces entropy into the system – that is, a life experience characterized by inconsistency, under- or overload, and exclusion from participation in decision making" (Antonovsky, 1987, p. 28). Thus, an individual in her 40s, who had developed a strong sense of coherence, but finds herself in a hopeless situation, such as a debilitating chronic illness, may over time, exhibit a decreased sense of coherence. Therefore, Antonovsky came to believe that sense of coherence may indeed be dynamic and changing, depending upon how meaningful, comprehensible and manageable life's events become to the individual (Antonovsky, 1987; Post-White et al., 1996).

Sense of Coherence in the Elderly Caregiver

The stress inherent in the caregiving role is a much-researched topic. In general, stress is "the nonspecific response of the body to any demand" (Selye, 1980, p. 127). As human beings, we are exposed to many different kinds of stress, including physical, chemical, emotional, spiritual, and intellectual. Selye asserts that stress can be unpleasant (distress) or pleasant (eustress), but regardless, demands that the body respond. The response to stress by the body will depend upon various physiological factors (age, gender, overall physical and mental health of the individual), the kind of stressor (distress or eustress), the coping strategies that the individual utilizes, and the perception of significance of the stress to the individual involved. Then, Antonovsky (1987) would assert, if the individual has a high SOC, he/she would evaluate the
stress (either consciously or unconsciously), and select the most appropriate coping strategy to deal effectively with the stress. Conversely, those with a low SOC may not be able to select positive coping mechanisms, and instead use a negative coping strategy such as substance abuse, which eventually, could further the deterioration of the individual's physical and mental health.

With the advent of people living longer with chronic illnesses, and the emphasis on cost containment, the chronically ill elderly are oftentimes cared for in the home by a family caregiver. This family caregiver may suffer from a chronic illness of his/her own, and must learn to balance his/her needs for self-care with the needs of the ill family member. A caregiver with a strong SOC would have a well-developed paradigm from which to operate. In this paradigm, the caregiver may have, as part of his/her coping mechanisms, such GRRs as strong social support, a supportive peer group of family and friends, and perhaps a religion that explicitly shows pathways to follow when stressful life situations emerge. "Caregivers with a strong SOC are more likely to cope in situationally appropriate ways: redefining the meaning of the situation, selecting realistic coping strategies, and avoiding potentially maladaptive or unhealthy behaviors" (Wagenfeld, Baro, Gallagher & Haepers, 1994, p. 259). Thus, for the caregiver with a strong sense of coherence, the caregiver role has meaning, is comprehensible, and with social support, is manageable.

Coe, Miller and Flaherty (1992) examined the relationship between sense of coherence and the perceived burden of caregiving for chronically ill elderly individuals in an exploratory study with 148 caregivers caring for persons with one of the
following conditions: Alzheimer's disease, confusion, urinary incontinence, recent fracture, or needing assistance with walking. Sense of coherence and perceived caregiver burdens were shown to have a statistically significant inverse relationship for each condition except urinary incontinence. Further, male caregivers were shown to have a higher sense of coherence than female caregivers.

Wagenfeld et al. (1994) explored the sense of coherence in samples of caregivers of demented and nondemented elderly individuals in Belgium. The SOC scale was adapted to a Flemish version that displayed good reliability and validity. Caregivers of 45 elderly individuals with a dementing disorder, 71 persons with a non-dementing disorder, and 10 individuals with both a dementing and a nondementing disorder were included in the study. Sense of coherence was consistently higher for caregivers of dementing individuals. Sense of coherence was found to be protective against role overload for the entire sample, but was more protective in situations of greater morbidity, thus, it appeared more protective in those caregivers of dementing patients. The authors speculated about the existence of a "threshold effect" for SOC which in essence would dictate that "When the going gets tough, the tough get going" (p. 259).

Examining sense of coherence in the caregiving population is an important first step in understanding sense of coherence in the CFS population, as the caregiving population deals with many of the same issues as CFS individuals. The fatigue, chronicity of illness, physical stress, and psychological strain of the caregiving situation may be similar in some ways to that of the CFS individual.
Sense of Coherence in Elderly Persons Diagnosed With Chronic Illnesses

The stress inherent in the caregiving role is also prevalent in those individuals diagnosed with a chronic illness. Callahan and Pincus (1995) studied 828 patients with rheumatoid arthritis. Participants were sent either the 13 item sense of coherence scale or the 29 item scale via mailed self-report questionnaires, as well as questionnaires on ADLs, a visual analogue pain scale, a Global Health Status Index, and the Rheumatology Attitudes Index. Those individuals reporting they were experiencing more difficulty in performing ADLs, increased pain, decreased global health status, and increased levels of perceived helplessness were more likely to have a lower sense of coherence.

Coe et al. (1990) examined sense of coherence in 240 older veterans in relation to measures of physical and mental health status and sociodemographic characteristics. Sense of coherence was strongly correlated to measures of subjective health status, particularly with a measure of mental health (morale), which could be expected to be strongly related to perceived ability to cope with stress.

Finally, in a study by Johansson, Hamrin and Larsson (1994), sense of coherence, as well as other possible predictors that may be utilized to assess the need for continued care once an elderly person has been discharged from the hospital, was studied in 53 Swedish elderly surgical and orthopedic patients at the time of hospital discharge and one month after discharge. Those individuals that were able to return home showed the highest sense of coherence, while those who were institutionalized showed the lowest. An interesting finding in this study showed that those who died
part way through the study had initially displayed a higher sense of coherence, than those individuals in the study who were institutionalized, perhaps suggesting that a lack of control (being institutionalized) may be related to one's SOC.

Examining SOC in the aging population is an important first step in understanding this concept and its utility to serve a growing elderly population. Those seniors with poor perceived health status, poor morale, or a weak support system most probably also display a weak sense of coherence and may be at increased risk for illnesses, because a weak sense of coherence does not provide mitigating buffers against stress (Callahan & Pincus, 1995; Coe et al., 1990; Coe, Romeis & Hall, 1994). Although Coe et al. (1994) did not find sense of coherence to be a predictor of long term survival in chronically ill veterans, more research is needed to see if other studies support this finding in the older population in general.

An understanding of sense of coherence in the elderly population may also give us some idea of how sense of coherence may apply in the CFS population, as those individuals diagnosed with CFS may also experience poor perceived health status as well as poor morale.

**Sense of Coherence in Non-Elderly Persons**
**With Terminal and Chronic Illnesses**

Sense of coherence has recently been examined in younger populations diagnosed with potentially terminal disease processes, including cancer. The diagnosis of cancer creates a profound psychological disturbance in most, if not all, people. Emotional distress is an understandable and realistic response since, notwithstanding...
advances in treatment, cancer may still entail grave consequences for the individual and family. Forsberg and Bjorvell (1996) measured sense of coherence and psychological well-being in 69 individuals diagnosed with gastro-intestinal cancer, and 20 patients with permanent ostomies. The cancer patients were retested one year post-operatively. Those with stronger sense of coherence rated themselves as less helpless, more socially linked, more confident, having more self-worth, and more hopeful than those with a lower sense of coherence. Further, those with a high sense of coherence also displayed a better acceptance of ostomy surgery.

Forsberg, Bjorvell and Cedermark (1996) studied 79 individuals diagnosed with colo-rectal or gastric cancer to investigate a possible relationship between well-being and sense of coherence. Sense of coherence, well-being (measured by a Health Index) and a symptom checklist were measured before surgery and six weeks after surgery. It was found that the sense of coherence score was positively correlated and significant with the Health Index score, indicating that the stronger the sense of coherence, the better the perceived well being.

Post-White et al. (1996) examined sense of coherence, hope, spirituality and quality of life in 32 cancer patients. These researchers conducted a combined study of qualitative and quantitative research and found that hope and sense of coherence were highly correlated, although no relationship was found between hope and spirituality.

Lundman and Norberg (1993) examined the significance of sense of coherence in 20 individuals diagnosed with insulin dependent diabetes and found a
significant correlation between sense of coherence and coping patterns, problems in relation to the environment, well being, and tedium. The authors concluded that sense of coherence was an important factor contributing to successful emotional coping with the demands of diabetes.

Other studies have examined sense of coherence in a younger population in relation to chronic illness and/or disabilities. Klang, Bjorvell and Clyne (1996) analyzed predialytic uremic patients' emotional and functional status, well being, and sense of coherence in relation to education, sex, marital status and disease duration. Those with less education reported a significantly weaker sense of coherence in comparison with those patients who had a college education. However, sex, marital status, and duration of disease did not significantly correspond to sense of coherence.

In another study, Motzer and Stewart (1996) examined 149 individuals with coronary heart disease who had survived a myocardial infarction, to determine the effect sense of coherence has as a predictor of quality of life for this population. Multiple regression was used to determine the amount of variability that sense of coherence, as well as other factors, such as social status variables (e.g. social support, etc.), self esteem, and instability of chronic illness trajectory, has as a predictor of quality of life. It was found that a large amount of additional variance in quality of life was explained by sense of coherence after controlling for multiple predictors used in past research.

Rena et al. (1996) examined the link between sense of coherence and adjustment to a disability situation. The sample consisted of 80 individuals with spinal
cord injury or a neurologically disabling condition and 72 of the spouses. Sense of coherence, disability acceptance, anxiety, and health perception were measured by personal interviews and questionnaires. The researchers found that the higher the sense of coherence, the better the adjustment. Also, the higher the sense of coherence, the fewer marital problems, the lower the sense of dependency, and the more involved one is in work or other important activities. Meaningfulness was found to be the strongest contributor to the sense of coherence scale. These findings suggest that the three components of sense of coherence may have independent values in different situations, and perhaps should be analyzed separately.

Santavirta et al. (1996) conducted a 5-year longitudinal study with 85 individuals diagnosed with chronic low back pain for which an anterior low-back fusion had been done. The researchers found that sense of coherence was an effective predictor of successful coping capabilities, and this predictive value was especially good in those individuals between 35 and 50 years of age.

Soderberg, Lundman, and Norberg (1997) examined sense of coherence, perception of well-being, and stress in 30 females diagnosed with fibromyalgia, an illness closely associated with CFS, and characterized by chronic pain, muscle aches, headache, and fatigue. They found no differences in sense of coherence between the fibromyalgia population and the general population. They did find that the fibromyalgia women with a stronger sense of coherence reported greater well being than those with a weaker sense of coherence, and concluded that women with a weaker sense of coherence may need extra support from the health care system to deal with
the chronic pain and fatigue.

Overall, the research into sense of coherence in the non-elderly indicates many similarities to research in the aging population. Those cancer patients with a strong sense of coherence also displayed a better perceived well being as well as increased confidence and hope (Forsberg & Bjorvell, 1996; Post-White et al., 1996). Those individuals afflicted with chronic illnesses or disabilities also exhibited a positive relationship between a strong sense of coherence and increased adjustment to the disability situation and improved quality of life (Motzer & Stewart, 1996; Rena et al., 1996; Schnyder et al., 1999).

Sense of Coherence and Psychological Distress

Unfortunately, few studies have examined sense of coherence in relation to mental or emotional, as opposed to physical health of the individual. Flannery and Flannery (1990), in a prospective study, researched the association between sense of coherence, life stress, and psychological distress. A sample of 24 males and 71 females were tested at two points in time (1 at baseline and 1 immediately before a midterm test), to assess psychological distress immediately before a known stressor. Multiple regression analysis, as well as factor analysis, was performed on the data. The results indicated that a high sense of coherence was negatively correlated with life stress and psychological distress, and appeared to lessen the impact of life stress.

Nyamathi (1991) studied 581 homeless or drug-abusing minority women in relation to sense of coherence, self-esteem, support available to mitigate emotional
distress, somatic complaints, and high-risk behavior. Multiple regression analysis revealed that self-esteem, sense of coherence, and the availability of emotional support accounted for 49% of the variance in emotional distress felt by these women. Further, the women that were high in any of these three resources also reported less somatic complaints and significantly less high-risk behaviors. Additionally, for women with a weak sense of coherence, emotional support tended to reinforce reduced somatic complaints, suggesting that when internal resources are weak, external resources in the form of social support may be especially valuable in mitigating emotional distress, somatic complaints, and high-risk behavior.

Sense of Coherence in Children and Adolescence

There is a paucity of research into sense of coherence in childhood and adolescence. Little is known about how or why an individual develops a particular sense of coherence, and the impact one's childhood has in its development. Antonovsky and Sagy (1986) examined 418 adolescents in Israel, 78 of which were to be evacuated from residences in the Sinai settlement, to determine the development of sense of coherence and its relevance to the adolescent's response to stressful life situations. Sense of coherence was negatively correlated to anxiety experienced in stressful situations in general. Additionally, age, sex, and general stability of the community in which one resides were related to sense of coherence development in this age group. The authors conclude that much more research in this area is needed.

Dahlin, Cederblad, Antonovsky and Hagnell (1990) undertook a longitudinal
study using sense of coherence in a salutogenic model, describing individuals who have been successful in coping with life despite a high risk childhood. One hundred and forty-eight individuals with at least three psychiatric risk factors in childhood, indicating an increased likelihood of adult dysfunction, were studied. Sense of coherence, as well as quality of life measures were examined in this population. Almost half the sample was successful in creating a reasonably happy life, in spite of severe dysfunction in childhood. Sense of coherence in this population compared favorably with mean scores in the general population.

Sense of Coherence Cross-Culturally

There have also been very few cross cultural studies outside of the Western world on sense of coherence. If this construct were found to be applicable cross-culturally, much of the research that has been conducted to date would be useful when dealing with peoples of differing cultures. Milanesi et al. (1994) conducted an exploratory study to investigate the possible application of the sense of coherence concept in other cultures by administering the questionnaire to nationals of a non-Western society who are bicultural and living in a Western society. Fifty-nine Japanese Americans and Anglo-American women were studied at two points in time. Blood work, as well as a complete health history, was done as an objective measure of stress and illness. Sense of coherence was found to be stable from time 1 to time 2 in both populations. Sense of coherence constructs were correlated to general self-reported health in both populations also, indicating that although more work needs to
be done, sense of coherence constructs is considered to be relevant across cultures.

**Summary**

In summary, the work on sense of coherence has only just begun. With the world's population increasing exponentially, and with this country's aging population ever increasing, it is imperative that medical researchers determine why we stay healthy. We have limited resources with which to treat those individuals who suffer from disability and chronic illnesses, such as CFS, and we still do not know why some people stay healthy despite very stressful life events, and others become ill under only moderately stressful circumstances. Current research indicates that a strong sense of coherence is related to increased perceived well being, hope, increased global health status, increased quality of life indicators, and better adjustment to disability and disease (Callahan & Pincus, 1995; Coe et al., 1994; Forsberg et al., 1996; Post-White et al., 1996; Rena et al., 1996; Soderberg et al., 1997). In the caregiving population, sense of coherence was found to be inversely related to caregiver burden (Coe et al., 1992; Wagenfeld et al., 1994). A weak sense of coherence was indicative of increased difficulties with ADLs, decreased global health status, increased level of perceived helplessness and dependency, anxiety, and decreased adjustment to disability and disease (Callahan & Pincus, 1995; Forsberg & Bjorvell, 1996; Klang et al., 1996; Rena et al., 1996). Sense of coherence has not been studied extensively in any population, but early indications show similar findings regarding sense of coherence over all ages.
Moreover, since no research has been published investigating sense of coherence in individuals afflicted with CFS, a basic understanding is necessary upon which to build a framework to begin to understand the relevance of this concept in CFS individuals. As medical sociologists, we need to understand how and why some individuals form a strong sense of coherence and others do not. It is important to more fully comprehend the relationship between the physical and mental health of those individuals afflicted with CFS, the disability exhibited in these persons, and sense of coherence. Given the degree of health issues facing individuals with CFS, a better understanding of how sense of coherence interfaces with this disease process will help health care providers to more appropriately care for these individuals.

