Predictors of quality of life and adjustment to chronic fatigue syndrome.

Janette Marie. Collier

University of Windsor

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UMI
PREDICTORS OF QUALITY OF LIFE AND ADJUSTMENT
TO CHRONIC FATIGUE SYNDROME

by

Janette Marie Collier, MA

A Dissertation
Submitted to the Faculty of Graduate Studies and Research
Through the Department of Psychology
in Partial Fulfillment of the Requirements for
the Doctoral Degree at the University of Windsor

Windsor, Ontario, Canada

2000

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ABSTRACT

The present research examined factors that contributed to the psychosocial adjustment and quality of life of individuals with Chronic Fatigue Syndrome (CFS). Variables studied included coping strategies, health locus of control, social support, quality of life, and psychosocial adjustment to illness. Forty CFS patients volunteered to participate in this study. Coping strategies were conceptualized in accordance with Lazarus and Folkman’s (1984) stress and coping paradigm and were assessed using the Ways of Coping Questionnaire (Folkman & Lazarus, 1988). Social support was conceptualized as a multidimensional construct involving social interaction, instrumental support, and positive and negative subjective support. Social support was assessed using both the Duke Social Support Index (Koenig et al., 1993) and the Social Support in Illness Scale (Ray, 1992). Health locus of control was assessed using the Multidimensional Health Locus of Control Scale-Form C (Wallston et al., 1994). Psychosocial adjustment was assessed using the Psychosocial Adjustment to Illness Scale-Self Report (Derogatis, 1978). Quality of life was conceptualised as a subjective construct involving several dimensions and was assessed using the Quality of Life Scale designed by Flannigan (1978). Correlational and multiple regression analyses were conducted with coping strategies, social support, and health locus of control as predictors of measured adjustment to illness, and quality of life. Results indicated that in general, emotion-focussed coping and negative social support were negative predictors of quality of life and psychosocial adjustment to CFS. Problem-focussed coping, an internal health
locus of control and social support were positive predictors of quality of life and psychosocial adjustment. CFS patients face numerous difficulties in dealing with their illness, requiring flexibility in their use of coping strategies and strong emotional support from the people in their lives. As with other chronic illnesses, patients must learn what aspects of their disease can be personally controlled while maintaining some belief in the influence of luck or fate to avoid feelings of guilt and hopelessness in the face of uncontrollable symptoms.
DEDICATION

This paper is dedicated to all those who struggle to cope with CFS and the impact it has had on their lives, in particular, my parents, William and Carol. It is heartbreaking to see you suffer each day with this illness, but I am awed at the courage you show in the face of it. Keep up your hope. I love you.

This paper is also dedicated in loving memory to my grandfather, William Ernest Collier, who unfortunately passed away before seeing its completion. I know that you are with me in spirit; I miss you very much.
ACKNOWLEDGEMENTS

This project is the culmination of many years of hard work, and it never would have been possible without the support of numerous people. I would like to thank my committee members; your input and suggestions along the way have been invaluable! Special thanks to Kathy, whose unfailing support and confidence in me often gave me the strength to keep going. Don’t ever forget, rabbits ARE superior to foxes and wolves! I would also like to thank our Graduate Administrator, Barb Zakoor, who patiently answered my many procedural questions and made sure I knew what I was doing! Thanks, Barb, those ten deep breaths helped!

Thanks is also given to the people who gave of their time and energy to participate in this study in spite of their illness. Special thanks to Dr. S and Lily, who worked so hard to recruit people for this study; keep up the fight!

I must also thank my fellow grad students, especially Dion, Laura, Cory, and Janet, for talking me out of quitting so many times! YAHO0, WE MADE IT!!

It is with love and gratitude that I acknowledge my parents. There is so much to thank you for that I am sure to forget something! You gave me the strength and courage to complete this degree, not to mention the very special gift of time! Without your love and support over the past few years, I am sure this project never would have reached completion. Thank-you for teaching me to value my work, and to have the stamina to keep going.
A very special thank you is reserved for the two men in my life, my husband, Tom and our son, Alexander William. The two of you continually remind me of what is important in life. You made me laugh when the pressure was too much, allowed me to cry when I needed to, and gave me a reason to keep going when all I wanted to do was quit. What could be more inspirational than watching Alexander grow over the past six months? I love you both very much.
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Chapter I

Introduction

An Overview of CFS

In the past several years, there has been increased interest in the investigation of a disease known as Chronic Fatigue Syndrome. This disease has come to be known by many different names, including Myalgic Encephalomyelitis, Chronic Fatigue Immune Dysfunction Syndrome, Post-Viral Fatigue Syndrome, and Epidemic Neuromyasthenia. As a result, CFS has been dubbed "The Disease of a Thousand Names" (Parish, Bell, Hyde, & Rubinstein, 1992). In the interest of brevity, the above will be subsumed under the term Chronic Fatigue Syndrome (CFS).

CFS is characterized by numerous symptoms, including: unexplained debilitating fatigue sufficient to impair functioning to less than 50% of normal levels, muscle aches and weakness, mild fever, sore throat, headaches, sleep disturbance, and a variety of other physical symptoms (Schmell, 1991; Ware, 1999). Patients with CFS also experience neuropsychological symptoms such as forgetfulness, excessive irritability, confusion, difficulty thinking, and an inability to concentrate, resulting in mental fatigue (Holmes et al., 1988; Ware, 1999). In addition, psychological symptoms such as emotional lability, anxiety, depression, and social withdrawal are common (Schmell, 1991; Stricklin, Sewell, & Austad, 1990). As noted by Levy (1991), nearly 60% of people with CFS report symptoms of anxiety and/or depression, in keeping with evidence that depression is commonly a secondary component to chronic illness (Karanci,
A unique feature of CFS is the extreme effect that any kind of mental or physical effort has on the experienced symptoms. Even minor tasks such as solving simple problems or going for a walk have been known to exacerbate physical symptoms, resulting in individuals being incapacitated for days (Calabrese, Danao, Camara, & Wilke, 1992; Wood, Bentall, Gopfert, & Edwards, 1991; Ware, 1999). (Please see Appendix A for a summary of the diagnostic criteria for CFS as outlined by Fukuda et al., 1994.)

Unfortunately, CFS is a disorder for which there is no known diagnostic test, no effective treatments, and no cure (Friedberg & Jason, 1998; Ray, Jeffries & Weir, 1997). In the search for diagnosis and/or treatment, patients are often subjected to extensive medical examinations. When no clear medical diagnosis is found, many patients are referred to mental health professionals with the assumption that their illness is psychological rather than medical. In fact, many medical practitioners do not accept CFS as a legitimate disorder, largely because of the lack of a diagnostic test (Jason, 1993; Murray, 1992). Patients can be misdiagnosed as depressed and prescribed antidepressant medication, which may relieve some, but not all, of their symptoms (Friedberg, 1996). Added to this is the lack of an effective treatment protocol. Although some doctors have had limited success in treating CFS patients through different combinations of medications, few patients are cured, and in fact many must maintain the medication regimen, carefully monitor their energy level and be prepared for periods of remission at any time (Friedberg, 1996; Schmall, 1991). What results
is a frustrating search for diagnosis and treatment, both for the patients and their doctors.

Much of the research to date on CFS has focussed on issues surrounding diagnosis, treatment, and cure. In the meantime, individuals have been left to cope with the effects of this illness on their own. As with other chronic illnesses such as Lupus, Multiple Sclerosis (MS), or chronic pain, CFS has a large impact on a person's life, affecting almost every aspect of daily living (Anderson & Estwing Ferrans, 1997). Chronic illness requires ongoing adaptation on the part of both the patients and the people around them (Enevoldsen Bowsher & Keep, 1995; Primomo, Yates, & Woods, 1990). Individuals typically experience uncertainty about the future, a sense of loss of control, distress, and helplessness (Taylor, Helgeson, Reed, & Skokan, 1991). Many CFS sufferers are unable to work due to the debilitating nature of the disorder, resulting in financial difficulty. Relationships can become strained as fatigue forces social isolation and family members assume the bulk of the household responsibilities (Levy, 1991; Ware, 1999). Researchers have begun to recognize the importance of these issues, and research on CFS in recent years has focussed more on the day-to-day impact of the disorder.

In the field of health psychology, the study of chronic illnesses has been approached from what can be termed a biopsychosocial or multifactorial perspective (Lewis, Cooper, & Bennet, 1994; Taylor, 1990). Such a perspective takes into account not only the biological aspects of the disorder, but also the psychological and social costs associated with it. In particular, researchers have
begun to focus on how individuals cope with illnesses and whether or not increased social support can have an impact on quality of life and experienced emotional distress (Levy, 1991; Schmall, 1991). Research on CFS is focussing more on the roles of coping, social support, and locus of control in CFS management. For example, Ray et al. (1997) investigated coping and locus of control as predictors of functional outcomes in CFS patients. Anderson and Estwing Ferrans (1997) investigated the quality of life of CFS patients. The current study strives to add to this growing body of literature.

Theoretical Framework

The theoretical framework for this study is based on Lazarus and Folkman's (1984) theory of stress, appraisal, and coping, as well as a model of illness behaviour outlined by Pearlin and Aneshensel (1986) incorporating this theory. Briefly, Lazarus and Folkman's theory takes a cognitive view of coping, defining it as a "person's constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources" (Jahanshahi, 1991, p.493). According to Lazarus and Folkman (1984), the process of choosing a coping strategy involves two stages: a primary appraisal by the individual of the significance of the event to his/her life (irrelevant, benign/positive, or stressful), and a secondary appraisal of the options available for reducing the stress. Coping strategies can be categorised as either problem-focussed (aimed at changing the situation causing the stress) or emotion-focussed (aimed at managing the emotional consequences evoked by the stressor) (Folkman & Lazarus, 1980). People
typically use problem-focussed coping strategies such as seeking information and/or social support when they determine that the situation can be changed (Schmalk, 1991). People use emotion-focussed coping strategies when they feel that action is not possible. Examples include wishful thinking, positive reappraisal, and self-control (Schmalk, 1991). Although people will use both of the basic types of coping strategies in different situations, one type usually dominates across those situations (Lazarus & Folkman, 1984). The decision about which to use is said to be a result of people's beliefs, their past experiences, and the specifics of the situation being faced (Schmalk, 1991).

Lazarus and Folkman's stress, appraisal and coping model has been widely accepted in the health field, with many researchers investigating how people cope with stressful situations (Schmalk, 1991). One area that has been of interest in recent years is how individuals cope with a chronic illness. Pearlin and Aneshensel (1986) describe an illness behaviour paradigm in which an illness is seen as a stressor and adjustment to the illness is seen as the outcome that can be influenced by illness behaviours. Illness behaviours are defined as perceptions, thoughts, feelings, and behaviours concerning the personal and social meaning of symptoms, illnesses, and disabilities (Pearlin & Aneshensel, 1986). Similar conceptualisations have been adopted by others in the investigation of coping and social support in chronic illness groups (de Ridder, Schreurs & Bensing, 1998; White, Richter & Fry, 1992).

In this model, coping and social support can influence adjustment to illness directly, or indirectly through their impact on illness behaviours. Social
support can be seen as buffering the effects of the stress caused by the illness. Members of the support network can provide support to improve or alleviate symptoms, or to facilitate adjustment in conjunction with the person’s own coping efforts. Coping can be directed at improving symptoms, at alleviating problems that stem from the illness, or at enhancing adjustment when symptoms are not alleviated. Illness behaviours themselves (such as resting or avoiding social activities) can be seen as attempts to cope with the illness stressor (Pearlin & Aneshensel, 1986).

People can cope with illness in many ways, including trying to change the health problem itself, reducing the distress associated with it, or changing what the illness means to them, and the impact it has on their lives (Pearlin & Aneshensel, 1986). One of the primary aims of coping in response to illness is to try to alleviate the symptoms, with individuals seeking information and help and/or complying with treatment schedules set out by health professionals (problem-focussed coping) (Pearlin & Aneshensel, 1986). Often, however, the nature of the illness itself may dictate certain behavioural responses to it, including the readiness of the person to seek out treatment. For example, irreversible or chronic health problems are often not responsive to medical intervention. In such cases, coping shifts from actively trying to change or reverse the health problem to adjusting to its presence and reducing the emotional distress associated with it (emotion-focussed coping) (Pearlin & Aneshensel, 1986). This is particularly true of CFS as it typically begins with relatively minor flu-like symptoms for which people would not generally seek out
treatment. It is not until individuals are in distress and generally experiencing impaired everyday functioning that they will seek medical assistance. Even then, as the disease progresses and it becomes apparent that the doctor is unable to effectively deal with the myriad of physical complaints, patients can stop seeking treatment and focus on reducing their emotional distress.

In theory, choice of coping strategy can be seen as being influenced by health locus of control (de Ridder & Schreurs, 1996) (See Figure 1). As mentioned by Felton, Revenson and Hinrichsen (1984), Lazarus and Folkman found that the individual’s appraisal of a situation’s amenability to personal control is an important predictor of emotion vs. problem-focussed coping. Health locus of control (HLOC) can be important during the primary appraisal stage, when individuals are determining whether the illness is a threat or challenge and are considering the responses open to them (Taylor et al., 1991). Specifically, those situations that are considered to be within the limits of personal control may be seen as less stressful. In addition, at the secondary appraisal stage, choice of coping behaviour in response to a chronic illness can be influenced by factors such as HLOC and the debilitating nature of the illness (Keller, 1988). Specifically, HLOC can be seen as impacting the appraisal of potential coping resources, with individuals with an internal HLOC orientation being more likely to engage in health promoting behaviours, and those with a chance HLOC orientation engaging in more emotion-focussed coping (Shaw, 1999). Numerous studies have highlighted the importance of feelings of control and personal
Figure 1

Theoretical Framework

Illness → Illness Behaviours → Adjustment

Coping and social support

Health Locus of Control
effectiveness for adjustment, attesting to its utility in this model (Karanci, 1988; Taylor et al., 1991; Watson, Greer, Pruyn, & Van den Borne, 1990).

**Statement of Problem**

In terms of adjustment to illness then, coping, social support, and locus of control can play a role in alleviating problems associated with the illness and possibly influence adjustment and quality of life (de Ridder & Schreurs, 1996; Jahanshahi, 1991; Pearlin & Aneshensel, 1986). As previously mentioned, a serious illness will likely result in hardships aside from the physical aspects of the disorder. Examples include strains in social relationships, emotional distress, or financial difficulties. These are themselves stressors that in turn can exacerbate the symptoms of an illness, increasing adjustment difficulties (Vilhjalmsson, 1998). This is particularly true of CFS, as the person’s entire lifestyle often has to change following onset of the illness. For example, many people with CFS are unable to work, either in or outside of the home, and do not receive long-term disability as CFS is not always recognized as a legitimate medical disorder (Jason, 1993). Even with the support and understanding of family members, individuals may feel useless and guilty for having burdened the family. In addition, the symptoms of CFS are both debilitating and transient, making the planning of social events very difficult (Ware, 1999). Many people with CFS find themselves becoming increasingly isolated as friends and family stop asking them to participate, either out of kindness or anger at their inability to attend. This in turn can lead to increased stress for the individuals, as they have more time to focus on the illness and the impact it has had on their lives (Jason, 1993).
Coping efforts and social support can be utilized to limit the number and intensity of the problems resulting from the illness. Health care professionals can help to identify the secondary problems that stem from the illness and work with patients to find appropriate coping strategies and/or social support to help deal with them. This leaves individuals to deal with the actual illness rather than its secondary effects, hopefully facilitating recovery and/or adjustment.