Chapter II has presented a review of the concepts of fatigue, sense of coherence, salutogenesis, and chronic fatigue syndrome. Chapter III will present the methods, instruments and procedures utilized in this research study.
CHAPTER III

PRESENTATION OF METHODS AND INSTRUMENTS

In this chapter, the methods and procedures utilized in this research study are presented. The sample, settings, data collection procedures with human subjects rights protection, the instruments, scoring techniques, and procedures for data analysis are discussed. The purpose of this study is to examine sense of coherence in those individuals diagnosed with chronic fatigue syndrome, and to explore the relationship between sense of coherence and functional ability/disability, as exhibited by work status and ability to perform activities of daily living (ADLs), in this population. The potential relationships between sense of coherence of the CFS individual and age, gender, work status, fatigue, and duration of illness will also be explored. Additionally, sense of coherence in the CFS patient will be compared to sense of coherence in other populations to explore any differences that may exist. Finally, the experience of the individual with CFS will be examined and described.

This study utilized data collected by student investigator, Sue Jensen, and Principal Investigator, Morton Wagenfeld. The research hypotheses are presented as an introduction to a discussion of the methodology.

Hypothesis 1: The older the chronic fatigue syndrome client is, the weaker the sense of coherence.

Although Antonovsky (1987) initially believed that SOC should be firmly
fixed in this age group, he also stated that entropy, or the degradation inherent in any system, is a normal part of life, and could erode one's sense of coherence. Therefore, it is plausible that over the years, the sense of coherence of an individual with a chronic illness may deteriorate simply on the basis of the ill individual's age and the chronic stresses of a lingering illness.

Hypothesis 2: Females diagnosed with CFS show a weaker sense of coherence than males who have been similarly diagnosed.

Although this hypothesis has not been supported by most other research (Callahan & Pincus, 1995; Klang et al., 1992), Coe et al. (1992) did find a higher sense of coherence in male caregivers as compared to female caregivers. One may hypothesize that society's treatment of females in general could lead to a decreased sense of coherence in the female gender, but no studies were found indicating that this was true.

Hypothesis 3: Those individuals who can no longer work outside the home because of CFS will exhibit a weaker sense of coherence than those who continue to work.

Work in our society is strongly tied to self-image and self-esteem. Therefore, when an individual in his/her productive years can no longer perform the function(s) for which he/she has been educated or trained to do, a weakened sense of coherence may be exhibited, as entropic forces damage an increasingly vulnerable SOC. No support for this hypothesis was found in the literature, however, as the relationship between sense of coherence and employment status has not been investigated in the
chronically ill population.

Hypothesis 4: The longer the duration of CFS, the weaker the sense of coherence.

The basis for this hypothesis is that it is thought that over time, the stressors inherent in any chronic illness may erode one's sense of coherence. Although Antonovsky originally hypothesized that sense of coherence was fixed by age 30, he also proposed that a natural entropy exists and that it is the nature of all things to erode overtime. Therefore, one’s sense of coherence may also deteriorate especially in the face of a long-term illness.

Hypothesis 5: The greater the functional disability reported by chronic fatigue syndrome patient, the weaker the sense of coherence.

Research has shown that those who have trouble performing ADLs exhibit a weakened sense of coherence (Callahan & Pincus, 1995; Santavirta et al., 1996). Sense of coherence also has been shown to play a significant role in adjustment to a disability, regardless of severity of the disability (Rena et al., 1996). Therefore, in the population of CFS clients, it can be hypothesized that as functional disability increases, a weakened sense of coherence is displayed. It is not known, however, if a weakened sense of coherence will be exhibited in greater functional disability or if a strong sense of coherence will yield greater functional ability.

Hypothesis 6: There is an inverse relationship between the average total daily fatigue scores and sense of coherence in the CFS patient.

The basis for this hypothesis is that because fatigue can be an all
encompassing symptom that, over time, can erode one's ability to perform even basic ADLs, and can diminish the person's ability to provide the most basic necessities for self and family, one's sense of coherence may eventually erode into a weakened SOC. However, no study was found investigating the relationship between fatigue and sense of coherence.

Hypothesis 7: Sense of coherence in the CFS population is weaker than that of other populations with other chronic illnesses.

The basis for this hypothesis is that because this population is chronically ill with an illness that is not, for the most part, validated by the medical community, this may, over time, lead to decreased social support (i.e. decreased family and friend support as well as the medical community), loss of employment and income, chronic and debilitating symptoms, and a decreased self-image and self-esteem. The resultant sense of coherence in these individuals may be weakened, especially because there is no “light at the end of the tunnel” for these persons.

Definitions of Concepts

The concepts defined are fatigue, Sense of Coherence, CFS patients, Activities of Daily Living (ADLs), functional ability/disability, before illness, pre-diagnosis and after-diagnosis.

Fatigue. Acute, normative, or chronic...a subjective feeling existing at one point in time on a continuum from weariness to complete exhaustion, resulting from physical, mental, or emotional activity. Acute fatigue is most often caused by excessive physical or mental exertion and can be relieved by rest. Normative fatigue may be influenced by circadian rhythms and result from the activities of daily living, while chronic fatigue is most often the result of
prolonged stress or tension on the body and is less likely to be relieved by rest alone (Jensen & Given, 1991, p. 182).

Sense of Coherence. ...a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands posed by these challenges, are worthy of investment and engagement (Antonovsky, 1996, p. 170).

CFS Patients. Those individuals, over the age of 18, who have been diagnosed with chronic fatigue syndrome by a medical practitioner.

Activities of Daily Living (ADLs). Basic self-care activities such as bathing, dressing, eating, and exercising, as well as activities with friends and family and home maintenance activities.

Functional Ability/Disability. The extent to which a disease, illness or injury interferes with an individual's ability to carry out activities of daily living.

Before illness. The period of time before the symptoms of CFS began.

Pre-diagnosis. The period of time between CFS disease onset and diagnosis.

After diagnosis. The period of time after a definitive diagnosis of CFS was made by medical practitioner.

Procedure

This study was conducted with the permission of Western Michigan University's Human Subject Institutional Review Board (Refer to Appendix A for HSIRB approval). Written permission was also obtained from the various support group leaders.
Sample

This study used a convenience sample drawn from chronic fatigue syndrome (CFS) support groups in Grand Rapids and Kalamazoo, and from clients attending a community medical center in Kalamazoo. The sample size for the quantitative portion of the study was 30 participants. These participants completed a questionnaire consisting of a number of different survey instruments.

Research Study Design/Data Collection Procedures

This study is cross sectional, survey research, utilizing both quantitative and qualitative methodology. The unit of analysis is the individual. A study packet, consisting of the consent form which included a short description of the study as well as 3 screening questions (see below), and the study instrumentation, which consisted of 3 parts (see Appendix B), were given to the leaders of the support groups to give to members of the support group. Support groups were drawn from the greater Grand Rapids and Kalamazoo areas. There were two support groups used in Grand Rapids – the first was a support group for chronic fatigue syndrome individuals and the second was a support group for CFS/fibromyalgia individuals. In the second group were individuals who had been diagnosed with fibromyalgia and CFS, or just one of these illnesses. Written and verbal permission was obtained from the leaders of both support groups, and this researcher attended various meetings (as per request of the support group leaders) to explain the study and enlist qualified participants. The CFS support group in Kalamazoo had recently disbanded, but a few members continued to
meet on an informal basis. This researcher contacted the former leader of the support group, and the leader consented to explain the study to members of the support group that still met informally (in the group leader’s home when illness did not interfere), and enlist appropriate candidates for inclusion in the study.

A community medical center in Kalamazoo was also included in the study. In the community medical center, clinicians were instructed by this researcher to give the study packet to appropriate patients (i.e., those diagnosed with CFS) if those individuals were willing to participate in a study. Individuals in both the support groups and in the community medical center interested in participating in the study filled out the consent form, indicating a willingness to participate in the study. If a respondent met the screening criteria and signed the consent form, further instructions invited the participant to complete the attached questionnaire. This questionnaire was completed either in the participant’s home, and subsequently mailed back to the researcher, or completed at the support group meeting, and either handed to the researcher, or mailed back to the researcher in the provided stamped, self-addressed envelope. The total time required to respond to the questionnaire was approximately 30 minutes.

The following were the criteria for selection of participants for this study:

1. A medical doctor must have diagnosed participants with chronic fatigue syndrome.

2. Participants must be at least 18 years of age.

3. Participants must be willing to participate in the study.

To complete the qualitative portion of the study, about half of the participants (12)
were asked to participate in a follow up in-home or telephone interview, of about 30 to 60 minutes, which was scheduled a few weeks after the initial survey was completed (see Appendix B). The responses to these questions were hand recorded and subsequently entered into a data file in the student researcher’s office.

Because the study sample was self-selected, and not the result of random selection, the results of this research should not be considered to be representative of all chronic fatigue syndrome individuals.

Operational Definitions of the Study Variables

Instrumentation: There was one "Chronic Fatigue Syndrome Questionnaire" (see Appendix B), consisting of 3 parts as delineated below.

Part 1 - General Questionnaire

To evaluate the characteristics of the participant and the participant's experience with CFS, a 29-item questionnaire was included. Respondents marked the number that expressed the most appropriate answer to the various questions. A combination of Likert-type questions, visual analogue scales and open-ended questions was utilized. This questionnaire was constructed with input from various members of the research committee. A portion of this questionnaire was devoted to the gathering of socio-demographic information.
Part 2 - SOC Questionnaire

The Orientation to Life Scale measuring Antonovsky’s concept of Sense of Coherence (SOC) is a 29 item Likert Scale that measures how one is able to actively adapt to an environment ubiquitous with stressors. The scale measures three constructs: the meaningfulness, manageability and comprehensibility of life. The scale was originally developed through extensive qualitative research examining the concept “salutogenesis”, a word coined by Antonovsky meaning origins of health, referring to one’s ability to manage and maintain one’s health even in the face of adversity (Antonovsky, 1987). A shortened adaptation (13 items) of Antonovsky's Sense of Coherence Scale was used to explore and describe sense of coherence in the population of CFS individuals. This shortened version of Antonovsky’s original 29-item scale was used because many of the CFS individuals were too ill to fill out many questionnaires and answer multiple questions. Therefore, the questionnaires were streamlined as much as possible in order to facilitate the data-collection procedure and alleviate the burden on the respondents. This shortened scale has been utilized effectively with different populations, and has a slightly smaller alpha of internal consistency, but is still considered within an acceptable range (Antonovsky, 1987). Respondents marked the number that expressed the most appropriate answer to the various questions, with numbers 1 and 7 being the extreme answers.

Part 3 - Activity Charts

To evaluate functional ability/disability in this population, an activity level
questionnaire was utilized. The research team developed this Activity Chart in an effort to explore if and how the experience of CFS changes one's activity level. This questionnaire had two parts. The first part asked participants to comment on their perception or memory of the frequency of various activities (i.e., gardening, paying bills, cooking, etc.) before the diagnosis of CFS. The second part asked the same questions on the frequency of the same activities after being diagnosed with CFS.

Reliability and Validity

To measure SOC in the population of CFS patients, a shortened sense of coherence scale (SOC-13), adapted from Antonovsky's original SOC-29 item scale, was utilized (see Appendix B, part 2).

Reliability: The SOC-13 has a smaller Cronbach's alpha than the original scale, but is still considered to be within an acceptable range (Babbie, 1995; Clayton, 1984; Polit & Hungler, 1987). The Cronbach's alpha coefficient for this study is .87. Antonovsky (1993) reported the average alpha from 15 studies using the SOC-13 was .88. He also stated (1987, p. 82) that "The consistently high level of Cronbach's alpha, which ranges from .84 to .93, points to a respectable degree of internal consistency and the reliability of the instrument."

To measure the functional ability/disability in the population of CFS patients, a scale was formed recording the responses of the study participants to the Activities of Daily Living (See Appendix B, part 3a) both before and after being diagnosed with CFS. The Cronbach’s alpha coefficient for this scale is .65, which is at a minimally
acceptable level (Babbie, 1995; Polit & Hunglar, 1987).

Validity: When the Orientation to Life Scale was compared to a 22-item sense of coherence scale, it had a .639 correlation, which is indicative of concurrent validity. Discriminate validity was tested when the SOC scale was compared with a test that could be expected to have a negative correlation (the Sarason Test Anxiety Scale), and was found to have a significant negative correlation (Antonovsky, 1987). Therefore, discriminate validity is suggested.

Although no validity has been established for the Activity Charts, this researcher asserts that the charts do exhibit face validity.

Scoring

The scoring for the SOC-13 is as follows: the responses to each item were recorded on a 7 point Likert scale, ranging from 1 to 7. Scores across all 13 items were added together, after reversing the scores where necessary. Scores could then range from 7 to 91. The higher the score, the stronger the individual's sense of coherence.

The scoring for the Functional Ability scale is also on a Likert scale, from 1 (never) to 5 (daily). There were 14 activities requiring responses as to the frequency of each activity. Individuals were to circle the appropriate number corresponding to the most appropriate answer to each question. Scores could range from 14 to 70, with the higher scores indicative of greater functional ability, and the lesser scores indicating greater functional disability.
To measure fatigue, two visual analogue scales were used (see Appendix B). To score the visual analogue fatigue questions, a measurement in centimeters was taken from the beginning of the line to where the CFS patient marked an “x” on the line. This distance, which could range from 0 to 10 centimeters, was given a numerical score for each of the two questions. These scores were then summed and averaged, giving a total fatigue score for each patient. Total fatigue scores could range from 0 to 20, with 20 being extreme fatigue, and 0 indicative of no fatigue. The rationale for obtaining a total fatigue score in this way was provided by Jensen and Given (1991), and Jensen (1990), who utilized a visual analogue scale developed by Piper et al. (1984).

Pretest of the Instrument

Although no pilot study was conducted, various members of the research committee critiqued the instruments and assessed the clarity of instructions and questions. The SOC-13 has been utilized in other studies and other populations of individuals with chronic disease. Antonovsky (1993) reported that the range of means from nine published studies using the SOC-13 was 55 to 68.7, with a standard deviation range of 9.8 to 17.8.

Statistical Analysis Strategy

Sociodemographic/economic data and information regarding age, level of education, employment status, income and other background information of the CFS
patient were analyzed using descriptive statistics. These variables are dealt with in Chapter IV.

The Pearson Product Moment Correlation Coefficients, as well as T-tests were calculated to test the appropriate hypotheses.