**Purpose of Present Research**

To date, few studies have investigated coping and adjustment in CFS patients. The aim of the present research was to explore factors in a group of CFS sufferers that predicted adjustment and quality of life. It was hoped that gathering basic information about the experience of the individuals living with the illness would provide some clues to assist other people in adjusting to life with CFS so that they may have a better quality of life. There is a need for patients, families, friends, and health professionals to better understand what people with CFS are experiencing and what has been found to be helpful in coping and adjusting to life with this illness. What follows is a brief review of the literature on a number of variables that might influence coping and adjustment in CFS patients.
Chapter II

Literature Review

Quality of Life and Adjustment to Illness

Two of the most prominent concepts in health psychology literature over the past several years have been quality of life and adjustment to illness. In the late 1940s, the World Health Organization (WHO) stated that health was a multidimensional construct, consisting of "complete physical, psychological and social well-being and not merely the absence of disease or infirmity" (WHO, 1948, cited in Parmenter, 1994 p.11). Health practitioners began to recognize the importance of their patients' mental, social, and physical functioning, and the impact such factors could have on adjustment to and recovery from illness as well as the quality of the lives their patients were leading (Gotcher, 1992). The number of publications in the medical field on quality of life (QOL) increased significantly in the 1970s with the recognition that the impact of therapies on patients should be considered in addition to health outcomes and the absence of symptoms (Bech, 1993). The research focus shifted from treatment strategies to an evaluation of how people perceived their QOL following treatment, and how well they adjusted to life with an illness.

Quality of life and adjustment continued to be important factors through the years as advances in medical technology resulted in a decrease in the mortality rate and a subsequent increase in the number of people living with chronic illnesses (Derogatis, 1986; Merluzzi & Martinez Sanchez, 1997; Simmons, 1994). In addition, increasing numbers of chronic psychiatric patients
were reintegrated into the community to cope on their own (Derogatis & Fleming, 1996). Whereas with an acute illness the immediate treatment objective is to add years to a person’s life, with a chronic illness the treatment objective is to add quality to the years people live with the illness (Bech, 1993). Research shows that the nature of people’s psychosocial adjustment (ADJ) can be as important as the status of their physical disease to the quality of the illness experience (Derogatis & Fleming, 1996). The relief of symptoms does not necessarily mean that patients will report a global sense of well-being or adequate QOL, and clinical researchers now assess QOL and ADJ as distinct outcomes of treatment (Corrigan & Buican, 1995).

As noted by Parmenter (1994), QOL has been used "to assess outcomes of clinical trials, to compare the efficacy of different treatments, to evaluate the cost-utility and cost-effectiveness of health care programs, to assist quality assurance, and to assist in the marketing and regulation of drugs" (p. 35). For the patient, QOL is an important variable if it improves the effectiveness of a treatment. For a clinician, QOL can be important in the assessment of client’s needs and in care planning and evaluation (Simmons, 1994). If clients report poor QOL or ADJ in specific areas of their lives (such as socially or vocationally), interventions can be targeted at improving functioning in those areas. Thus, the investigation of these outcome variables has the potential to translate into very practical treatment goals. This is especially true of persons trying to cope with a chronic illness such as CFS, which impacts almost every area of their lives. For example, CFS sufferers may appear to have a good QOL because they are able
to work and fulfil their financial obligations, when in fact their QOL in other areas (e.g., socially) is very poor. Clinicians can use such information to improve patients' QOL and ADJ in all areas.

One of the difficulties that people suffering from chronic illnesses face is the continual need to maintain a positive attitude and adjust to a situation of constant stress (Burckhardt, Woods, Schultz and Ziebarth, 1989). Despite their ill health, they must also continually try to maintain their quality of life and sense of well-being in an effort to avoid feelings of depression and anxiety. It is therefore important for health care professionals to consider and understand variables that help people interact effectively with their environment and its stressors, and help to prevent the feelings of despair that may result from the constant extreme stress involved with having a chronic illness (Enevoldsen Bowsher & Keep, 1995). One can view CFS as similar to other chronic illnesses such as chronic pain, MS, and mental illnesses in which there is no cure and patients must learn how to live a fulfilled life in spite of their illness.

The few studies that have investigated QOL in CFS patients have generally found that CFS has a significant impact on every area of life. In particular, Anderson and Estwing Ferrans (1997), in their study of both quantitative and qualitative aspects of QOL in CFS patients, found significant disruptions in the areas of Health and Functioning, Socioeconomic, Psychological/Spiritual, and Family. For individuals with CFS, it might be helpful to assess QOL and ADJ in order to identify problem areas, as well as to
investigate whether certain coping strategies can be used to improve functioning in these areas.

With this in mind, the present study assessed QOL and ADJ across a variety of domains and investigated variables that could be related to such. Studies have found that problem-focussed coping is related to better QOL and ADJ, suggesting that it may be beneficial to design psychological treatments around improving a person's reliance on such coping strategies (Felton et al., 1984; Osowiecki & Compass, 1999; Schmall, 1991). Studies have also suggested that QOL and ADJ are related to other factors such as social support and the amount of control the person feels she or he has over the illness (Hickey & Stilwell, 1992). The present study examined the relationships that existed among these variables with an eye towards helping design practical intervention strategies.

Assessing Quality of Life

One of the major difficulties with assessing QOL is that few researchers have a clear understanding of what is meant by "quality of life". Although most clinicians and researchers agree that QOL is a multidimensional construct with psychological, social, and physical factors, they disagree on what exactly it refers to, or they investigate it without adequately defining it (Costain, Hewison, & Howes, 1993; Simmons, 1994). A brief review of the literature provides us with many different definitions for QOL, most of which are vague and not easily operationalized for measurement purposes (Simmons, 1994). For example, QOL has been defined as "individuals' overall satisfaction with life and their
general sense of well-being", as well as "primarily a product of relationships between people in each life setting" (Parmenter, 1994. p.19).

Measurement of QOL suffers from similar difficulties, with researchers using many different indices to represent QOL. In the medical field QOL is seen as a physical phenomenon that should be measured objectively, but the measures used are inconsistent. Quality of life measures may include domains such as physical complaints, sexual functioning, and daily activities (Parmenter, 1994). Some investigators take the absence of physical complaints as an indication of good QOL, while others look at type of housing, living arrangements, or financial status (Simmons, 1994).

Professionals assessing disabled persons or the mentally ill tend to consider both objective and subjective dimensions of QOL such as health, employment, and living arrangements, as well as friendships, intimacy, social networks, and overall life satisfaction but again do not always use the same dimensions (Romney, Brown, & Fry, 1994). Still other researchers focus primarily on the more subjective components of QOL, contending that the ultimate determinant of QOL is psychological well-being (Romney et al., 1994). The result is that researchers have developed their own QOL measures consistent with their views and definitions. For example, Burckhardt et al. (1989) noted that researchers often selected items from instruments such as the Sickness Impact Profile (SIP) without providing rationales for the inclusion or exclusion of items, or providing psychometric data such as the reliability and validity of the altered scales. Others have developed their own scales, again
failing to provide psychometric data for them. The resulting measures are therefore of little use to other researchers, as they are not necessarily valid or reliable (Burckhardt et al., 1989).

In an effort to address these issues, several measures have been designed for use with specific populations. Simmons (1994) has provided descriptions of several popular measures designed specifically for use with chronic psychiatric populations, such as the Quality of Life Questionnaire-Respondent Self-Report Version by Bigelow, McFarland, and Olson (1990). A review of cancer research reveals numerous examples of QOL measures, such as the Karnofsky Performance Status Index (Costain et al., 1993). Another example of a health-related QOL measure is the Quality of Life Index (QOLI) designed by Spitzer et al. (1981).