Rationale for the Use of Quantitative and Qualitative Methods

The focus of this study is to examine the experience of those individuals diagnosed with chronic fatigue syndrome in relation to such variables as sense of coherence and functional ability/disability. Multiple recruitment strategies were used in the year long data collection portion of this study. Because a large sample is necessary to adequately quantify data sets, and because it would be very difficult to adequately describe the experience of the CFS individual with quantitative data only, a qualitative component was thought necessary to further elaborate on the experience of CFS. This qualitative component allowed the researcher to explore the various symptoms associated with CFS, the feelings associated with chronic illness, and the emotions accompanying some of the participants’ decisions to change employment, or terminate a long-lasting relationship because of illness. The qualitative component also allowed the researcher to explore how a declining functional ability affected the CFS individual’s life. This framework allowed the researcher to better understand the respondents’ perspective in order to further elucidate the experience of the CFS individual. Additionally, qualitative data is often used to validate quantitative findings, especially if the sample size is small.
Qualitative Research

Sample

The qualitative component of this research sought to explore the “lived” experience of the CFS patient. Those individuals with an even case number were called by telephone a few weeks after the researcher received the completed questionnaires. Given the predominance of females with a CFS diagnosis, interviews were conducted with females only. Therefore, if a male had an even case number, he was not called, but the next even-numbered female was called. An appointment was scheduled to be conducted either in the respondent’s home or by telephone per respondent’s request. At the designated time, the researcher called or visited the respondent’s home. Five questions were asked and the researcher listened and took abundant notes:

1. Please describe your experience with the process of diagnosis with CFS?
3. Which area(s) of your life has CFS affected the most? Please describe.
4. How do you think CFS will impact your life in the future?
5. How could our current health care system better treat those with CFS?

This portion of the study was concluded after 12 interviews were completed.

Instrumentation

The student researcher was the one human instrument for the twelve
qualitative interviews. The student researcher was a master's prepared registered nurse (RN) conversant with medical language and experienced in interviewing patients and obtaining complete personal histories relating to health issues.

**Data Collection and Recording**

Data collection was accomplished by the student researcher taking hand written notes during the twelve qualitative interviews. This note taking system was recommended by Lincoln and Guba (1985) to assist the researcher to record his/her own thoughts during the interview and to avoid technical problems inherent in the use of devices of modern technology (i.e., the use of tape recording devices). After each question was asked, the participant was encouraged to answer fully while the student researcher wrote down what the participant said verbatim. If the answer was very short, the participant was prompted by the researcher to more fully develop the response. If the participant got off the topic in her response, the researcher would repeat or rephrase the question in an effort to re-focus the participant. Fidelity was established during this research by the student researcher maintaining original field notes as well as typed copies of each statement made by the respondents; the researcher reproduced the exact data as it came from the field for a peer review.

**Triangulation**

The combined data collection methods of gathering qualitative and quantitative data produced much data for triangulation. Questions in the interview portion of
the qualitative study were addressed in a comprehensive manner and the respondents had ample opportunity to explain and elaborate on the variables that affected the overall experience of the CFS individual. As the qualitative data was analyzed, the quantitative data was referred to for respondent consistency in both phases of the research.

**Member Checking**

At the end of each of the qualitative interviews, the researcher examined her field notes and reiterated them to the participant to insure that the correct information had been recorded. Taylor and Bogdan (1998) state: “Any interpretation of a social scene will be richer if you have induced members of that scene to comment on it and react to it” (p. 159). Therefore, member checking is considered useful to validate the information that has been given to the researcher, and perhaps to further elucidate on the various concepts discussed.

**Data Analysis**

A Content Analysis approach was followed to analyze the data. Various researchers (Bryman & Burgess, 1994; Taylor & Bogdan, 1998) state that data analysis in qualitative research is an ongoing process. The first step in content analysis is identification of themes. This step was an ongoing process in this research. Taylor and Bogdan (1998) state: “They (qualitative researchers) keep track of emerging themes, read through their field notes or transcripts, and develop concepts and
propositions to begin to interpret their data” (p. 141). The next step in the data analy­sis process involved taking the various themes that emerged from each question and categorizing and coding them by key phrases. These key phrases were then place on notecards for future reference and analysis. The notecards as well as the complete transcripts of each interview were read multiple times and the content analysis con­tinued until all data gathered had been categorized.

Protection of Human Rights

Specific procedures were followed to assure that the rights of the study partic­ipants were not violated. Approval of the human rights protection procedures was granted by Western Michigan University’s Human Subjects Institutional Review Board on September 29, 1998 (Appendix A). An explanation of the research study and goals, the approximate time the participant would be involved in the study, the nature of the questions to be asked, and assurances of anonymity were provided to each participant. Signed consent forms were required from the candidate before par­ticipation in the study could begin. Each participant was assigned a case number. No names or personal identifiers were attached to the data set. Consent forms and ques­tionnaires were separated when returned to the student investigator. Consent forms were kept in a locked file cabinet in the office of the principal investigator. Questionnaires are kept in a separate locked file cabinet in the office of the principal investigator for a period of three years after study completion, and will be destroyed at the end of the 3-year period. All quantitative data was transcribed into aggregate
form for computer analysis. Coding was done directly on the survey instrument, with codes entered into an SPSS data file. A back-up disk for the SPSS data file was also created, with both the original data file and the back-up disk stored in a locked file cabinet in the office of the principal investigator. This will be maintained for a period of 3 years after study completion. Following completion of home/telephone interviews, the data that was collected was transcribed into a computer file, using only participant number for identification. The notes taken during home interviews and/or telephone interviews for the qualitative portion of the study are kept in a separate locked cabinet in the office of the principle investigator.

Summary

In Chapter III, a discussion of the methods utilized in this study was presented, along with a detailed discussion of the sample, definition of the study concepts, reliability and validity of the instruments used, quantitative and qualitative data collection procedures, statistical analysis strategy, and human rights protection. In Chapter IV, the data that describes the study sample and addresses the research hypotheses are presented.
CHAPTER IV

PRESENTATION OF QUANTITATIVE DATA

Overview

The purpose of this study is to examine and describe the experience of the chronic fatigue syndrome individual in relation to functional ability/disability and sense of coherence (SOC). There may also be a relationship between age, gender, employment status, fatigue, illness duration, and sense of coherence, which will be examined. Finally, sense of coherence in the CFS patient will be compared to the sense of coherence in other populations with chronic illnesses to examine any differences that might exist.

In this chapter, quantitative data that describes the study sample and addresses the research hypotheses are presented. The study sample is described by age, gender, employment status, education, duration of illness, and income. Descriptive data related to the experience of the CFS individual are presented. Additionally, data describing functional ability/disability and work issues surrounding those with CFS are explored.

Several statistical techniques were used to analyze the data. Descriptive statistics include frequencies, percentages, means, standard deviations, and ranges. Other statistical techniques utilized include the Pearson Product-Moment Correlational Analysis, Crosstabulations, and T-Tests. The data are presented as follows:
descriptive data pertaining to the sample, descriptive data related to sense of coherence, the experience of the CFS individual, data related to functional ability/disability and employment status of this sample, and descriptive and inferential data pertaining to the research hypotheses.

Descriptive Analysis of Data

Study Sample

The sample consisted of 30 individuals who had been diagnosed with chronic fatigue syndrome, were 18 years of age or older, and consented to participate in the study.

Sociodemographic Descriptors

The sociodemographic descriptors used in the present study were age, gender, employment status, duration of illness, education, and income. The age of the chronic fatigue syndrome client ranged from 24 to 75 years with a mean of 45.8, a median of 45.5 and a standard deviation of 11.56 years. The CDC now states that most individuals become ill with CFS between the ages of 25 to 50, with a mean of 30 years (CDC Website, 2000). See Table 1 for age distribution of CFS patients.

Eighty percent (N=24) of the CFS patients in the study were female, while 20% (N=6) of the participants were male. While the Centers for Disease Control originally reported that 90 to 98% of CFS individuals were Caucasian females, they recently stated that the figure ranges from 55% to 75% (CDC Website, 2000).
Table 1

Distribution of Age in Chronic Fatigue Syndrome Patients

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>30-39</td>
<td>4</td>
<td>13.33%</td>
</tr>
<tr>
<td>40-49</td>
<td>12</td>
<td>40%</td>
</tr>
<tr>
<td>50-59</td>
<td>9</td>
<td>30%</td>
</tr>
<tr>
<td>60-69</td>
<td>1</td>
<td>3.33%</td>
</tr>
<tr>
<td>70+</td>
<td>1</td>
<td>3.33%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>30</td>
<td>100%</td>
</tr>
</tbody>
</table>

Participants were asked questions as to the number of hours worked inside and outside the home before they became ill and after diagnosis with CFS. "Work was not defined by the study, therefore “work” was whatever the respondent identified as “work”. Before illness, 25 of the 30 participants worked 21 or more hours a week outside the home. After diagnosis, only 7 continued to work 21 hours or more outside the home. Sixty percent (N=18) of the participants reported that they were unemployed or no longer able to work, while 40% (N=12) were able to continue employment although perhaps in a diminished capacity (see Table 2).

The mean of hours worked outside the home of the study participants before their illness began was 36.43 hours, with a median of 40 and a range of 0 - 60. The
Table 2

Work Status Outside the Home of CFS Patients Before and After Diagnosis

<table>
<thead>
<tr>
<th>Hours worked/week</th>
<th>Before illness</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>1 - 20</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>21 - 30</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>31 - 40</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>41+</td>
<td>13</td>
<td>2</td>
</tr>
</tbody>
</table>

mean of hours worked outside the home after diagnosis was 11.34 hours, with a median of 0 and a range of 0-70.

The work statuses of study participants inside the home presents a similar picture (see Table 3).

The mean of hours worked inside the home of the study participants before illness was 15.7, with a median of 10 and a range of 0-60. The mean of hours worked inside the home after diagnosis was 10.57, with a median of 10 and a range of 0-45. To get an overall picture of work status of study participants, hours worked inside the home as well as outside the home before illness as well as after diagnosis were added together. The mean of the total number of hours worked before illness was 52.13, with a median of 51.5 and a range of 5-90. The mean of the total hours worked after diagnosis was 21.59, with a median of 15 and a range of 0-89 (see Table
Table 3

Work Status Inside the Home of Study Participants Before and After CFS

<table>
<thead>
<tr>
<th>Hours worked/week</th>
<th>Before illness</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>1 – 20</td>
<td>15</td>
<td>22</td>
</tr>
<tr>
<td>21 – 30</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>31-40</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>40+</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

4). The average number of hours the CFS individual was able to continue to work both inside and outside the home decreased rather dramatically after diagnosis.

As Table 4 shows, 25 of the 30 respondents (83%) worked an average of 31 or more hours before they became ill. After they became sick, only 7 (23%) of the participants were able to continue working 31 or more hours/week and 5 (17%) reported not being able to do any work at all.

For comparative data on the average number of hours worked inside and outside the home before and after diagnosis, see Table 5.

The duration of illness in years for the study participants ranged from 2 to 24 years, with a mean of 10.25, a median of 10, and a standard deviation of 5.24. See Table 6 for the distribution of the duration of illness.

The duration in months that participants experienced symptoms before
Table 4
Total Work Status of Study Participants Before and After CFS

<table>
<thead>
<tr>
<th>Total Hrs Worked</th>
<th>Before illness</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>1 - 20</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>21 - 30</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>31 - 40</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>41+</td>
<td>22</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 5
Comparative Data for Worked Hours

<table>
<thead>
<tr>
<th>Average Hours Worked</th>
<th>Mean</th>
<th>Median</th>
<th>Mode</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>BEFORE DX</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inside home</td>
<td>15.70</td>
<td>11.50</td>
<td>0</td>
<td>16.34</td>
</tr>
<tr>
<td>Outside home</td>
<td>36.43</td>
<td>40.00</td>
<td>40</td>
<td>17.84</td>
</tr>
<tr>
<td>TOTAL</td>
<td>52.13</td>
<td>51.50</td>
<td>50</td>
<td>18.89</td>
</tr>
<tr>
<td>AFTER DX</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inside home</td>
<td>10.57</td>
<td>10</td>
<td>0</td>
<td>9.97</td>
</tr>
<tr>
<td>Outside home</td>
<td>11.34</td>
<td>0</td>
<td>0</td>
<td>18.59</td>
</tr>
<tr>
<td>TOTAL</td>
<td>21.83</td>
<td>15</td>
<td>0</td>
<td>22.0</td>
</tr>
</tbody>
</table>
Table 6

Distribution of Duration of Illness

<table>
<thead>
<tr>
<th>Duration of Illness</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5 years</td>
<td>6</td>
<td>21.42%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>11</td>
<td>39.29%</td>
</tr>
<tr>
<td>11-15 years</td>
<td>6</td>
<td>21.42%</td>
</tr>
<tr>
<td>16-20 years</td>
<td>4</td>
<td>14.29%</td>
</tr>
<tr>
<td>21+ years</td>
<td>1</td>
<td>3.57%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>28</td>
<td>100%</td>
</tr>
<tr>
<td>Missing*</td>
<td>2</td>
<td>7.14%</td>
</tr>
</tbody>
</table>

*Two participants were unable to pinpoint when symptoms of disease began.

diagnosis ranged from 2 to 180 months, with a mean of 42.63, a median of 24, and a standard deviation of 43.13. See Table 7 for the distribution of months experiencing symptoms before diagnosis.

The educational level of the study participants was distributed over five categories from less than high school to a graduate level in college or a professional degree. The mean educational level was 13.5 years, with a median of 13 and a range of 12-18 years. This population was, as a whole, highly educated, compared to the general population, as all 30 participants reported obtaining a high school or equivalent education, and 73.3% (N = 22) reported some college education (see Table 8).

Gross annual household income ranged from less than $15,000 a year to more than $70,000 per year with a median of $25,000. Ten participants (35.71%) reported
Table 7

Distribution of Months Experiencing Symptoms Before Diagnosis

<table>
<thead>
<tr>
<th>Months</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 2</td>
<td>11</td>
<td>40.74%</td>
</tr>
<tr>
<td>13 - 24</td>
<td>3</td>
<td>11.11%</td>
</tr>
<tr>
<td>25 - 36</td>
<td>1</td>
<td>3.7%</td>
</tr>
<tr>
<td>36 - 48</td>
<td>2</td>
<td>7.4%</td>
</tr>
<tr>
<td>49 - 60</td>
<td>6</td>
<td>22.22%</td>
</tr>
<tr>
<td>&gt; 60</td>
<td>4</td>
<td>25.93%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>27</td>
<td>100%</td>
</tr>
<tr>
<td>Missing*</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

*Three participants were unable to remember how long they had symptoms before they were diagnosed with CFS.

Table 8

Distribution of Participant Education

<table>
<thead>
<tr>
<th>Education</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than high school</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>High school grad/GED</td>
<td>8</td>
<td>26.67</td>
</tr>
<tr>
<td>Some college/associate</td>
<td>14</td>
<td>46.67</td>
</tr>
<tr>
<td>College grad/bachelors</td>
<td>4</td>
<td>13.33</td>
</tr>
<tr>
<td>Masters/doctoral</td>
<td>4</td>
<td>13.33</td>
</tr>
</tbody>
</table>
household income of $20,000 or less, while only two (7.14%) reported incomes of $60,000 or more (see Table 9).

Table 10 summarizes the descriptive statistics for the demographic variables in the current study. The age of the study participants, education, duration of illness and number of months between the initial appearance of symptoms until diagnosis with CFS is made are described.

Table 9

Distribution of Household Income

<table>
<thead>
<tr>
<th>Income (in thousands)</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>$15,000 or less</td>
<td>8</td>
<td>28.57%</td>
</tr>
<tr>
<td>$15,001 - $20,000</td>
<td>2</td>
<td>7.14%</td>
</tr>
<tr>
<td>$20,001 - $25,000</td>
<td>4</td>
<td>14.29%</td>
</tr>
<tr>
<td>$25,001 - $30,000</td>
<td>2</td>
<td>7.14%</td>
</tr>
<tr>
<td>$30,001 - $35,000</td>
<td>1</td>
<td>3.57%</td>
</tr>
<tr>
<td>$35,001 - $50,000</td>
<td>6</td>
<td>21.43%</td>
</tr>
<tr>
<td>$50,001 - $60,000</td>
<td>3</td>
<td>10.71%</td>
</tr>
<tr>
<td>$60,001 - $70,000</td>
<td>1</td>
<td>3.57%</td>
</tr>
<tr>
<td>$70,001 +</td>
<td>1</td>
<td>3.57%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Missing*</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

*Two participants chose not to disclose their household income to the researcher.
### Table 10

Descriptive Statistics for Demographic Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
<th>Mode</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>45.8</td>
<td>11.56</td>
<td>45.5</td>
<td>44</td>
<td>24-75</td>
</tr>
<tr>
<td>Education</td>
<td>13.5</td>
<td>2.91</td>
<td>13</td>
<td>13</td>
<td>12-18</td>
</tr>
<tr>
<td>CFS Duration (yrs)</td>
<td>10.25</td>
<td>5.24</td>
<td>10</td>
<td>10</td>
<td>2-24</td>
</tr>
<tr>
<td>Months experiencing symptoms before dx</td>
<td>42.63</td>
<td>43.13</td>
<td>24</td>
<td>12</td>
<td>2-180</td>
</tr>
</tbody>
</table>

Descriptive Data Related to the Experience of Chronic Fatigue Syndrome Patients

The sample of CFS patients reported experiencing many more symptoms than just fatigue. Some of the symptoms would plague the individual for months, disappear, and then reappear in stressful times or for no discernable reason. Other symptoms remained for years. One individual reported body aches “like the flu” that never disappeared since her symptoms first appeared in 1982. Table 11 provides a more complete description of symptoms and comorbidity experienced by this population.

When participants were asked how they would rate their health status before illness, their current health status, and how they felt their future health status would be, 86.7% stated that their health was good or excellent before becoming ill with
Table 11

Descriptive Statistics for Reported Symptoms/Comorbidity

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood conditions</td>
<td>2</td>
<td>6.7%</td>
</tr>
<tr>
<td>Cardiac conditions</td>
<td>6</td>
<td>20%</td>
</tr>
<tr>
<td>Depression</td>
<td>19</td>
<td>63.3%</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>23</td>
<td>76.7%</td>
</tr>
<tr>
<td>Headache</td>
<td>18</td>
<td>60%</td>
</tr>
<tr>
<td>Impaired memory</td>
<td>29</td>
<td>96.7%</td>
</tr>
<tr>
<td>Multijoint pain</td>
<td>19</td>
<td>63.3%</td>
</tr>
<tr>
<td>Muscle pain</td>
<td>25</td>
<td>83.3%</td>
</tr>
<tr>
<td>Sore throat</td>
<td>10</td>
<td>33.3%</td>
</tr>
<tr>
<td>Poor sleep</td>
<td>27</td>
<td>90%</td>
</tr>
<tr>
<td>Tender lymph nodes</td>
<td>14</td>
<td>46.7%</td>
</tr>
</tbody>
</table>

CFS, but only one respondent (3.33%) felt his/her health was good after diagnosis. Similarly, respondents were pessimistic about their future health, but were more optimistic about the future that the present. Eight respondents (26.6%) felt that their future health would be excellent or good, while only one respondent (3.33%) currently reported his/her health as good or excellent. Refer to Table 12 for a summary of health statuses.

When participants were asked what strategies they used to attempt to alleviate their discomfort, the majority replied that they used such measures as rest, various
stress reduction programs, and eating a balanced diet. See Table 13 for specific strategies.

Descriptive Data Related to Sense of Coherence

As previously discussed, the SOC scale has been used in numerous studies in both ill and well populations. To provide a frame of reference, Antonovsky (1987) published normative data from some of these studies. See Table 14 for normative data on the SOC-13 scale (Antonovsky, 1987).

The range of the SOC scores for the study participants was from 34 to 86 with a mean of 54.80, a median of 54.5 and a standard deviation of 14.63. The mean of 54.80 for the CFS sample in this study was low when compared to the normative data in Table 14. See Table 15 for a frequency distribution of SOC-13 scores for this study.
Table 13

Strategies to Combat Fatigue

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Frequency</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress reduction</td>
<td>21</td>
<td>70%</td>
</tr>
<tr>
<td>Rest</td>
<td>28</td>
<td>93.3%</td>
</tr>
<tr>
<td>Reduced work schedule</td>
<td>22</td>
<td>73.3%</td>
</tr>
<tr>
<td>Exercise</td>
<td>12</td>
<td>40%</td>
</tr>
<tr>
<td>Balanced diet</td>
<td>22</td>
<td>73.3%</td>
</tr>
</tbody>
</table>

Table 14

Normative Data From Published Studies on SOC-13

<table>
<thead>
<tr>
<th>Sample</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>CVA*</th>
</tr>
</thead>
<tbody>
<tr>
<td>US university faculty (men)</td>
<td>145</td>
<td>66.7</td>
<td>9.8</td>
<td>0.147</td>
</tr>
<tr>
<td>US university faculty (women)</td>
<td>157</td>
<td>66.4</td>
<td>10.6</td>
<td>0.160</td>
</tr>
<tr>
<td>US male patients in VA clinics, 55+</td>
<td>240</td>
<td>61.9</td>
<td>17.8</td>
<td>0.288</td>
</tr>
<tr>
<td>Kibbutz (secular), mean age, 43</td>
<td>1215</td>
<td>66.4</td>
<td>9.9</td>
<td>0.149</td>
</tr>
<tr>
<td>US undergrads</td>
<td>59</td>
<td>58.5</td>
<td>12.1</td>
<td>0.207</td>
</tr>
</tbody>
</table>

*CVA: coefficient of variation (standard deviation/mean), a measure of heterogeneity of response in a sample.
Table 15

Distribution of Scores on SOC-13

<table>
<thead>
<tr>
<th>Mean Scores</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-39</td>
<td>6</td>
<td>20%</td>
</tr>
<tr>
<td>40-49</td>
<td>6</td>
<td>20%</td>
</tr>
<tr>
<td>50-59</td>
<td>6</td>
<td>20%</td>
</tr>
<tr>
<td>60-69</td>
<td>7</td>
<td>23%</td>
</tr>
<tr>
<td>70-79</td>
<td>3</td>
<td>10%</td>
</tr>
<tr>
<td>80-89</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>30</td>
<td>100%</td>
</tr>
</tbody>
</table>

Data Related to Functional Ability/Disability and Employment Status in the CFS Individual

The study participants were asked to complete an Activity Chart describing functional ability/disability both before and after the illness began. The first Activity Chart asked respondents to rate various aspects of ‘functional ability’ on a scale of 1 (never) to 5 (daily), describing these activities before becoming ill with CFS. This Activity Chart is considered, for the purposes of this study, to be a baseline measurement of functional ability. The Activity Chart uses ‘retrospective recall’, or “a research method that asks respondents to recall and narrate experiences, thoughts, feelings, and so forth that occurred in the past” (Polit & Hunglar, 1987, p. 145).

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Although retrospective recall is not the preferred method of obtaining information, it is, according to Polit and Hunglar (1987), an accepted method of data extraction to be used when there is no other way to obtain the data. However, the results gathered by retrospective recall should be viewed with caution.

The second Activity Chart asked the respondents to again rate the same activities, but this time, rate them after the symptoms of CFS began. The range of functional ability scores before illness was 46 to 63, with a mean of 53.92 and a median of 54. The range of functional ability scores after diagnosis was 23 to 45, with a mean of 35.17 and a median of 35. Lower values indicate increased functional disability. Therefore, this data shows that functional ability declined substantially in individuals after diagnosis with CFS. See Table 16 for the cross tabulation of Functional Ability scores before illness and after diagnosis.

A Paired Samples T-Test was performed on the means of the Functional Ability scores before illness and after diagnosis, to see if the difference in means was significant. The $t = -11.49$, which was significant at $p=.000$, therefore there was a significant difference in the functional ability/disability of the CFS individuals in this study after diagnosis (see Table 17). The decreased functional ability in the CFS individual could result in a decrease in the amount of work that the individual is able to do. Therefore, a Paired-Samples T-test was performed on the means of total average hours worked before illness and after diagnosis. The $t= -6.74$, which is significant at .000 level of significance (Refer to Table 17).

There was a significant difference in the functional ability of the CFS
Table 16
Crosstabulation of Functional Ability Scores

<table>
<thead>
<tr>
<th>Before illness</th>
<th>After diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0-10</td>
</tr>
<tr>
<td>0-10</td>
<td>0</td>
</tr>
<tr>
<td>11-20</td>
<td>0</td>
</tr>
<tr>
<td>21-30</td>
<td>0</td>
</tr>
<tr>
<td>31-40</td>
<td>0</td>
</tr>
<tr>
<td>41-50</td>
<td>0</td>
</tr>
<tr>
<td>51-60</td>
<td>0</td>
</tr>
<tr>
<td>61-70</td>
<td>0</td>
</tr>
</tbody>
</table>

* only 23 participants completed the entire activity charts

Table 17
Comparative Data – Before Illness and After Diagnosis

<table>
<thead>
<tr>
<th>Mean of:</th>
<th>Before Illness</th>
<th>After Diagnosis</th>
<th>T-test</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Hrs Worked</td>
<td>52.13</td>
<td>21.59</td>
<td>-6.74</td>
<td>.000*</td>
</tr>
<tr>
<td>Functional Ability</td>
<td>53.92</td>
<td>35.17</td>
<td>-11.49</td>
<td>.000*</td>
</tr>
</tbody>
</table>

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individual after he/she became ill and there was a significant difference in the average total hours worked before illness and after diagnosis with CFS.

Presentation of the Data Related to the Research Hypotheses

In this section, descriptive and inferential statistics are presented related to the individual research hypotheses.

Hypothesis 1: The older the chronic fatigue syndrome client is, the weaker the sense of coherence.

The correlation coefficient for Hypothesis 1 was -.06, indicating that there is no relationship between age and SOC in the CFS patient. This finding is supported by Klang et al. (1996) and Callahan and Pincus (1995), who found no correlation between age and SOC in the chronically ill population. Antonovsky (1987, 1996) believed that SOC should be firmly established in this age group, thus this finding is not surprising.

Hypothesis 2: Females diagnosed with CFS show a weaker sense of coherence than males who have been similarly diagnosed.

The mean SOC for males was 50.7 (N=6), and the mean of SOC for females was 55.83 (N=24). The Independent Samples T-test showed a t = -.768, with a level of significance of .449. Thus, there is no relationship between gender and sense of coherence. In this sample of CFS patients, females did not exhibit a lower sense of coherence, but in fact had a higher mean SOC (55.83) than did the male CFS patients (50.7). This difference is not statistically significant, however. For the most part,
this finding is supported by the literature. Most researchers have not found a significant relationship between gender and sense of coherence (Callahan & Pincus, 1995; Klang et al., 1996). However, Coe et al. (1992) did find male caregivers displayed a higher sense of coherence than female caregivers. One caution when considering this finding in that in this study sample, the N is very small (N=30), therefore, this small N may be giving misleading results.

Hypothesis 3: Those individuals who can no longer work outside the home because of CFS will exhibit a weaker sense of coherence than those who continue to work.

After excluding those individuals over 59 years of age who may already be retired, the mean SOC for those individuals no longer employed outside the home was 52.69, with a standard deviation of 13.03 (N=16). The mean SOC for the CFS patients who remain employed was 55.69, with a standard deviation of 16.21 (N=12). Utilizing the Independent Samples T-test to test this hypothesis shows a t = -.558, with a significance level of .582. Thus, we can state there is no relationship between sense of coherence and employment in this CFS population. Those individuals not working outside the home did not exhibit a lower SOC than those who were able to continue working outside the home. One reason for this finding may be that since the majority of the study population is female (80%), and it is still socially acceptable for a female to remain in the home in the “homemaker” role, no difference in SOC was noted. Fourteen female study participants (47%) were unemployed and three (50%) of the male study participants were unemployed. No study was found that
investigated the relationship between SOC and employment status in those individuals with chronic illness.

Hypothesis 4: The longer the duration of CFS, the weaker the sense of coherence.

Pearson Product Moment Correlation Coefficients were used to determine if a relationship existed between the duration of CFS and the SOC in the CFS patient. The correlation coefficient for this hypothesis was -.005, indicating no relationship between illness duration and SOC. The basis for this hypothesis was that over time, chronic illness takes a toll on the individual and may negatively affect the SOC of the CFS patient. The findings from this study are supported by Klang et al. (1996) and Callahan and Pincus (1995), who also found no relationship between duration of chronic illness or disability and SOC.

Hypothesis 5: The greater the functional disability reported by chronic fatigue syndrome patient the weaker the sense of coherence.

The analysis for this hypothesis, utilizing the SOC-13 and the Functional Ability scale, was done with the Pearson Product Moment Correlation. There was a low to moderate relationship (although not significant; p=.07) between functional ability and SOC (.332), indicating those individuals exhibiting decreasing functional ability also tend to report a weaker SOC. If the N in this study would have been larger, perhaps the finding may have been significant as this finding has also been supported by other researchers. Callahan and Pincus (1995) reported that those individuals diagnosed with rheumatoid arthritis had more difficulty performing ADLs.
(activities of daily living) and were more likely to have a lower SOC. Rena et al. (1996) investigated sense of coherence and disability after a spinal cord injury or CVA and found that SOC was significantly related to disability adjustment.

Hypothesis 6: There is an inverse relationship between the average combined daily fatigue scores and the sense of coherence in the CFS patient.

Using the Pearson Product Correlation Coefficients, a slight to moderate inverse relationship between fatigue and SOC was found (-.303). However, since this finding was not significant at the accepted level of significance (p=.112), we can state that although there is a slight inverse relationship between fatigue and sense of coherence scores in this population, it was not shown to be significant. This finding does indicate that those reporting higher fatigue levels also report lower SOC scores. Both Coe et al. (1992) and Callahan and Pincus (1995) found that those individuals who reported decreased global health status were likely to have a lower SOC. No study was found describing the relationship between sense of coherence and fatigue.

Hypothesis 7: Sense of coherence in the CFS population is weaker than that of other populations with other chronic illnesses.

The One Sample T-test was utilized to determine if a difference existed between the sense of coherence mean scores of other populations experiencing chronic illnesses and the CFS population. The populations selected for this analysis were Forsberg and Bjorvell’s (1996) study of cancer patients, Callahan and Pincus’s (1995) study of rheumatoid arthritis patients, Nyamathi’s (1991) study of drug addicted, homeless women in the U.S., Lundman and Norberg’s (1993) study of
insulin dependent diabetics, and Soderberg et al.'s (1997) study on fibromyalgia patients. These studies were selected because of the chronicity of the illnesses and because each disease has the possibility of worsening, causing increased morbidity and perhaps even mortality. See Table 18 for comparisons.