For the purposes of this research, QOL was conceptualized as a person's perceived satisfaction within areas of life that previous chronic illness groups had identified as important for QOL. The Quality of Life Scale (QOLS) designed by Flannigan (1978) was used to assess QOL. The QOLS takes a multidimensional view of QOL, looking at people's perceived satisfaction with the quality of their lives across 16 items: material well-being, health, relations with a significant other, having and raising children, relations with relatives, relations with friends, helping others, activities related to local and national governments, intellectual development, personal understanding and planning, occupational role, creativity and personal expression, socialising, passive recreational activities, active recreational activities, and independence (Burckhardt et al., 1989; Flannigan,
The QOLS has established reliability and validity and has been found useful in studies assessing the QOL of people suffering from chronic illnesses (Burckhardt et al., 1989).

**Adjustment to Illness**

A concept closely related to QOL is adjustment to illness. Chronic illness has a significant impact on the lives of individuals, affecting their perceptions of themselves and the roles they take in the various aspects of their lives on a long-term basis. Such a significant change in so many aspects of daily living is certain to require a great deal of adjustment on the part of the patient. As such, clinicians and researchers have focused on assessing how well-adjusted patients are and what factors have helped them adjust to life with chronic illnesses.

Although ADJ has been studied for a number of years, clinicians have defined and assessed it differently. Specifically, Friedman, Baer, Lewy, Lane, and Smith (1988) pointed out that the definition and measurement of ADJ has been approached in three major ways: 1/ by inferring ADJ from clinical indicators such as mood states; 2/ by inferring ADJ from the behavioural correlates of mood states (e.g., sleeping or eating patterns); 3/ by measuring ADJ in specific areas of psychosocial functioning, such as vocational roles, and/or social relationships in addition to affect or mood state.

A brief review of the literature reveals a variety of factors that have been used to indicate level of ADJ. Some of the more consistently used variables include self-esteem, mood or affect, social functioning, and/or hopelessness
(Felton et al., 1984; Jones & Reznikoff, 1989; Lloyd, 1990; Nelson, Friedman, Baer, Lane, & Smith, 1994; Zenmore & Shep, 1989). Of these, emotional state was used most often to indicate overall adjustment. However, as noted by Nelson et al. (1994), this tendency to equate ADJ primarily with emotional well-being can limit the potential for tailoring interventions to the specific needs of the individuals because it fails to consider the impact of an illness on other behaviours or roles that may be important to a person's overall sense of well-being. Pakenham, Dadds, and Terry (1994) stressed the importance of measuring ADJ in multiple domains, pointing out that different types of coping and different elements of social support have been shown to be related to ADJ in different domains. Many researchers now either use several measures designed to assess the specific indicators of ADJ that they are interested in, or use one scale which encompasses several different domains found to be important in ADJ.

Another approach to the assessment of adjustment is to conceptualise it in terms of the roles people have in society. Derogatis and Fleming (1996) contended that ADJ intuitively suggests more than just an intrapsychic process; interactions between individuals and their social environment are also important to consider. They noted that the efficiency with which people perform their roles (e.g., as spouse, parent, or worker) tends to be highly correlated with judgements about ADJ (Derogatis & Fleming, 1996). As a result, many of the domains of ADJ can be associated with important role behaviours as well as emotional well-being.
One of the most promising assessment tools for ADJ is the Psychosocial Adjustment to Illness Scale (PAIS), originally designed by Derogatis in 1978. In keeping with the assertion that ADJ was a multidimensional construct, Derogatis designed the PAIS to reflect ADJ in seven specific psychosocial areas, all of which had been found to be relevant to ADJ to a medical illness. Examples of domains assessed by the PAIS include: Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationships, Extended Family Relationships, Social Environment, and Psychological Distress (Derogatis, 1986; Nelson et al., 1994). The PAIS has established reliability and validity, and has been found useful in studying psychosocial adjustment in a number of populations (Kaplan De-Nour, 1982). For the purposes of this research study, Derogatis’ conceptualization of ADJ was adopted and the PAIS-SR was used to measure ADJ.

Coping and Social Support in Health

Since the 1970s, investigators in the health field have been interested in the impact of social support and coping on people’s health and well being. Early theories and review papers suggested that social support had beneficial effects on a wide range of health outcomes, and it is still regarded as a central issue in health research, with the focus being on enhancing the support available to distressed individuals (Schreurs & de Ridder, 1997; Shinn, Lehmann, & Wong, 1985; Wortman & Conway, 1985). Early research also suggested that the ways in which people coped with stressful situations were related to their health and well being (Connell, Davis, Gallant, & Sharpe, 1994; Jahanshahi, 1991). It
appears that many health professionals now consider coping and social support, their effects on the well-being of people, and their use as intervention tools to be important variables in research as they are typically included in research studies.

According to Pearlin and Aneshensel (1986, p. 418), *coping* in general refers to "the things people do on their own behalf to avoid or minimise the stress that would otherwise result from problematic conditions of life, particularly conditions that impose demands challenging to the resources of the individual". *Social support* generally represents the social resources one is able to call upon in dealing with such conditions (Pearlin & Aneshensel, 1986). These two constructs have become very important in the area of health research because of their potentially powerful roles in mediating health outcomes and possibly increasing ADJ and QOL, as well as their usefulness in explaining what would otherwise be inexplicable. For example, coping and social support can help to explain why two people experience such different outcomes given the same stressful circumstances (Brownell & Shumaker, 1984; Pakenham et al., 1994; Pearlin & Aneshensel, 1986).

According to Brownell and Shumaker (1984), social support is particularly popular for several reasons. First, humans are social beings, and social contact has long been considered to be central to the quality of a person's life. The harmful effects of social isolation and/or the loss of important social ties in people's lives are evidence of this. In addition, much of the research on social support points to its beneficial effects. Brownell and Shumaker (1984) also contend that social support may be popular because it is a relatively easy target
for intervention programmes designed to increase people's sense of well-being (e.g., support groups).

For many years, theories and research on social support occurred independently of those on coping, despite the fact that seeking the help and support of others is often considered to be a coping method (Bennet, 1993; Schreurs & de Ridder, 1997; Schwarzer & Leppin, 1991). More recently, researchers have recognised that coping and social support do not operate in isolation of one another. Much of the current health research now includes measures of variables such as coping, locus of control, quality of life, and social support in their investigation of health status.

History of Social Support

Although social support was not formally researched in the psychological literature until the 1970s, the supportive aspects of interpersonal relationships had been described in the sociological literature as early as the 1950s (Brownell & Shumaker, 1984). In 1974, a physician by the name of John Cassel reviewed research on health and urban development and hypothesised that the disruption of social ties that can occur under stressful conditions could increase a person's susceptibility to illness. He further argued that the support provided by family, friends, or other group members would buffer the harmful effects of such stress (Brownell & Shumaker, 1984). Later that same year, Cassel's theories were further developed by Gerald Caplan, who stated that social support consisted of significant others who help people mobilise the psychological resources they have available, share in people's tasks, and provide individuals with various
types of support such as information, money, skills, and/or advice to help them cope with the stress (Brownell & Shumaker, 1984). According to Brownell and Shumaker (1984), a person who had access to various supportive individuals could potentially go through life being almost completely buffered against stress. These theories have been expanded on more recently, and much research has focussed on the role of social support in health.

Several reviews of research on the association between social support and health suggest that the presence of support can have a large impact on a person's health status. For example, Dimond (1979), found that while there was some ambiguity within the research regarding the relationship between social support and adaptation during illness, social support was generally associated with less depression and/or anxiety, and greater progress in rehabilitation programs. In later reviews, Schwarzer and Leppin (1991), and DiMatteo and Hays (1981) noted that research on social support since the 1970s pointed to social support having a significant impact on health-related variables such as disease onset and/or coping with chronic illness. Social support has also been found to be an important predictor of adjustment to a chronic illness or disability (Dimond, 1979; Dunkel-Schetter, 1984; Schwarzer & Leppin, 1991; White et al., 1992). More specifically, increased social support has been found to be associated with the following: increased rehabilitative progress in patients with tuberculosis (Dimond, 1979); decreased anxiety and increased self-esteem in kidney transplant patients (Dimond, 1979); increased morale and activity in dialysis patients (Dimond, 1979); decreased fear and pain in terminal cancer
patients (Weidman-Gibbs & Achterberg-Lawlis, 1978); increased overall
adjustment to cancer (Dunkel-Schetter, 1984); and lower levels of depression in
patients with diabetes (Connell et al., 1994). Corrigan and Buican (1995) also
noted that patients with larger and more satisfactory social networks reported
better quality of life.