There is a significant difference between SOC scores of CFS patients and all populations described above, with the exception of U.S. homeless women. We can, therefore, reject the null hypothesis and state that CFS individuals in this sample population do exhibit a lower sense of coherence than other populations with chronic illnesses. There was no significant difference between CFS sense of coherence mean in the CFS sample (54.8), and that of U.S. homeless women (55). One explanation for this may be that CFS patients are dealing not only with a debilitating chronic illness,

<table>
<thead>
<tr>
<th>Population</th>
<th>N</th>
<th>Illness Duration</th>
<th>SOC Mean</th>
<th>SD</th>
<th>T-test</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer pts</td>
<td>25</td>
<td>&gt;12 mo</td>
<td>67.8</td>
<td>11.7</td>
<td>-.487</td>
<td>.000*</td>
</tr>
<tr>
<td>RA pts</td>
<td>828</td>
<td>14.6 yrs</td>
<td>65.2</td>
<td>14.8</td>
<td>-3.93</td>
<td>.000*</td>
</tr>
<tr>
<td>Fibromyalgia pts</td>
<td>30</td>
<td>------</td>
<td>64.3</td>
<td>-----</td>
<td>-3.56</td>
<td>.001*</td>
</tr>
<tr>
<td>Diabetics</td>
<td>20</td>
<td>19 yrs</td>
<td>64.1</td>
<td>8.5</td>
<td>-3.48</td>
<td>.002*</td>
</tr>
<tr>
<td>Homeless women</td>
<td>581</td>
<td>------</td>
<td>55</td>
<td>0.7</td>
<td>-0.75</td>
<td>.94</td>
</tr>
<tr>
<td>CFS pts</td>
<td>30</td>
<td>10.25 yrs</td>
<td>54.8</td>
<td>14.63</td>
<td>------</td>
<td></td>
</tr>
</tbody>
</table>

*P<.05
but also with a disbelieving public, and these two factors may, over time, lead to a weakened sense of coherence. Much as U.S. homeless women may experience hopelessness, so may CFS individuals. Post-White et al. (1996) found that hope and sense of coherence are highly correlated, thus as hope diminishes so may SOC.

This presentation of the quantitative data has shown some interesting results, especially because the SOC in the population of CFS individuals is substantially lower than the SOC in individuals faced with other chronic illnesses. A more detailed discussion and analysis of this data will be presented in Chapter VI, after the presentation of the qualitative data in Chapter V.
CHAPTER V

PRESENTATION OF QUALITATIVE DATA

This chapter will include a presentation of the qualitative data, as well as a brief discussion of the experience of the CFS patient. The specific research questions for this portion of the study are as follows:

1. Please describe your experience with the process of diagnosis with CFS.


3. Which area(s) of your life has CFS affected the most? Please describe.

4. How do you think CFS will impact your life in the future?

5. How could our current health care system better treat those with CFS?

Qualitative data was collected in addition to quantitative data because not much is written or known about the lived experience of CFS individual in today’s world.

Qualitative research is often based on the premise that knowledge about humans is not possible without describing human experience as it is lived and as it is defined by the actors themselves...Qualitative approaches are generally more holistic than quantitative approaches, and try to capture the totality of some aspect of human experience (Polit & Hunglar, 1987, p. 367).

The utilization of both qualitative and quantitative methods, a hoped-for result is convergence on truth. This chapter will briefly review the procedure utilized when collecting qualitative data, describe the participants for this portion of the study, and then present the qualitative data. Data analysis and discussion of both the
quantitative and qualitative results will be presented in Chapter VI.

Qualitative Data Collection Procedures

For this portion of the study, respondents who had been assigned even participant numbers were contacted by telephone a few weeks after completion of the initial questionnaires. If the participant was willing to continue in the study, a time was scheduled to conduct the interview either in the respondent’s home or by telephone. During the interview, the participant responses were hand recorded verbatim whenever possible, and after completion of the interview, were entered into a computer file at the researcher’s office. Twelve participants took part in this portion of the study. As noted in Chapter III, only females were included in this portion of the study. Four participants chose in-home interviews, while eight opted for a telephone interview. One potential participant refused this portion of the study saying, “I’m just not up to it”.

The qualitative portion of the study was analyzed according to the procedure discussed in Chapter III. The in-home or telephone interview consisted of the researcher asking the five questions as listed above. The cases were initially analyzed using a content analysis format. Berelson (as cited in Polit & Hunglar, 1987) stated (Content analysis)... “is a research technique for the objective, systematic, and quantitative description of the manifest content of communication” (p. 362). For each question, themes were identified and organized under key phrases. These key phrases (wherever appropriate) were classified into two general categories: as either a
general resistance resource (GRR) or a general resistance deficit (GRD). Each case was analyzed separately by creating visual description of the GRRs and GRDs reported by each respondent, with the GRDs in a circle on top of a circle containing the respondent’s GRRs. The data were then compiled into aggregate form. A visual depiction (Miles & Huberman, 1994) was created from the aggregate data describing the GRRs and GRDs, which, according to Antonovsky (1987), are indicative of one’s sense of coherence and are normally present in most individuals during their lifetime. Figure 1 depicts the normal balance of GRRs and GRDs in an individual’s life. This depiction may vary in different individuals, but overall, the GRRs, identified by Antonovsky (1987) such as education, social support systems, general health, self-esteem, income and employment, in the lower oval support and perhaps mitigate the effects of the chronic stressors (GRDs) an individual encounters in his/her lifetime (the upper oval), resulting in a fairly stable SOC. Antonovsky (1987) states that GRRs such as wealth, ego-strength, cultural stability, social support, education, etc., determines a person’s rank on a health ease-disease continuum.

The higher one is on the continuum, the more likely it is that one will have the kind of life experiences that are conducive to a strong SOC; the lower one is, the more likely it is that the life experiences one undergoes will be conducive to a weak SOC (p. 28).

Therefore, in a well individual, GRRs support and perhaps mitigate the chronic stress inherent in life.

Cross-Case Analysis

The cross-case analysis used for this research is a compilation of the 12 single
One’s sense of coherence is, over time, predicated on the interplay between one’s GRDs and GRRs. Antonovsky (1987, p. 29) states “...chronic resources or chronic stressors, built into the life situation of the person, are generated and long-lasting. They are the primary determinants of one’s sense of coherence.” For the CFS individual, the chronic stressors, the GRDs that have been growing larger and CFS individual has received little or no validation of his/her illness from the medical community, thereby decreasing the social support normally provided by practitioners.

Figure 1. Balance of GRRs/GRDs Leading to Sense of Coherence.

case analyses. Two peer consultants reviewed the 12 single case analyses and compared these with the cross-case analysis. Each agreed that the cross-case analysis did represent raw data results. See Figure 2 for the visual display of The Experience of CFS Related to GRRs/GRDs.
Figure 2. The Experience of CFS Related to GRRs/GRDs.

A more detailed description and discussion of the GRRs and GRDs inherent in the role of the CFS individual will be presented in Chapter VI.

Description of the Participants

The mean age of the 12 respondents that participated in this portion of the study was 48 years. The average duration of the CFS illness in these individuals was 13.9 years. Six women were married, three divorced (2 more had been divorced and remarried after their illness began and are reported in the married category), and three women were single. The average fatigue level reported by these women was 7.8 on a scale of 1 to 10. Nine of the twelve CFS individuals had been diagnosed with
fibromyalgia and nine had received a diagnosis of depression. Seven women reported attaining some college education, two had graduated from college and three had a high school education. Of the seven women who had reported working full time before their illness began, only one has continued with full time employment. The various types of employment these individuals reported included elementary school teacher, landscape horticulturist, artist, insurance claims representative, beautician, restaurant owner, and waitress. Of the remaining five individuals, three were home-makers before and after their illness began, one was attending college and working part time, and one volunteered at a local hospital on a part time basis. The individual attending college was forced to quit school and move back home to live with her parents after her illness began, but the woman who volunteered at the local hospital was able to continue her activities.

In general, respondents reported a decreased earning ability and stated that household income had greatly declined after the illness began. Some participants noted, however, that they were not the main breadwinners before their illness, and since their spouse/significant other continued to work, they did not currently have nor foresee any financial problems. Others maintained that they were experiencing severe financial difficulties relating to their decreasing ability to maintain employment.

The Process of Diagnosis

The first query "Please describe your experience with the process of diagnosis
with CFS" brought the lengthiest responses, with one participant talking for 30 minutes describing her frustration with her medical care. Overwhelmingly, the CFS patients reported going through a lengthy period of intense stress about one year before they became ill. The majority of stressful events reported were of a personal nature. One participant reported her “husband was cheating on her.” Others reported a prolonged and painful divorce, some after years of physical and/or emotional abuse. One woman stated: “I began having symptoms at age 26, approximately 20 years before I was diagnosed. Because the symptoms varied, I was tested by many different doctors for many different things...thyroid, kidney, muscle and joint problems, and anemia. I also have a history of scoliosis and was in a train accident at age 30, so my spine is a mess. It was also during this time that I was undergoing tremendous stress...my husband was physically abusive at times and he stole all my money and left me over $100,000 of debt”.

Most reported that the illness began with flu-like symptoms. Generalized complaints such as body aches, joint pain, nausea, extreme fatigue and weight loss were common, and unlike the flu, these symptoms did not subside with time. Many individuals made multiple trips to their personal physician. Some of these doctors, after some routine blood work could not pinpoint the problem, told their patients that “it’s all in your head,” or “it’s stress-related...get the stress out of your life.” One physician tried estrogen injections; one diagnosed his patient with Lyme’s disease and placed her on long term IV antibiotics; another did multiple tests (x-rays, CT scan, MRI, bone scan) and finally diagnosed his client with CFS. In general, these
were family physicians, not eager to refer their patients elsewhere. One respondent, who had been feeling CFS symptoms for approximately eight months but had not seen her doctor, found an article about the CFS disease process and brought it to her physician. After reading it, he contacted her and agreed that she probably did have CFS. The symptoms experienced by the study participants and the difficulty with diagnosis are echoed by numerous other studies (Bombardier & Buchwald, 1995; Hartz et al., 1998; Joyce et al., 1997; Katon & Russo, 1992; Wilson et al., 1994).

Only two of the participants reported symptoms that began more slowly, from adolescence, and could not relate their symptoms to any particular stressful event. One stated:

I had trouble with fatigue ever since I can remember. In 1982, my senior year, I was diagnosed with mono and never recovered. But even when I was younger, I was always tired. I chose a sedentary life as a child...always preferred to sit and read.

Most respondents were not diagnosed at the time of their initial visit to their family doctor. The majority of study participants reported multiple physician visits to many different physicians over the period of a few years. One individual reported that the process of diagnosis spanned 10 years and over 15 physicians. On average, most of the study participants reported seeing from 4 to 6 physicians before receiving a diagnosis of CFS. This finding is also consistent with the current literature on CFS (Bombardier & Buchwald, 1995; Hartz et al., 1998; Katon & Russo, 1992; Wilson et al., 1994).

Respondents reported a continuing problem with finding a treating physician. Only a handful of physicians, according to the consensus of the study participants,
want to take the time to learn about CFS in order to successfully treat this illness and most of these physicians are not taking any new patients. Additionally, many of the study participants are no longer able to work and have lost insurance benefits. Most have applied for disability through SSI with varying degrees of success, and some have Medicaid. Many physicians will not treat a “private pay” or Medicaid client, especially if he/she has an expensive illness and no means to pay for treatment.

Overall, the majority of study participants underwent a lengthy and very stressful time in their lives approximately one year before onset of CFS symptoms. When they went to their doctors, they, in general, received little support. Some physicians thought the illness was “in the patient’s head,” while others thought that a reduction in stress would alleviate the problem. Because the symptoms continued, some physicians tried various treatment modalities such as IV antibiotics, estrogen injections and physical therapy, to no avail. The study participants began to seek out other medical opinions and usually received many different diagnoses from different practitioners. Eventually, the majority of physicians abandoned their clients when they did not improve, saying they had nothing more to offer and perhaps the client should seek treatment elsewhere. Reimbursement also became an issue because most of the study participants have terminated their employment and may have lost insurance benefits, although some continue to be covered through their spouse’s policy. Many physicians do not take Medicaid patients because the reimbursement is not high enough, and also do not take “private pay” patients unless they really do have the ability to pay their bills.
The second question asked, “Has CFS affected your self-image/self-esteem? Please describe.” The overwhelming response to this question was “yes.” One respondent stated: “Life has cheated me...I cannot travel. This disease has broken me down...the person I see in the mirror is not me, but a stranger.” Another respondent said:

You stop being who you were...it (CFS) destroyed everything I was...It turns your life upside down and you don’t know who you are anymore. Now, I am always bitchy, always yelling at my kids and not pleasant to be around. All your goals from your early years are gone and there is nothing to put in their place because there is no hope. You are what you do for work...but now I’m facing disability at 33 and it has shattered my self-image.

A third said “I had to break off my engagement two years ago because I didn’t feel I could be a good companion...I have problems having sex and have chronic bladder pain after sex. I have realized that I can never be in a relationship again because of this.” Another stated:

My self-esteem has gone from 9+ to 0 at times because you are unable to function like others around you. It’s very degrading not to be able to keep up with even the housework, and because I had to quit my job, I lost self-esteem there too.

A fifth respondent stated “I worked so hard to become a teacher and now I will never be able to do that again. I feel inadequate and I feel like a failure. Actually, I just want to be dead.” Two other CFS patients reported severe depression and thoughts of suicide. One of those responded saying “I cannot wait to die...would have no problem taking my own life, but I still have a few unfinished things to do.”

Charmaz (1991, p. 137) states “Inability to handle routine tasks evokes
existential dilemmas about self-worth, living at all, and limitation.” She states that to compensate and attempt to maintain self-worth, people will simplify their lives in whatever way they can. This is echoed by study participants who, for the most part, simplified their lives by first terminating their employment. However, many interpreted this loss of employment as loss of self.

Loss of self means being involuntarily dispossessed of former attributes and sentiments that comprise one’s self-concept, as well as the actions and experiences upon which they are based. It also means losing the self-definitions with which one had most identified. With loss of self, earlier boundaries of the self-concept shrink and become permeable. The self grows vulnerable to demeaning images reflected by others. The attrition of former attributes and sentiments results in changed feelings about self. Resignation follows” (Charmaz, 1991, p. 257).

Only two respondents reported that CFS had little or no effect on their self-esteem. One stated that she became ill after she had completed her education so she at least feels good about her educational status. However, she reported:

It took a tremendous amount of adjustment to accept myself as a worthwhile person because I could no longer work...a nun talked about the transition from ‘human doing’ to ‘human being’, which has helped me to understand that I have value as a human being even though I cannot be productive in the normal sense of being productive.