Despite the fact that social support is generally thought to be associated
with health and well being, the results are not always clear-cut. Schwarzer and
Leppin (1991) noted that while the majority of studies since the 1970s have
shown that social support has a positive impact on health, few studies can agree
on the size of this impact. Researchers point to many inconsistencies in the
literature to help explain this ambiguity. For example, the majority of the social
support research is said to be plagued with difficulties such as: a heterogeneity
of theories; deficits in measurement; differing definitions; failure to examine
interactions with other variables such as coping style; failure to account for type
or severity of illness; and, not considering the negative impact that is sometimes
associated with social support (Dimond, 1979; Dunkel-Schetter, 1984;
Schwarzer & Leppin, 1991; Wortman, 1984). In addition, studies have generally
been correlational, with social support emerging as a predictor of adjustment,
leaving open the possibility that other variables may be involved (Wortman,
1984).

Longitudinal studies aimed at addressing the issue of causality have
investigated the influence of social support on recovery from illness and have
also produced mixed results. Some investigators found a relationship between
social support and subsequent recovery (Funch, Marshall, & Gebhardt, 1986), while others found no such evidence (Revenson, Wollman, & Felton, 1983). Intervention studies in which patients were assigned to treatment groups to supplement the support they were already receiving provided evidence that social support facilitated recovery from health problems (Wortman & Conway, 1985).

While social support is generally thought to be helpful and beneficial, there is a growing awareness that some well-intentioned efforts can be unhelpful and may actually have long-term consequences that are negative (Shinn et al., 1985). In fact, some studies have shown that negative elements of social interaction tend to be more strongly and consistently related to mental health outcomes than were positive ones (Dunkel-Schetter, 1984). For example, it is often thought that patients should remain as optimistic about their condition as possible and avoid discussing their feelings about the illness. Friends and family members tend to minimise the patient's concerns and problems, which is generally found to be unhelpful by patients (Dunkel-Schetter, 1984). Providing help may also carry the implicit assumption that patients are incapable of solving their own problems, thus undermining their self-esteem and reinforcing the perception of themselves as impaired (Dunkel-Schetter, 1984).

Research is also beginning to suggest that too much social support can actually be detrimental for people suffering from chronic illnesses. As noted by Shinn et al. (1985), research has shown that chronically ill patients who received more attention and assistance from family and friends were actually more
disabled than those who were not treated any differently following the onset of their illness. Although the results are correlational and therefore do not suggest causation, it is highly likely that the increased disability arose from the support since researchers carefully excluded any disabilities that could have been caused by the illness. In addition, the degree of disability associated with preferential treatment was higher for those with a less serious illness, suggesting that something other than illness severity was impacting on the level of disability experienced.

Social support has also been shown to interfere with compliance to medical regimens if the treatment goes against the beliefs, values, or typical behaviour of the family (Shumaker & Brownell, 1984). In addition, one's social network can have an impact on how readily one seeks help for emotional distress associated with the illness. People tend to discuss their distress with friends or family members to test out their perception of how important their distress is before approaching a professional. Beliefs and previous experiences of members of the social network can then influence how readily a person seeks out further help from a mental health professional.

In more recent years, researchers have recognised that social support is a more complicated variable than once thought and have begun to focus on the specific types of support provided by specific people within the social network. Jahanshahi (1991) noted that in order for social support to function as an effective buffer against stress, the amounts and types of support provided must match the needs of the individual. Primomo et al. (1990) suggested that it is
particularly important for people who live with chronic illnesses to understand the nature of supportive relationships and what they can provide, in addition to understanding what is involved in the illness experience.

With this in mind, researchers are taking a closer look at who is providing the social support and what types of support are considered helpful to different patient groups at different stages of an illness. For example, Revicki & Mitchell (1990) noted that the quality of social support is a better predictor of health-related outcomes than the quantity of social support. Ben-Sira (1984) and Dunkel-Schetter (1984) both found that emotional support from one's physician was the most sought-after (but least attainable) resource in alleviating emotional distress associated with a chronic illness. Wortman (1984) found that while social support was significantly associated with adjustment in cancer patients, this was only true for those with a good prognosis and not those with a poor prognosis. Other studies have found that information and advice was seen as helpful when provided by health-care professionals, but not when provided by family and friends (Shinn et al., 1984). What can be seen from this brief review of the social support literature is that while researchers generally agree that adequate support is associated with a decreased risk for illness and improved health-outcomes, the question remains "what are adequate supports and how do they work?" (Gore, 1985).

Social Support and Illness

A person who is ill has a need for many different types of support, each of which becomes important at different stages of the illness (Pearlin, 1985).
Specifically, patients may face different tasks as the illness progresses. When the illness is first diagnosed, patients may have to appraise their symptoms and begin treatment, tasks that would require informational support. They may feel uncertain and fearful about the future and may need information to help clarify the situation. As the illness progresses, however, patients may find themselves in need of more tangible support as they begin to have difficulty meeting the responsibilities in the home. They may also need validation and reassurance that the feelings and fears experienced are a normal consequence of the illness. They may also experience a threat to their self-concept and may require emotional support and reassurance that family and friends will love them.

Unfortunately, it is often difficult for patients to receive the kind of support they need (Shinn et al., 1985). There are many reasons for this: some diseases such as cancer and AIDS tend to evoke physical aversion and repulsion in others; facing a person who is ill may upset and challenge people's beliefs, leaving them feeling threatened and uncomfortable and leading to unsupportive behaviour; dealing with a person who is in pain or who requires a great deal of support can itself be stressful for caregivers, leading to feelings of frustration, inadequacy, and perhaps anger because there is so little they can do and because the disease has disrupted life in such a major way; and, many people believe that they need to be cheerful and optimistic when faced with an ill person (Wortman & Conway, 1985). Unfortunately, this often leads to avoidance of the patient or of open discussion about the illness and the impact it is having on people's lives.
With an illness such as CFS, many of the above mentioned difficulties are relevant. As previously mentioned, the ambiguous and transient nature of the symptoms of CFS often leads to disbelief and minimisation on the part of family and friends of CFS sufferers (Friedberg & Jason, 1998; Ware, 1999). As the disease progresses and its chronic and debilitating nature becomes apparent, individuals become increasingly socially isolated (Jason, 1993). Family members who are placed in the role of caretakers may recognise that stress can exacerbate the symptoms of CFS and therefore avoid open discussion of their own feelings. This lack of communication can eventually lead to distance in interpersonal relationships, leaving the patient to feel increasingly isolated and unsupported (Friedberg & Jason, 1998).

In addition, one of the keys to adjusting to CFS is to maintain some level of daily activity to ensure that muscles do not become deconditioned (Jason, 1993). Family members may react to individuals’ illness and fatigue by encouraging them to remain bedridden, forcing them to become dependent on others for the simplest tasks (e.g. making a meal). Patients may come to perceive themselves as impaired, impeding their resumption of normal activities (Friedberg & Jason, 1998). If individuals feel that they will not be able to reciprocate the support that is being received, they will be less likely to accept the needed support (Shumaker & Brownell, 1984). This is particularly true given that the support could extend over a long period of time.

Thus, social support can play an important role for a person suffering from CFS. When social support is offered by one who is understanding and accepting
of the disease and its impact on the patient's lifestyle, it can have a large influence on the patient's outlook as well as his or her adjustment on a daily basis (Friedberg & Jason, 1998). Emotional support is very important throughout all stages of CFS, particularly in letting the patient know that his or her perception of him or herself as physically ill is valid. In fact, a review of studies on the impact of social support on health outcomes found that emotional support is a more important predictor of health outcomes than other types of support (Wortman & Conway, 1985). In the few studies looking at social support in CFS patients, social support has been positively associated with improved functional status and well being (Friedberg & Jason, 1998). Specifically, a dissertation by Hynick (1997) looking at factors associated with adaptation to CFS in adolescence found that social support was associated with decreased fatigue and increased perceived competence. In a study looking at coping strategies in CFS patients, Heigmans (1998) found that seeking social support was positively associated with better mental health. With this in mind, the present investigation examined the types of social support that CFS patients find helpful, and which contribute to their overall adjustment to the illness, and to their quality of life.