The Effects of CFS Upon Life

The third question was: “Which area(s) of your life has CFS affected the most? Please describe.” Most participants report CFS has changed the course of their life for the worse. The majority reported problems in their personal life as a result of the illness. One respondent reported that her sex life has been very affected due to a lack of ability to feel sensation related to nerve damage. She also reported
an increased difficulty to socialize because she is now homebound in a wheelchair, and also because she cries frequently and stated that she is too depressing for others to be around. A respondent in her early 30s reported that CFS has affected her family the most...

my husband says I’m not the same person he married. We are going to therapy again, but my marriage is in trouble. My husband says he is just tired of living like this and I’m always grouchy and in pain. It has affected my professional life (as a claim’s adjuster) also, as I’m faced with termination because I can’t get short or long term disability because my doctor can’t give a date when I should be better as is required for these types of disability. So I will have lost my job and be fighting for my marriage.

Another stated:

My relationship with my boyfriend of 16 years fell apart because he just couldn’t handle me always being sick. It’s also hard to get my family and my two daughters to understand that I really am sick. My doctors have told them that this is all in my head just because they can’t find out what’s wrong with me...so nobody really believes me.

A third individual stated:

The idea of ever being a parent is completely gone. I had no kids before (I became ill), and now I can’t raise them. This was always an unquestioned goal for my life, and now I know that it’s one that will never be attained...I just don’t have the energy to raise kids.

Most participants reported problems with maintaining employment and school activities. One individual responded:

CFS has affected my life’s plans the most. I never would have moved back to live in my home town if I wasn’t sick, but my parents live three blocks away from me now and my mom comes over and helps me with the kids when I am too sick to take care of them. I never was able to finish college and I ended up breaking up with my boyfriend at college when I moved back home. But I never would have met my husband, gotten married and had the kids if I hadn’t moved back here, so CFS changed the entire course of my life.

Another individual, a former teacher, stated that CFS has affected her work and
social life greatly. She can no longer teach and states “I can’t do much around the house now. I used to volunteer in various community organizations, but have had to stop all that now. I just can’t do anything”.

Finally, one study participant said:

I will probably end up selling the restaurant because I can no longer do what needs to be done here. I need to get disability, but I can’t if I still own this. And as I have said before, I broke off my engagement because I couldn’t be a true companion. This disease affects everything.

The study participants overwhelmingly reported that CFS has affected their entire life course, mostly negatively. Most are no longer employed. Some have relationship difficulties or have terminated their relationships because of continuing stress, while others need help with caring for their children. One respondent stated she has given up on the goal of ever having a family because she doesn’t have the energy to raise children.

Future Impact of CFS

The fourth question asked, “How do you think CFS will impact your life in the future?” The study participants were overwhelmingly pessimistic about the future as it related to their individual health and as it related to society. One individual stated:

I think society will be overwhelmed by the effects of this disease. It (CFS) is spreading very fast and it will not stop. It is more deadly than cancer…it leads to brain tumors, breast cancer, and many other illnesses. CFS eats away and destroys you physically, mentally and emotionally. I also think this disease will greatly impact social security disability in the very near future. It is more common than AIDs and I don’t think the government wants us to know how widespread it really is in the general population. I think it is
contagious as well as infectious and everyone is at risk. Imagine the impact on our economy and society as a whole if the majority of our population falls ill and can no longer work.

When remarking on the future impact of CFS on a personal level, one individual stated:

I have learned that I will have to pace myself and can never plan anything too far ahead, as I may not be able to do it. I can’t even plan to get my hair cut two hours from now because I might not be up to it. I am forced to live life on a day to day, minute to minute basis.

Another said:

I am seriously thinking about getting SSI...I now feel that I will not be cured and that I will be living with this all the rest of my life. I don’t know if my marriage will survive, and I probably won’t be able to return to work, so the future looks pretty bad.

A third individual, a former elementary school teacher responded: “I hold a very gloomy view of the future (respondent very close to tears). I don’t think I will ever get better. My current husband also has CFS and he’s doing better right now, but that can change very quickly.” A fourth individual said:

I know I will need to sell the restaurant soon and get disability, because I am totally exhausted both physically and mentally. I am having more problems with my eyes, a hard time focusing. And I am having a hard time concentrating mentally, problems with irritable bowel as well as generalized pain and fatigue. I often have to leave work early because of these problems. No one else thinks I feel as bad as I do. I am not very optimistic about the future.

A sense of depression, hopelessness, and powerlessness permeated the responses to thoughts of the future by these study participants. Miller (1986, p. 257) states “powerlessness can have physically and mentally detrimental effects on the individual...prolonged powerlessness leads to anxiety, depression, and
hopelessness...eventually, this state may hasten death.” It would appear that this population of CFS individuals feel that there is no treatment and/or cure at this point, and feel powerless to affect any positive changes in their lives.

Current Health Care System Treatment of CFS

The last question asked was, “How could our current health care system better treat those with CFS?” Again, the overwhelming response indicated that having a health care provider that believed what his/her patient was reporting was extremely important.

Doctors could BELIEVE you...it’s very frustrating when they tell you ‘it’s all in your head.’ Also, there is no outside help available for me, like a nurse to come to help me. I can only get volunteers to come in and that’s not very reliable. I’m only 56 and I’m almost completely bedridden now.

Charmaz (1991, p. 24) states

“Lacking the physician’s validation of illness is even more troubling. People with esoteric illnesses often felt that their physicians portrayed them as feigning illness, either by magnifying insignificant symptoms or by psychologically inducing physical distress. The feeling of being discounted and distrusted intensifies when family and friends share the physician’s view. Doubt multiplies. When everyone else doubts that ill people are sick, they even begin to distrust their own bodily sensation.”

Disbelief by the medical community has been a major issue with most study participants.

Another respondent stated:

One of the biggest things is to educate physicians to recognize the disease. Most don’t have a clue what to look for and how to treat it. Then, doctors need to learn to treat the whole person...this disease takes a huge toll on people psychologically and emotionally as well as physically, so they need to treat the whole person. Finally, they need to believe what we are saying,
learn as much as they can about the disease and take us and the disease seriously.

A third stated “The NIH (National Institutes of Health) needs to ‘get off their butts’ and acknowledge this as a real disease...We also need better education for MDs/DOs about this disease and how to treat it.” Another individual said: “People judge you badly when you are chronically ill and there’s no objective data that shows you are sick. I’ve had lots of problems with SSI, judges, doctors...nobody believes you!”

Another common theme was that more money needs to be allocated for research. Most felt that changing the name of the illness is also very important, because the name ‘chronic fatigue syndrome’ isn’t taken seriously. Respondents felt that CFS is an immune system disorder and the name should reflect that. Others felt that insurance companies had too much authority in the tests that were ordered, and their physicians had no say in diagnostic tests or treatment options. Some felt that because there were often so many forms for the physician to fill out relating to disability, their doctors were reluctant to take them on as patients.

Overall, the responses to these questions showed women who were frustrated with their illness, and also frustrated and discouraged by the lack of medical response and treatment options available for CFS. These women have, for the most part, lost their livelihoods, and some were in danger of losing their marriages and families. Society, as well as the medical community, has labeled them as individuals who cannot be believed. Other individuals have opted to break up long term relationships and to not start families because they don’t have the stamina and energy required for
these kinds of relationships. These respondents' stories are, for the most part, stories of loss, grief, and hopelessness. By delving into the world and experience of the CFS individual, we may be able to better understand this disease process and its effects upon the person stricken with it.

This chapter has presented the qualitative data. Data analysis and discussion of both the quantitative and qualitative results will be presented in Chapter VI.
CHAPTER VI

SUMMARY AND INTERPRETATION OF THE FINDINGS

Overview

In Chapter VI, a summary and interpretation of the combined methods research are discussed. Included are qualitative and quantitative findings regarding the hypotheses, the CFS population and the following concepts: sense of coherence, generalized resistance resources (GRRs) and generalized resistance deficits (GRDs), individual boundaries, and entropy. Limitations of both the quantitative and qualitative aspects of this study, the significance of this research to sociology and nursing, as well as recommendations for future research are presented.

Overview of Study

First, a brief study overview will be presented. A sample of 30-CFS patients participated in the "Coping with Chronic Fatigue" study to more fully explore sense of coherence in those individuals diagnosed with CFS. Sense of coherence is a concept developed by Antonovsky that attempts to explain an individual's response to illness by quantifying how meaningful, manageable, and comprehensible life events are to the individual (Antonovsky, 1996; Antonovsky, 1995; Antonovsky & Sagy, 1986).

CFS patients are a unique population because they appear to be suffering
from a chronic, devastating and debilitating illness that has little objective data as defining criteria. Therefore, there are many health care professionals, as well as the general public, who do not give much credibility to this disease process or those that claim its symptoms. This, when combined with dealing with the chronicity of a long-term, debilitating illness, makes the CFS population rather unique in today’s medical landscape. The vast majority of medical illnesses (and most psychiatric illnesses) do have identifiable, objective data that validates the ill individual’s subjective complaints. As previously discussed, this objective data allows the medical community to affix a “diagnosis” thus indicating the individual’s eligibility for the sick role. In the United States, being labeled as ‘disabled’, albeit calling for a ‘stigma’ label, does allow for the initiation of governmental benefits such as long-term disability, as well as socially acceptable release from certain responsibilities such as work, etc. However, if there are no objective data on which the medical practitioner can base a diagnosis of illness, that sick role legitimacy may be denied, along with the benefits that role might bring in today’s society.

In the present study, the shortened, 13-item scale developed by Antonovsky (1993) was used to measure SOC of the CFS patients. Various sociodemographic indicators were also utilized, as well as an original Functional Ability scale. The purpose of this study was to examine sense of coherence in those individuals diagnosed with CFS, and to explore the relationship between sense of coherence and functional disability in this population, as well as describe the experience of the CFS patient. To more fully examine the experience of CFS, a subset of 12 respondents was asked
5 additional questions via in-home or telephone interviews. These findings are presented in detail in Chapter V and are incorporated with the quantitative findings in this chapter.

Statement of Results

The quantitative data were analyzed and showed that the majority of CFS patients were female with a mean age of 45.8 years. No relationship was found between age of the CFS patient and sense of coherence or between gender and SOC. No relationship was found between employment status and SOC or duration of illness and SOC. Additionally, no relationship was found between fatigue and SOC.

However, there was a significant difference between the SOC scores of CFS patients and the samples of other individuals diagnosed with chronic illnesses, such as cancer patients, fibromyalgia patients, diabetics, and rheumatoid arthritis patients, all of whom displayed a significantly higher SOC than did the CFS study sample. The only group that displayed a similar SOC to that of the CFS sample in this study was that of U.S. homeless, drug addicted women.

Discussion of Conclusions

As previously stated, Hypotheses 1, 2, 3, 4, 5, and 6 were not supported. There was no relationship found between SOC and the CFS patient in relation to age, gender, employment status, duration of illness or fatigue. These findings are supported in part by Klang et al. (1996) and Callahan and Pincus (1995) who also found no relationship between age and SOC or between duration of illness and SOC.
Callahan and Pincus (1995) and Klang et al. (1996) found no relationship between gender and SOC. There were no studies investigating the possible relationship between SOC and employment status or fatigue in the CFS patient, thus no statement of similarities or dissimilarities can be made.

Although the relationship between functional ability and SOC was not significant, \( p = .07 \), perhaps a larger N would have yielded a significant finding. While no study reported on the relationship between SOC and functional ability/disability in the CFS patient, Callahan and Pincus (1995) found a lower SOC in those individuals diagnosed with rheumatoid arthritis who were experiencing more difficulties performing ADLs. Coe et al. (1990) also found a relationship between measures of physical health, ADLs, and SOC in their study of older veterans. Klang et al. (1996) reported that in the population of pre-dialytic patients, SOC was negatively correlated to anxiety and influenced functional disability in daily life.

A significant difference was found between SOC in the CFS patient and the SOC of other populations diagnosed with a chronic illness. Why was this so? Antonovsky (1993) reported higher SOC scores in those more highly educated. The study population was, in general, a highly educated group who were very involved in normal life activities of relationships, raising families, employment in their chosen fields, etc., before they became ill. It would follow then, that these individuals should have a much higher sense of coherence than is shown in this research. Instead, these individuals displayed a much lower SOC than other individuals struggling with a chronic illness (Antonovsky, 1993; Callahan & Pincus, 1995; Coe et al.,
1990). This finding may indicate that CFS is different in its effects upon the individual than are other chronic illnesses. Thus, over time, the individual's SOC is diminished.

What makes CFS different from other chronic illnesses? After all, rheumatoid arthritis individuals, diabetics, cancer patients, and those individuals diagnosed with fibromyalgia, all face similar problems as does the CFS patient. Fatigue, pain, depression, anger and decreasing functional ability become part of life for many chronically ill individuals. However, the symptoms and complaints of most chronically ill individuals are supported by objective data of the disease process, so the subjective complaints of these individuals are validated by diagnostic tests and subsequently confirmed by their physicians. As a result, the individual receives a definitive diagnosis and subsequent treatment plan. Consequently, the ill individual's health care provider, employer, and family all understand the implications of the illness, and (usually) provide the necessary physical and emotional support. Also, because the disease process and etiology of the chronic illness has been identified, these individuals have hope that life may some day be better. Post-White et al. (1996, p. 1571) stated:

When faced with cancer, a sense of hope can provide meaning, direction, motivation, and a reason for being. Maintaining hope and expectation for a favorable outcome can be important in facing uncomfortable side effects, continuing with daily activities, maintaining a functional role within the family, and possibly even surviving cancer.

However, for the individuals in this study, no diagnostic tests for CFS exist, therefore, eventually receiving this diagnosis for symptoms that cannot be validated.
does not contribute to the credibility of the CFS individual. Over time, with no effective treatment plan, little or no emotional and physical support, and the chronicity of fatigue and pain, the individual’s emotional health may be affected. The individuals in this study appear to have abandoned all hope that they will be believed and that a cure or even a treatment to alleviate the symptoms will be found.

The group that the CFS individual has the most in common with, according to the similarities with SOC scores, is U.S. homeless and drug addicted women. It would appear that both populations find life increasingly chaotic, with little meaningfulness, comprehensibility or manageability. One could certainly expect that the individual living on the streets would find life chaotic, but what are the components that would make the life of an individual living with a chronic illness increasingly chaotic? Indeed, most research on SOC and chronic illnesses do not conclude that chronic illness contributes to a weakened sense of coherence (Coe et al., 1990; Coe et al., 1994; Forsberg & Bjorvell, 1996). However, in the CFS sample in this study, what other factors might explain the low sense of coherence scores? To more fully address this question, one must delve more deeply into the feelings, attitudes and experiences of the individuals diagnosed with CFS.

Qualitative Support for Components of Sense of Coherence

The role that the three components of sense of coherence (meaningfulness, comprehensibility and manageability) play in one’s SOC seemed to be supported in this study by both qualitative and quantitative findings. Those participating in the
qualitative interviews, sometimes referred to these exact words when responding to the researcher's questions, and other times referred to their concepts.

**Meaningfulness**

In general, the participants reported a decrease in meaningfulness in their daily lives due to chronic fatigue, loss of meaningful work and decreasing functional ability. One respondent stated:

You stop being who you were...It destroyed everything I was...It turns your life upside down and you don't know who you are anymore...All your goals are gone, everything that once meant something to you and you have nothing to put in its place.

Another said, "Employment is completely gone now. Parenthood...always an unquestioned goal in my life will never be attained...I just don't have the energy to raise kids."

A third responded:

I worked so hard to become a teacher and now I can't do that. I feel inadequate and I feel like a failure...the things that once had the most meaning in my life are all gone...I just want to be dead.