**Defining Social Support**

While social support is widely accepted as an important variable in health research, few researchers have defined it explicitly and there is no one clear definition for it (Brownell & Shumaker, 1984; Hupcey, 1998). In early studies, investigators used many different indicators of social support, including frequency of social contact, marital status, presence of a confidante, participation
in outside activities, involvement in self-help groups, and the receipt of information (Wortman & Conway, 1985). Such variables were taken on their own or in various combinations as indicative of the presence or absence of social support in a person’s life, depending on what the researcher decided to use. As a result, little comparison of research results could be done, and one was left with little understanding of how or why social support could impact a person’s health (Brownell & Shumaker, 1984).

In fact, as noted by Shinn et al. (1985), many authors confused social support and social network, assuming that the number of people available for support was indicative of actual support without consideration of the nature of the relationships and/or interactions that actually took place. It is necessary, however, to differentiate between social network and social support. Both Procidano and Heller (1983) and Schwarzer and Leppin (1991) stated that social network refers to the connections within a person’s environment that have the potential to serve various functions. Such connections can be assessed in terms of characteristics such as size, density, sex composition, homogeneity, and a host of others. While the members of the social network can potentially provide support to an individual, the provision of this support is not necessary to the definition of a social network. In contrast, social support involves the provision of some sort of assistance to an individual, and is considered to consist of more than just network characteristics. Social support is perceived when an individual believes that his/her needs have been met (Procidano & Heller, 1983).
In an attempt to address the need for a more precise and systematic conceptualisation of social support, researchers have tried to identify different types or components of support, recognising that it is a multidimensional construct. For example, structural indices such as marital status, participation in community organisations, or size of social network, as well as functions such as love, information, or tangible aid, have all been considered to be components of social support (Wortman & Conway, 1985). Many authors have outlined the various functions that social support can have, including: providing positive affect so that one knows that s/he is loved and cared for; acknowledging or agreeing with the patient's beliefs, interpretations, or feelings; encouraging the open expression of feelings and beliefs; the offering of advice, information, or new sources of information; letting the person know that s/he is part of a social network which involves both giving and receiving help; and, providing tangible aid (Pearlin, 1985; Shumaker & Brownell, 1984; Wills, 1985; Wortman & Conway, 1985). Researchers recognise the importance of these factors and include many of them in their conceptualisations of social support.

Measuring Social Support

Given that researchers agree that social support is a multidimensional construct with different functions which can be studied either in isolation or in combination with one another, the question becomes, how can these functions be measured? Although social support has been studied since the early 1970s, its measurement continues to be a major issue and there are many different measures available (Depner, Wethington, & Ingersoll-Dayton, 1984; Gore, 1985;
Hupcey, 1998). One of the major contributors to this plethora of social support measures is the lack of a clear definition for social support. As noted by Depner et al. (1984), one must operationally define social support before one is able to design or choose an appropriate assessment tool to measure it. Each researcher tends to use his or her own measures to reflect his or her conceptualisation, and there is no one generalised assessment tool for measuring social support (Brownell & Shumaker, 1984).

In more recent years, researchers have begun to recognise this problem and have come forth with some suggestions as to how to measure social support depending on the purpose of the research. House and Kahn (1985), in their review of measurement approaches to social support, examined researchers' assessment strategies in three areas, according to existence of interpersonal relationships, type of support given, and network structure. This breakdown suggests that when selecting a measure of social support one should consider what it is about each of these three major areas that is important to include (Depner et al., 1984). For example, is it important for the study to differentiate who is providing the support and what specific kind of support is being given?

One should also consider the importance of assessing network structure. While Wortman and Conway (1985) suggested including some measure of social network, they also noted that such characteristics are not typically related to health outcomes. Subsequently, they endorse including a consideration of perceived social support in a social support measure. In addition, Shinn et al. (1984) suggested that social interaction should be distinguished from perceived
support, and that both the positive and negative aspects of such interactions are important to consider.

Keeping the above in mind, social support in this study was conceptualised as a multidimensional construct with both positive and negative aspects. Specifically, social support was viewed as involving social interaction, as well as instrumental and perceived support. These conceptualisations were in line with the two social support scales used in this research. The first is the Duke Social Support Index (DSSI), which consists of 35 items examining four different dimensions, including social network, social interaction, subjective support, and instrumental support (Koenig et al., 1993; Landerman, George, Campbell, & Blazer, 1989). The DSSI can be abbreviated to a 23-item or an 11-item scale for use with chronically ill populations who have difficulty completing longer questionnaires, such as those with CFS. For the present study, the 23-item scale was used, with the Social Network subscale being omitted from the original DSSI. The second scale used was a Social Support in Illness Scale designed by Ray (1992) specifically for use with a CFS population. The Social Support in Illness Scale also considers both positive and negative aspects of perceived social support, something that is now becoming more and more important in the literature.

Coping

Another important variable in health research is coping strategy. Interest in this concept arose in the late 1970s when Lazarus and Folkman introduced their theory on stress, appraisal, and coping. As previously stated, this theory
takes a cognitive view of coping and considers both primary and secondary appraisal in the process of choosing a coping strategy (Lazarus & Folkman, 1984). Coping strategies can be categorised as either problem-focussed or emotion-focussed (Folkman & Lazarus, 1980).

One of the most widely-used assessment measures for coping strategy is the Ways of Coping Checklist (WCCL) designed by Lazarus and Folkman in 1980. The WCCL consisted of 68 items depicting a wide range of thoughts and behaviours that people used to deal with stressful situations (Blakely et al., 1991). Respondents were asked to respond to each item with "yes" or "no" to indicate whether or not they had utilised a particular strategy in a specific situation. Items were arranged into 8 scales including confrontive, planful problem-solving, seeking social support, distancing, self-control, accepting responsibility, escape/avoidance, and positive appraisal (Blakely et al., 1991). The first three scales can be categorised as problem-focussed coping while the remaining scales can be categorized as emotion-focussed coping styles (Taylor, 1999). The WCCL was revised in 1988 to allow for an assessment of how frequently coping behaviours are used (Wineman, Durand, & McCulloch, 1994). The revised Ways of Coping Questionnaire (WOCQ) contains 66 items, and requires respondents to rate items on a 4-point Likert-type scale using the same categorisation of items into the 8 scales. For the purposes of this investigation, the WOCQ was used to assess coping strategy employed by CFS patients.

Lazarus and Folkman's stress, appraisal and coping model has been widely accepted in the health field, with many researchers investigating how
people cope with stressful situations (Schmall, 1991). Another intriguing theory in the study of stress and coping is Hobfoll's (1998) Conservation of Resources (COR) theory. According to Hobfoll, all individuals have resources (objects, conditions, and personal characteristics) that they have come to value because of their importance to survival. Examples include shelter, food, family ties, employment, personal skills, money, and knowledge. Stress occurs when circumstances represent a threat of resource loss, when resources are actually lost, or when a reasonable gain is not achieved following a significant resource investment (Hobfoll, 1998). The loss of resources is considered more salient than the gain of resources, and according to COR theory, people will seek to protect against such loss by investing further resources in the hopes of gaining. Oftentimes this takes the form of actively working to solve the problem, similar to problem-focused coping. For example, when people become ill, immediate loss of income may occur due to the need to take sick days. As time goes by, individuals may come to fear the loss of additional income, or even the loss of their employment, so they may invest some of their energy and remaining health so that they may return to work to protect against the potential loss.