The meaningfulness in the lives of the study sample revolved around work issues and family matters. An important consideration is that many individuals commented that their former goals and dreams that provided meaning and substance for their lives were gone and there was nothing, no goal nor dream nor vision, to put in its place. Thus, life's meaning, for the majority of this sample was diminished.
Comprehensibility

The study sample also had trouble finding comprehensibility in their illness, although no one used the word ‘comprehensibility.’ One respondent stated:

It (CFS) turns your life upside down and you don’t know who you are anymore...All your goals from your early years are gone and there is nothing to put in their place because there is no hope...nothing makes sense anymore...You are what you do for work...but now I’m facing disability at 33 and it has shattered my self-image.

Another related:

This disease has broken me down and I don’t recognize the image I see in the mirror anymore...it is a total stranger...nothing makes much sense and nothing really matters...As long as our health care system denies us a real diagnosis, then we will continue to live in a wasteland where no one really believes us and no one really cares.

Finally, one individual said,

I am totally exhausted both mentally and physically. I am having more and more trouble with my eyes, a hard time focusing, am having a hard time concentrating mentally, am having trouble with irritable bowel, generalized pain, fatigue, etc...but no one else thinks I feel as bad as I do...I just don’t understand how life can get this bad and no one understands.

In general, the participants related how their symptoms and decreasing functional ability was mentally and physically troubling to themselves and to others. Life, and what life has brought with it was not understandable, not comprehensible. This disease was not just something that one has to pass through, such as an individual who is undergoing chemotherapy, but believes that the end result of the mentally and physically exhausting chemotherapy will be a cure or at least a remission. For the CFS individual, there is no promised cure, no palliative treatment, and no light at the end of the tunnel.
Manageability

Manageability, the last of the three components in Antonovsky’s sense of coherence concept, was another concept that the study population found difficult. In general, as the disease took over more and more of their lives, the fatigue, depression, malaise, etc. made it increasingly difficult to manage the activities of daily living. One respondent stated “Now I am always bitchy, always yelling at my kids and not pleasant to be around...we are going to therapy again, but my marriage is in trouble...My husband is just tired of living like this...life is just too hard.” Another responded “I no longer have a life plan...I now live on an hour to hour basis because if I make plans for 2 hours in the future, I may not be able to do it when the time comes...pacing yourself is hard.” A third stated:

It’s like living in a cage...constant choices and frustrations...constant trade-offs. If I do this, then will I still be physically able to do that? There is both mental disability and physical disability...we are always asking ourselves ‘How much can I do today’?

Manageability, then, is also a component that the CFS individuals found difficult. In the wake of chronic and sometimes overwhelming mental and physical fatigue, managing life’s daily activities becomes increasingly problematic for this population.

The qualitative findings of this study, therefore, mimic the results of the quantitative findings. The components of meaningfulness, manageability and comprehensibility are all challenged in the CFS individual, and the end result of that challenge appears to be a weakened sense of coherence. A further exploration into
Antonovsky's salutogenic orientation is warranted.

General Resistance Resources (GRRs)/General Resistance Deficits (GRDs)

General resistance resources are, in general, characteristics of the person, the group or the environment that facilitates effective tension management (Antonovsky, 1989; Strumpfer, 1990). In this study, items usually identified as GRRs (e.g. the health care system, support from family and friends, employment in chosen field) sometimes became GRDs, and became chronic stressors. Because the health care system, for the most part, negates the experience of the CFS individual by not authenticating the disease process and, subsequently, not allowing entrance into the sick role with its resultant gains, the health care system becomes a GRD. Many times, families and friends desert the ill individual after a lengthy chronic illness, especially one in which there is no end in sight and no validation of the actual disease. Therefore, where once friends and families provided emotional support to the ill person, the family and/or friends may now regard the CFS individual much as the health care system does...as one whose subjective symptoms cannot be validated and therefore, must be a charlatan, feigning illness for secondary gain purposes. In this case, family and friends may also become a GRD. Finally, employment is often regarded as a GRR. One's life's work can be very important in defining that individual. If the work one has been educated to do can no longer be done because of illness, then one loses this as a GRR, and the resultant loss in self-esteem becomes a GRD (Antonovsky, 1987).
Antonovsky (1987) asserted that the individual with a strong SOC did not necessarily have to see the entire world as coherent, but instead, that individual is able to set boundaries. What happens inside those boundaries is seen by the individual as 'coherent', and what goes on outside the boundaries is simply not of importance, therefore, may or may not be manageable, comprehensible or meaningful. He discussed an individual’s boundaries as being fluid, or contracting or expanding depending upon the individual’s current life situation. There are four major spheres of importance to bear in mind when considering an individual’s boundaries, and all four of these spheres are affected in the CFS patient. The first sphere is the individual’s personal feelings. In the CFS individual, because of the chronicity of symptoms and the constant malaise in the internal environment, and the changes in the external environment of job loss, etc., the individual’s personal feelings are bombarded with GRDs. The second sphere, concerning immediate interpersonal relations, is also threatened because of the decreasing support of the health care system, family and friends, and the loss of work associates. The third sphere, or the major sphere of activity, can also be threatened if the major activity is work-related and the individual is no longer able to continue with his/her current employment. If the major sphere of activity is in the personal/family realm, the sphere can be threatened if the person is no longer able to continue caring for his/her family, or must end a relationship because of illness issues. The fourth sphere, the existential issues of death, failure, shortcomings, conflict, and isolation, is also very much threatened as
most of the ill individuals stated that they feel like failures, and most also report becoming increasingly isolated because of the demands of personal interactions and because they are no longer pleasant to be around.

Overall, the boundaries of the CFS person are threatened in all spheres. While individuals with other chronic illnesses may have some of their boundaries threatened (i.e. the first sphere containing personal feelings, perhaps the third sphere if their major activity is threatened), individuals with other chronic illnesses do not have ALL their spheres threatened. Because persons with the other chronic illnesses are validated in their disease processes by objective data showing that they are indeed ill, these persons are allowed to be sick, allowed to enter the sick role...therefore, they are less likely to lose the social support (GRR) of the medical profession, and are less likely to lose the emotional support of family and friends (again, GRRs). Subsequently, the fourth sphere is less likely to be challenged. An individual diagnosed with rheumatoid arthritis, for example, would not necessarily feel like a failure if he/she could no longer perform a certain job that required motions and movements that were too painful. Once the arthritic conditions began causing deformities, coworkers and family could see that certain movements are no longer possible. However, for the CFS individual, no such objective data exists, and though the ill individual continues to assert that he/she no longer is capable of a certain action, there are no accompanying objective signs to validate these claims. Therefore, the CFS individual must eventually contract his/her boundaries more than individuals with other chronic illnesses because all four spheres are under assault from internal and external...
GRDs, with a diminishing number of GRRs to ward off the fight. This contraction of the boundaries leads to increasing isolation for the CFS individual, which most likely is an additional contributor to a diminishing sense of coherence.

Entropy

The final concept inherent in Antonovsky's salutogenic orientation is the idea of entropy. Entropy is the continuous tendency of all things in the universe to move towards disorder. In his early writings, Antonovsky asserted that sense of coherence was most likely fixed by age 30, and would, for the most part, remain constant over one's lifetime, with occasional dips and peaks which were transient in nature and dependant upon current life circumstances (Antonovsky, 1987; Strumpfer, 1990). As time went by, he realized that entropic (disorderly) forces were at work on all human organisms and that these forces were powerful. He stated "In sum, the person with a strong SOC can suck orderliness from the environment which counterbalances the pressures toward disorder from the internal and external environments. Entropy is controlled by feedback, by the constant introduction of negative entropy" (order) (1987, p. 121). But what happens in the case of the CFS patient, where there is little or no meaningfulness, manageability or comprehensibility, and the GRDs may far outweigh the GRRs in warding off stress and its devastating effects? The result of natural entropic forces, combining with overwhelming GRDs and a decreasing number of GRRs is, in the opinion of this author, a sense of coherence that reflects an internal and external environment that is chaotic, without meaning, comprehensibility.
or manageability; in short, a weakened sense of coherence.

The CFS Experience

Although it is not known how or why CFS strikes a particular individual or even what this disease really is, this author asserts that the following characterizes the illness experience for the majority of CFS individuals. Some of the statements are supposition while others are validated by the findings of this study. Because this sample is a relatively highly educated group, and Antonovsky found that, in general, those individuals with a higher education also exhibited a stronger sense of coherence, the CFS individuals most likely had a higher sense of coherence before their illness began. Then, a prolonged period of constant unrelieved stress depleted the individual’s reserves and greatly taxed his/her coping abilities. Most study participants reported undergoing a lengthy period of intense and unrelenting stress for approximately one year before experiencing symptoms of CFS. This stress depressed the immune system making the individual increasingly susceptible to invading organisms (bacteria, viruses, etc.). Once the individual was exposed to this agent (perhaps an as-yet-to-be-identified virus), the incubation period of up to one year provided the virus with much time to replicate itself, eventually causing the various symptoms reported by the CFS patient (Ablashi, 1995; CFS Website, 2000; Freud & McGuire, 1995).

After vague symptoms of malaise and generalized fatigue did not diminish with time, the study participants eventually went to their family physician, who,
overall, didn’t take their client’s complaints very seriously. Some physicians pre-
scribed antidepressants for complaints of fatigue and generalized malaise, while
others did some routine blood work, and sometimes advised their clients to reduce
the stress in their life. In general, the study participants found treatment by primary
care practitioners as episodic and unsatisfactory. Over time, and after many visits to
many different health care providers who stated that the gradually worsening symp-
toms are probably stress-related and “in your head,” the individuals suffering from
CFS felt invalidated and began to doubt themselves. If they experienced further diffi-
culties maintaining employment and encountering illness-related difficulties in their
personal life, then ultimately, life became less comprehensible, certainly less man-
ageable, and therefore, less meaningful. Post-White et al. (1996, p. 1578) states:

Antonovsky originally viewed sense of coherence as stable and fundamental
to an individual’s makeup (1979), but he more recently recognized the dyna-
ic nature of life’s experiences in shaping one’s sense of coherence (personal
communication, 1992). If hope and sense of coherence are indeed dynamic
and changing, measuring these constructs at one point in time may not accu-
rately reflect the value given to each of the components, particularly when
disease state or physical and emotional responses change.

Thus, continuing frustrations with health care providers, illness-related difficulties
maintaining employment and managing personal life, and increasing fatigue and
functional disability inherent in the CFS individual may lead to increasing despair
and hopelessness. GRRs disappear, some becoming GRDs, adding increased stress to
a fragile system. The individual’s boundaries constrict and his/her world becomes
smaller and smaller. Entropy continues to erode the already fragile system...
eventually, a perhaps once orderly world becomes increasingly chaotic.
Consequently, over time, the sense of coherence that was once strong in this individual could become diminished and weak.

**Limitations of the Quantitative Study**

Interpretations of the findings of this study are offered with caution because of several serious limitations. First, the SOC scale has not been tested in the population of CFS individuals. The validity, both content and construct, of Antonovsky's SOC-13 scale has not been established in this population. Second, the scale utilized to measure fatigue in the CFS individual is a visual analogue scale, which some patients may find difficult to understand. Although all 30 participants did fill out this part of the questionnaire completely, some marked their responses above or below the line, possibly decreasing the reliability of the measurements. Also, because the study sample was not given specific instructions as to a specific time of day to fill out the questionnaire, some may have filled it out in the early morning, while others filled it out at the end of a long day when they were more fatigued, thereby giving misleading results. Further, the subjective feelings reported on the questionnaires were measured at one point in time and may not reflect the true feelings of the CFS individual over time.

Additionally, because SOC was measured at one point in time, causation is difficult to be established. It is difficult if not impossible to determine if a decreased SOC is the result of increased GRDs, decreased GRRs, entropy and isolation, or whether an already low SOC resulted in the individual becoming ill.
Another limitation is that because the activity charts used to measure the functional disability were original, no reliability of the charts has been established. Also, there was much missing data on these activity charts, greatly decreasing their utility. Also, there may be other intervening variables that are not controlled for in this study. Finally, because the study sample was self-selected and not the result of random selection, and because of the small sample size (N=30), the results of this study should not be considered to be representative of the entire CFS population as a whole.

Limitations of the Qualitative Study

The twelve participants for this portion of the study were mainly middle-class (at least originally), Caucasian, and female, therefore the data obtained cannot be generalized to the general population. Many of the respondents had been ill for years, and this time lag could induce forgetfulness on the part of the participants, and could have affected their ability to correctly recall some of the details asked for in the various questions. Also, the interviews were not audiotaped (in an effort to minimize the respondent's discomfort and eliminate any intimidation that audiotaping might cause), which means that some of the details could have been missed. However, some of the participants slowed their speech so that the interviewer could write everything that was said. Of course, this tendency to speak more slowly and pause more often may have inhibited and slowed the thought processes of the participants more than if the interviews had been taped.
Significance of Study Findings to Sociology

Although this study is not representative of the CFS population as a whole due to the study sample being small (N=30), self-selected and Caucasian, there are important implications to consider for sociology. As medical sociologists, it is important to develop theory that is useful in explaining and examining trends in health care, as well as health behaviors of individuals, in order to better understand the needs and strengths of our current health care system. Antonovsky’s salutogenic orientation to health is one such theory that could become increasingly important in facilitating our understanding of ‘what keeps us healthy?’ This salutogenic orientation should be used, according to Antonovsky (1987), in conjunction with the pathogenic orientation in order to more accurately describe the total, or “holistic” health picture of each individual. For the CFS individual, a more complete understanding of both the pathogenic as well as the salutogenic perspectives is necessary to truly understand the disease and its effects upon individuals. Since we don’t understand the pathogenic origins, or the medical underpinnings of this disease process, a clearer understanding of ‘what keeps us healthy’ would indeed be illuminating.

Further, additional research is needed to ascertain whether SOC is indeed lower in those individuals who are forbidden to enter the sick role (both pre and post-diagnosis), due to lack of identifiable, objective data, but who are unable to continue performing their usual daily functions due to their subjective ratings of ill health. As medical sociologists, we need to further understand chronic illness in relation to the GRRs/GRDs inherent in today’s society. In addition, how does entropy play a role in
the SOC of those diagnosed with a chronic illness? Further, continuing to develop and understand the salutogenic orientation to health will inevitably assist those individuals in the applied areas, such as health care providers, to better support persons with chronic illnesses.

Significance of Study Findings to Nursing

Nursing has done much research with various populations in the area of salutogenesis, and specifically, sense of coherence. The goal of the nurse is to provide emotional and social support to the ill individual, as well as to prevent illness among healthy individuals. Sullivan (1989) discussed the role of the nurse as a GRR for the ill individual. In the CFS sample in this study, the nurse was not referred to specifically, but in general, health professionals did not provide emotional/social support necessary for the study participants to regard them as GRRs. Instead, in many cases, health care providers became GRDs, as no real support was provided to the ill individual. Nursing is in a unique position, however, because while the nurses treat physical illnesses, they also care for the individual holistically, supporting the “whole” person...physically, emotionally, and spiritually. As an integral part of health care professionals, nurses need to understand the relationship between sense of coherence and chronic illness. How can we best support an individual diagnosed with a chronic illness? Does one’s sense of coherence affect how an individual will react to being diagnosed with a chronic illness, and does SOC have an impact upon the disease outcome? Finally, if indeed, sense of coherence can weaken over time
with chronic illness, what can health care providers in general, and nurses specifically, do to support and perhaps strengthen sense of coherence, leading to a better quality of life for the ill individual?