Unfortunately, as Hobfoll points out, people facing ongoing chronic stress tend to experience a significant loss of resources with little chance for gain. Individuals then struggle to maintain a balance in terms of resource expenditure to avoid further loss, and may appear to stop actively trying to find solutions to their problems. Focussing on what people stand to lose or gain by using certain
coping techniques presents an interesting way of examining people's responses to stressful situations.

One area that has been of interest in recent years is how individuals cope with a chronic illness. Lipowski (1970) defined coping in the context of illness as "...cognitive and motor activities which a sick person employs to preserve his bodily and psychic integrity, to recover reversibly impaired function and compensate to the limit for any irreversible impairment" (p. 14). Illness can be conceptualised as a stressor with which the patient must cope. The ambiguity or unfamiliarity of symptoms experienced as people begin to get sick can make them feel threatened and upset (Pearlin & Aneshensel, 1986). This in turn can increase discomfort and make people more aware of symptoms as they arise. Individuals focus more on the illness, what it means to them, and how it impacts on their life and the resources they have available to them. This recognition of symptoms and the appraisal of their meaning and seriousness can influence the number of available options considered for coping with the illness.

People can cope with illness in many ways, including trying to change the health problem itself, reducing the distress associated with it, or changing what the illness means to them and the impact it has on their lives (Pearlin & Aneshensel, 1986). Individuals can use problem-focussed coping to try to alleviate symptoms and emotion-focussed coping to help them adjust to living with the illness (Pearlin & Aneshensel, 1986). Individuals with irreversible or chronic conditions such as CFS are particularly likely to use a variety of coping strategies in an effort to maintain optimum physical and emotional health in the
face of new symptoms, remissions, and periods of relatively good health (Badger, 1990; de Ridder et al., 1998; Sidell, 1997).

In fact, studies on coping with CFS have found that individuals use many different strategies in coping with their illness. Specifically, in their study of 58 CFS patients, Blakely et al. (1991) found that patients tended to use emotion-focussed coping strategies such as escape/avoidance or distancing more than other strategies. Other studies have found other coping strategies to be important, such as confrontive, planful problem-solving, and accepting responsibility (Capuano Sgambati, 1998; Lewis et al., 1994; Schmell, 1991). Ray et al. (1997) designed a coping measure specifically for use with CFS patients to reflect their unique ways of coping with their illness. The Illness Management Questionnaire assesses coping strategies along 4 dimensions: maintaining activity, illness accommodation, focus on symptoms, and information seeking. According to Pearlin and Aneshensel (1986), no matter what the actual coping response to the illness is, it likely follows through stages involving recognition of a health problem, interpretation of its significance, evaluation of potential responses, and some action directed at alleviating or adjusting to it.

People suffering from chronic illnesses usually have to deal with the social, medical, and economic costs of the illness in addition to the physical and psychological effects of it. Changes include the loss of social and vocational roles, changes in lifestyle due to financial loss, threats to self-image and self-esteem, and uncertain or unpredictable futures (White et al., 1992). The chronically ill must continually re-evaluate their situation and adjust to such
changes, using different coping strategies as appropriate. In addition, individuals must discover the limits that the disease imposes on them and learn how to function within those limits (White et al., 1992). Studies have found that the lessening of emotional distress through the use of emotion-focussed coping techniques generally promotes the use of problem-solving techniques, which can then be effective in dealing with the secondary problems that come from having a chronic illness (Badger, 1990).

**Coping and Adjustment to Illness**

In general, studies have shown that coping style has an impact on a person's adjustment to illness. Specifically, studies have emphasized the importance of problem-focussed coping to better ADJ in patients with illnesses such as diabetes, hypertension, arthritis, and cancer (Felton et al., 1984; Osowiecki & Compas, 1999; Schmall, 1991). In addition, it has been found that seeking advice or obtaining knowledge about the medical condition were more effective than other strategies in promoting ADJ, although they were not used as often by patients suffering from non-life threatening chronic illnesses (Feifel, Strack, & Tong Nagy, 1987). Studies have also found that emotion-focussed coping strategies such as avoidance, escape, and blame were associated with negative affect, lower self-esteem and poor ADJ in individuals suffering from disorders such as diabetes, heart disease, cancer, and arthritis (Felton et al., 1984; Feifel et al., 1987; Ray, Weir, Stewart, Miller, & Hyde, 1993; White et al., 1992). Emotion-focussed coping strategies such as wishful thinking have also been associated with depressive symptoms, less satisfaction with available
social support, and a perceived lack of control over the illness in individuals suffering from torticollis, a chronic, neurological disorder (Jahanshahi, 1991).

In studies looking at coping strategies employed by CFS patients, conflicting results have been obtained. Specifically, some coping strategies have been associated with improvement or increased impairment, while others have not. In his dissertation on factors associated with adaptation to CFS in adolescence using the Jalowiec Coping Scale, Hynick (1997) found that emotion-focussed coping strategies were associated with lower perceived competence in a number of domains. Antoni et al (1994) using the COPE found that emotion-focussed coping strategies were associated with greater disturbances in physical and psychosocial domains. Heijmans (1998), in a study on coping and adaptive outcomes in CFS patients, found that problem-focussed coping strategies were associated with better mental health, and avoidant strategies such as giving up or not dealing with the illness were associated with poor social functioning, poor mental health, and lower vitality.

However, Capuano Sgambati (1998), in her dissertation looking at coping strategies in 25 CFS patients, found that problem-focussed coping was generally associated with greater illness impact. Schmall (1991) found that in a group of 30 women suffering from CFS, those who scored highest on measures of psychological well being employed emotion-focussed coping strategies such as positive reappraisal and distancing. The emotion-focussed strategy of escape-avoidance, however, was associated with lower scores on measures of well being, suggesting that some emotion-focussed strategies may be more effective
than others (Schmall, 1991). In two studies, Ray and colleagues found that both problem-focussed and emotion-focussed coping strategies were associated with increased functional impairment and emotional distress (Ray et al., 1995; Ray et al., 1997). Information regarding which coping strategies are most effective with certain illnesses, and the interaction of factors that contribute to coping, may help health professionals determine the specific needs of their patients to help them better adjust to life with their illness.

Locus of Control

Another important variable to consider when studying chronic illness is locus of control. This construct was first introduced in 1966 by Rotter and was based on social learning theory (Furnham & Steele, 1993). Rotter sought to explain human behaviour in complex social situations by focussing on a person's belief that specific behaviours would initiate specific, valued reinforcements (Enevoldsen Bowsher & Keep, 1995). Rotter defined of locus of control as:

when a reinforcement is perceived by the subject as...not being entirely contingent upon his action, then, in our culture, it is typically perceived as the result of luck, chance, fate, as under the control of powerful others, or as unpredictable because of the great complexity of the forces surrounding him. When an individual interprets the event this way, we have labelled this a belief in external control. If the person perceives that the event is contingent upon his own behaviour or his own relatively permanent characteristics, we have termed this a belief in internal control. (cited in Furnham & Steele, 1993, p.444).
Specifically, Rotter's theory explained that the likelihood of a person behaving in a certain way depends in part on whether or not a valued reinforcer could be attained via the behaviour (Enevoldsen Bowsher & Keep, 1995). What is important is not the particular reinforcement the person will get by performing a certain behaviour, but his or her belief that the behaviour will have an effect on attaining a certain reinforcer (Furnham & Steele, 1993). The value of both the reinforcer and situation for the person also affects this belief. The more valuable the reinforcer, the more likely the person is to behave in a certain way in order to get the reinforcer.

Rotter translated his locus of control (LOC) theory into practice by developing the Internal-External Control scale (I-E scale) which required people to choose between an internal and an external belief for each of 29 items (Furnham & Steele, 1993). According to Furnham and Steele, Rotter's intent was to explain beliefs about control and expectancy of success across a wide variety of situations, such as in academics, socially, or in love and affection. Although Rotter noted that the specific characteristics of a certain situation gave clues about whether or not a person could expect to get reinforcement, general beliefs about control had an influence on whether a person expected to succeed or not across a variety of situations (Furnham & Steele, 1993). It was presumed that assessing whether people typically had an external or internal LOC would provide valuable information about their expectancy for success in general.