Recommendations for Future Research

Based on the findings of this research, several recommendations are advanced. To be most useful to the health care practitioner, much more research is needed to determine if one's sense of coherence can indeed change significantly when conditions in life worsen or improve dramatically. It does appear from the research done up to this point that the effects of chronic illness alone are not related to a change in SOC (Callahan & Pincus, 1995; Coe et al., 1990; Coe et al., 1994), but other factors such as functional disability and support from health care providers (i.e. being believed and validated, etc.), may play a role, as suggested by this research. Further, the study by Martensson, Pettersson, and Fridlund (1995) indicated that perhaps sense of coherence could be strengthened by specific interventions (e.g., ego strengthening) by the health care professional. More research is necessary to determine if sense of coherence can be strengthened, and, if so, the most effective ways to accomplish this.

Another area of focus for researchers is the etiology of sense of coherence. How and why an individual develops a strong sense of coherence will help health care professionals and educators design programs with the express purpose of assisting the individual to develop a strong sense of coherence. A fourth area of research is
to continue to measure sense of coherence across the ages, and in different illnesses and disabilities to determine if other patterns emerge. Further, sense of coherence should continue to be researched across different groups to determine if race, education, or income level is a useful predictor of a particular sense of coherence.

Another much needed area of research into sense of coherence is investigating the relationship of sense of coherence to mental illness. Although a weak sense of coherence has been linked to increased anxiety and neuroticism (Antonovsky & Sagy, 1986; Gibson & Cook, 1996), much more research is needed to investigate the possible relationship between decreased mental health and a weak sense of coherence. As found in this study, many CFS individuals reported being diagnosed with depression, which also could ultimately affect SOC.

Finally, additional studies should be conducted on sense of coherence cross-culturally to determine how applicable the construct is once the medical model paradigm is no longer prevalent as is the case in many of the world’s cultures. As we now exist in a global economy, understanding the world’s peoples, their belief systems, and what motivates them to maintain health is imperative.

As previously stated, future research into sense of coherence is of extreme importance. As medical sociologists, we need to know how and why some individuals form a strong sense of coherence, and why others do not. Also, we need to increase our understanding of the relationship between chronic illnesses, such as CFS, and sense of coherence. It would appear from the findings of this study, that declining functional ability (a GRD), along with the bombardment of other GRDs
such as overwhelming fatigue, chronic persistent symptoms, job loss and entropy may contribute to a weakened SOC, but there are other factors which may also contribute to this finding, such as lack of social support (especially from the medical community) related to an unverifiable disease process. More research is needed to more fully explore if, indeed, sense of coherence can become weaker over time, and if so, what factors are responsible for this decrease. Once this is understood, health care providers would perhaps be increasingly cognizant of how to avoid weakening an already fragile sense of coherence in an ill individual. Conversely, since it is probable that those with a stronger sense of coherence will experience less disability and illness over a lifetime, researchers are exhorted to discover ways to strengthen sense of coherence in those with weaker coherence, and to discover ways to establish a strong sense of coherence in those younger individuals who have not yet established their sense of coherence in order for these persons to have a healthier and happier life.
Appendix A

Human Subjects Institutional Review
Board Approval Letter
Date: 29 September 1998

To: Morton Wagenfeld, Principal Investigator
   Sue Jensen, Student Investigator for dissertation

From: Sylvia Culp, Chair

Re: HSIRB Project Number 98-09-02

This letter will serve as confirmation that your research project entitled "Coping with Chronic Fatigue" has been approved under the expedited category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 29 September 1999
Date: 14 June 1999

To: Morton Wagenfeld, Principal Investigator
    Sue Jensen, Student Investigator for dissertation

From: Sylvia Culp, Chair

Re: Changes to HSIRB Project Number 98-09-02

This letter will serve as confirmation that the changes to your research project “Coping with Chronic Fatigue” requested in your memo dated 14 June 1999 have been approved by the Human Subjects Institutional Review Board.

The conditions and the duration of this approval are specified in the Policies of Western Michigan University.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: 29 September 1999
Thank you for your interest in participating in this study. This research was designed to more fully understand chronic fatigue syndrome and its effects upon individuals diagnosed with this disease. Should you agree to participate in this research, your responses will be kept strictly confidential. No names will be affixed to the data. The questionnaires will be coded, and the student investigator will keep a separate master list with the names of participants and the corresponding code numbers. Once the data are collected and analyzed, the master list will be destroyed. All other forms will be retained for three years in a locked file in the principal investigator’s office.

Any participant can withdraw his/her consent to the research or discontinue participation in the research without prejudice, penalty, or risk of any loss of service he/she would otherwise have. There are no anticipated risks or benefits to the participants.

This study consists of 2 parts: the first is a questionnaire which will take approximately 30 minutes to complete. Approximately half of the total study participants will be randomly selected for the second part of the study, which will be a personal interview conducted in your home, or a similar convenient setting, by the student investigator. If you are selected for this part of the study, the researcher will contact you approximately 3 weeks after you complete the initial questionnaire, to schedule a convenient time to meet. This portion of the study will also take approximately 30 minutes to complete. If you are interested in continuing, please answer the following questions:

1) Have you been given a diagnosis of chronic fatigue syndrome by a medical doctor?
   a. yes
   b. no

2) Are you at least 18 years of age?
   a. yes
   b. no

3) Are you willing to participate in this study?
   a. yes
   b. no

If your answers to these questions are “yes”, then continuation implies: “I am aware of the nature and purpose of this research, and by signing below, provide my consent to participate.”

Name

Address

Phone ___________________________ Date ___________________________

Should any questions or problems arise during the course of the study, the participant may also contact the Chair, Human Subjects Institutional Review Board (387-8293) or the Vice President for Research (387-8298). Other questions or comments should be addressed to the Principal Investigator/Advisor, Dr. Morton Wagenfeld (387-5292), or Student Investigator, Sue Jensen (616 868-0370).

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right hand corner. Subjects should not sign this document if the corner does not show a stamped date and signature.

Date of consent & investigator initials
Appendix B  
Case Number_______

Chronic Fatigue Syndrome Questionnaire  
Part 1 - Characteristics of the Participant

Thank you for your participation in this study. This questionnaire was designed to more fully explore the experience of chronic fatigue syndrome. Please provide answers to the following questions in either the spaces provided, or by circling the correct response. Please do not put your name on this questionnaire. Your responses will be kept strictly confidential.

1) What is your date of birth? ___/___/___
   mo day year

2) What is your gender?
   a. male
   b. female

3) What is the approximate date when you first started to notice the symptoms of chronic fatigue syndrome (CFS)? ___/___/___
   mo day year

4) Approximately how many health care providers did you see regarding your fatigue before you received the diagnosis of CFS? ______

5) In terms of your current treatment for CFS, which kinds of practitioners are you currently seeing? (circle all that apply)
   a. general practitioner/family doctor (M.D. or D.O)
   b. medical specialist (M.D. or D.O)
   c. chiropractor
   d. alternative therapist (e.g. homeopathic healers, etc.)
   e. clinical nurse specialist, nurse practitioner, physician's assistant
   f. other (describe) ____________________________

6) In terms of directing your treatment for CFS, who is your primary treatment provider?
   a. general practitioner/family doctor (M.D. or D.O)
   b. medical specialist (M.D. or D.O)
   c. chiropractor
   d. alternative therapist (e.g. homeopathic healers, etc.)
   e. clinical nurse specialist, nurse practitioner, physician's assistant
   f. other (describe) ____________________________
7) If seeing a medical specialist, which specialty? (e.g. neurologist, allergist, etc.)

8) What tests, if any, were done prior to receiving the diagnosis of CFS? (Circle all that apply):
   a. history and physical examination
   b. mental status examination
   c. lab tests/blood work
   d. urinalysis
   e. MRI (magnetic resonance imaging)
   f. other (please list)

9) For about how many months did you experience symptoms before a diagnosis of CFS was made?

10) Have you been diagnosed with any of the following? (Circle all that apply)
    a. depression
    b. fibromyalgia
    c. cardiac conditions
    d. blood conditions

11) Over the course of an average day, does your fatigue level:
    a. increase
    b. stay the same
    c. decrease

12) Please mark your fatigue level normally experienced at the beginning of the day, with 0 being no fatigue and 10 being severe fatigue, making an "X" on the line

13) Please mark your fatigue level normally experienced at the end of the day, with 0 being no fatigue and 10 being severe fatigue, making an "X" on the line
14) Circle all the symptoms that you normally experience during an average day:
   a. impaired memory or concentration
   b. sore throat
   c. tender lymph nodes in the neck or under the arm
   d. muscle pain
   e. multijoint pain (without swelling or redness)
   f. headache
   g. unrefreshing or inadequate sleep
   h. fatigue lasting more than 24 hours after exercise or work
   i. Other ____________________________

15) Your current treatment regimen includes: (Circle all that apply)
   a. stress reduction
   b. a balanced diet
   c. rest
   d. a reduced work schedule
   e. referral to an occupational therapist/rehabilitation therapist
   f. exercise program/physical therapy
   g. medications (Please list all medications prescribed or recommended)
      ___________________________________________________________
      ___________________________________________________________
   h. Other (please describe)______________________________________
      ___________________________________________________________

16) What is the average number of hours you currently work outside the home in a week?
    ________________________________ hours

17) Before your diagnosis of CFS, what was the average number of hours you worked outside the home in a week?  ________________________________ hours

18) What is the average number of hours you currently work inside the home in a week?  ________________________________ hours

19) Before your diagnosis of CFS, what was the average number of hours you worked inside the home in a week?  ________________________________ hours
20) Have you had to change or modify your job as a result of CFS?
   a. yes, I have modified my job
   b. yes, I had to quit my job
   c. no
   d. not applicable

21) If you currently work outside the home, what percentage of the time do you:
   a. sit __________
   b. stand __________
   c. walk __________
   d. TOTAL 100%
   d. not applicable

22) If you currently work outside the home, did you have to change the amount of time that
    you sit, stand or walk in your job as a result of CFS?
   a. yes
   b. no
   c. not applicable

23) Do you currently attend a support group for CFS?
   a. yes
   b. no

24) Have you ever attended a support group for CFS?
   a. yes
   b. no

25) How would you rate your health before you were diagnosed with CFS?
   a. excellent
   b. good
   c. fair
   d. poor

26) How would you rate your current health status?
   a. excellent
   b. good
   c. fair
   d. poor
27) How do you anticipate your health status will be in the future?
   a. excellent
   b. good
   c. fair
   d. poor

28) Please circle the highest level of education you have obtained:
   a. less than high school
   b. high school graduate/GED
   c. some college/associate level
   d. college graduate/bachelor level
   d. masters or doctoral level

29) Please circle your yearly household income level, including all sources:
   a. $15,000 or less
   b. $15,001 - $20,000
   c. $20,001 - $25,000
   d. $25,001 - $30,000
   e. $30,001 - $35,000
   f. $35,001 - $50,000
   g. $50,001 - $60,000
   h. $60,001 - $70,000
   i. $70,001 +
Sense of Coherence Questionnaire - Part 2

Thank you for participating in this study. Below are a few questions which relate to various aspects of our life. Every question has 7 possible responses. The statements under numbers 1 and 7 express the extremes of possible answers. If the answer under number "1" is most applicable to you, then circle 1. If the answer under "7" fits you best, then circle 7. If you feel that your answer lies between 1 and 7, then circle the number which in your judgment fits you best. Please read the questions carefully and provide a single response for each question. Please do not put your name on this questionnaire. Your answers will be kept strictly confidential.

1. Do you have the feeling that you don't really care about what goes on around you?
   1  2  3  4  5  6  7
   very seldom or never
   very often

2. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?
   1  2  3  4  5  6  7
   never happened
   always happened

3. Has it happened that people whom you counted on disappointed you?
   1  2  3  4  5  6  7
   never happened
   always happened

4. Until now your life has had:
   1  2  3  4  5  6  7
   no clear goals or purpose at all
   very clear goals and purpose

5. Do you have the feeling that you're being treated unfairly?
   1  2  3  4  5  6  7
   very often
   very seldom or never

6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?
   1  2  3  4  5  6  7
   very often
   very seldom or never
7. Doing the things you do every day is:
   1  2  3  4  5  6  7
   a source of deep pleasure and satisfaction  a source of pain and boredom

8. Do you have mixed-up feelings and ideas?
   1  2  3  4  5  6  7
   very often  very seldom or never

9. Does it happen that you have feelings inside you would rather not feel?
   1  2  3  4  5  6  7
   very often  very seldom or never

10. Many people—even those with a strong character—sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?
    1  2  3  4  5  6  7
    never  very often

11. When something happened, have you generally found that:
    1  2  3  4  5  6  7
    you overestimated or underestimated its importance
    you saw things in the right proportion

12. How often do you have the feeling that there's little meaning in the things you do in your daily life?
    1  2  3  4  5  6  7
    very often  very seldom or never

13. How often do you have the feelings that you're not sure you can keep under control?
    1  2  3  4  5  6  7
    very often  very seldom or never
### Part 3a - Activity Chart

**Before your diagnosis with CFS, how often did you participate in the following activities? Please circle the most appropriate response.**

<table>
<thead>
<tr>
<th>Activity</th>
<th>2-times/ month</th>
<th>1-month</th>
<th>2-times/ week</th>
<th>1-week</th>
<th>Daily</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone calls</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities with friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hobbies with physical exertion</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hobbies with mental exertion</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities with family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparing meals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Running errands</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual activity</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yardwork/ gardening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housework</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paying bills</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Before your diagnosis, did you normally:**

- need no assist with
- need assist with
### Part 3b - Activity Chart

*After your diagnosis with CFS, how often did you participate in the following activities?*

<table>
<thead>
<tr>
<th>Activities</th>
<th>Never</th>
<th>2-3times/month</th>
<th>Once a week</th>
<th>2-3times/week</th>
<th>Daily</th>
<th>Need no assist with</th>
<th>Need assist with</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone calls</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Activities with friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Hobbies with physical exertion</td>
<td>1</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Hobbies with mental exertion</td>
<td>1</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Activities with family</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Preparing meals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Running errands</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Exercise</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Sexual activity</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Yardwork/gardening</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Housework</td>
<td>1</td>
<td>2</td>
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<td>4</td>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Driving</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Volunteer activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>2</td>
</tr>
<tr>
<td>Paying bills</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

*After your diagnosis, did you normally:*

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BIBLIOGRAPHY


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Post-White, J. (1994). The role of sense of coherence in mediating the effects of mental imagery on immune function, cancer outcome, and quality of life. In McCubbin, Thompson, Thompson, & Fromer (Eds.), *Sense of coherence and resiliency: Stress, coping & health* (pp. 279-291). Madison, WI.


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Wagenfeld, M., Baro, F., Gallagher, T., & Haepers, K. (1994). The correlates of coherence in caregivers to demented and nondemented elderly in Belgium. In McCubbin, Thompson, Thompson, & Fromer (Eds.), *Sense of coherence and resiliency: Stress, coping & health* (pp. 249-263). Madison, WI.