One can think of LOC as a trait or personality variable that generally influences a person's expectations across a variety of situations, but is subject to
change given certain experiences and circumstances. While people may typically have an internal or external LOC and behave accordingly across a wide variety of situations, a generalized measure of LOC is less predictive of behaviour in specific situations (Casey, Kingery, Bowden, & Corbett, 1993). This is in large part due to the fact that a person's expectations and beliefs are a function of both past experiences, and fears or desires (Anderson, DeVillis, Sharpe, & Marcoux, 1994; Wallston, Stein, & Smith, 1994). Thus, people's beliefs about their health status may differ from their beliefs about control in other areas of their life, simply because of what they have learned over their lifetime. As noted by Wallston et al. (1994), it is even possible for people's beliefs about specific health conditions to differ from their beliefs about their general health.

In 1976, Wallston, Wallston, Kaplan and Maides adopted Rotter's general LOC theory in their construct of health locus of control (HLOC), a LOC construct specific to health concerns (Wallston et al., 1994). Their purpose was to better explain health-related behaviour in terms of the control that people felt they had over the illness in question. Health locus of control is said to refer to people's beliefs about whether or not their behaviour will have an effect on their health (Wallston, Wallston, & DeVellis, 1978). According to Wallston et al. (1994), HLOC is one of several factors that determines which health-related behaviours people will engage in, and in turn, influences people's health. For example, patients who believe that their health is controlled by external factors (such as doctors) may leave the responsibility for their health care to the "experts". In
contrast, those who believe that their health is controlled by internal factors (such as their own personal characteristics) are likely to actively participate in their health care (Barlow, Macey, & Struthers, 1993).

Health Locus of Control and Adjustment to Illness

Health locus of control is considered an important variable when studying health-related behaviour and coping and adjustment to illness. As previously mentioned, choice of coping behaviour can be influenced at both the primary and secondary appraisal stages by factors such as LOC (de Ridder & Schreurs, 1996; Keller, 1988; Shaw, 1999). Numerous studies have highlighted the importance of feelings of control and personal effectiveness for adjustment (Karanci, 1988; Osowiecki & Compas, 1999; Taylor et al., 1991; Watson et al., 1990). More specifically, HLOC has been found to influence the patient's tendency to adopt positive behaviours in the face of illness or to adhere to a particular treatment regimen (Watson et al., 1990). In her study of 43 patients suffering from a variety of chronic health problems (including hypertension, MS, diabetes, arthritis, etc.), Keller (1988) found that individuals who believed that they had control over their illness (internal HLOC) tended to be more knowledgeable about their disease and used more problem-solving strategies. In contrast, patients who believed that their illness was due to fate or chance (chance HLOC) did not typically use problem-solving coping strategies. In fact, patients who were having difficulty performing activities of daily living coped by using emotion-focused strategies such as "putting the problem out of your mind" or "withdraw from the situation and resign yourself" (Keller, 1998). In his
study of 205 individuals with a variety of chronic medical illnesses, Schussler (1992) found that those patients with an internal HLOC tended to use more problem-focussed coping strategies, whereas those who believed that they did not have control over their illness tended to use more emotion-focussed coping strategies. It has also been suggested that some people spontaneously generate feelings of control when faced with a chronic illness, which may help them to better adjust to the situation (Taylor et al., 1991).

Studies have also shown a positive relationship between control and both psychological and physiological well being (Enevoldsen Bowsher & Keep, 1995). In general, people with an internal HLOC orientation have been found to experience less depression and/or anxiety in the face of stress than those with an external HLOC orientation (Karanci, 1988; Kuehn & Winters, 1994; Nada Raja, Williams, & McGee, 1994; Taylor et al., 1991; Wallston et al., 1994; Watson et al., 1990). Other studies have shown that an internal HLOC orientation is associated with better overall adjustment to illness (Blood, Kauffman, Dineen, & Raimondi, 1993; Taylor et al., 1991). Taylor et al. (1991) noted that with few exceptions, the literature suggests that feelings of personal control help medically ill patients cope with their disease with less distress and experience better QOL. For example, Wallston and Wallston (1982) found that people suffering from a chronic illness were high on the Internal and Powerful Others HLOC scales, but low on the Chance HLOC scale.

The relationship between HLOC and effective coping is not, however, as clear-cut as has been suggested. For example, Kraus (1986, cited in Kuehn &
Winters, 1994, p. 326) found that people classified as "extreme internals" (i.e. those who have a strong tendency to not believe in chance or powerful others) used ineffective coping strategies in the face of unavoidable stressors. Taylor et al. (1991) pointed out that individuals faced with chronic illnesses or diseases in the advanced stages which are not necessarily amenable to personal control would be working against the facts if they believed that they had control over the course of their illness. It has been argued that those suffering from such a chronic illness may experience feelings of helplessness as their personal efforts to control or influence the course of their disease prove futile; in such cases, maintaining beliefs in personal control may actually be maladaptive (Taylor et al., 1991). Barlow et al. (1993), in their study of individuals with a form of chronic arthritis, found that individuals also lowered their expectations of personal control over the illness in response to its unpredictable course, the difficulty it presents for diagnosis, and the fact that it does not respond well to medical intervention or treatment. The few studies looking at HLOC in CFS patients have suggested that an internal HLOC may be beneficial in enhancing adjustment to the illness (Ray et al., 1997; Unger, 1997). Specifically, Unger (1997) in his dissertation on HLOC in a group of CFS patients, found that an internal HLOC was associated with better health status.

Given that CFS is a chronic disease of uncertain course and duration, determining how much control individuals feel they have over the illness may be an important factor in assessing how well they are coping. For example, patients who tend to believe that they or their doctors should have complete control over
their CFS may have difficulty accepting that there is no set treatment regimen that they can follow to help relieve their symptoms. It is possible that such extreme HLOC orientations may contribute to a patient's feelings of helplessness and despair as they realize that their efforts are futile. It is also possible that patients who feel that they and their doctors have no control over their illness will not seek out new treatments or engage in healthy behaviour such as regular light exercise, which may help relieve some of their symptoms. This is particularly plausible given that many doctors do not believe in the existence of CFS, leaving it up to the patient to research new treatments. In addition, at this time doctors have not yet found an effective treatment for CFS, and patients must often try different combinations of different herbs and medications to relieve some of their symptoms (Anderson & Estwing Ferrans, 1997). One purpose of this study, then, is to investigate which HLOC orientations contribute most to effective coping and to adjustment to CFS.

Assessing Health Locus of Control

The Health Locus of Control scale was developed by Wallston, Wallston, Kaplan and Maides in 1976 to measure the HLOC construct (Wallston et al., 1978). The scale was designed to be more specific than the I-E Scale, but still general in that it was not specific to any one health behaviour or condition (Wallston et al., 1994). The HLOC scale used a Likert-type response format for 11 items to determine whether a person was a "health-internal" who believed that one stays or becomes healthy or sick as a result of his or her behaviour, or a
"health-external" who believed that his or her health was affected by factors such as luck, chance, fate, or powerful others (Wallston et al., 1978).

Over the years, LOC has changed from being thought of as a unidimensional construct (internal vs. external control) to one that is multidimensional. As noted by Furnham and Steele (1993), researchers in the early 1970s examined the factor structure of the I-E scale and suggested that LOC consisted of at least three orthogonal dimensions. It was proposed that in addition to internal locus of control, external locus of control should be separated into a belief in powerful others such as family or doctors, and a belief in an unordered, unpredictable world, or chance (Furnham & Steele, 1993). In response to this, Levensen developed the Internal, Powerful Others and Chance (IPC) scales, and Wallston, Wallston, and DeVellis revised the original HLOC scale to include similar dimensions (Wallston et al., 1978). The revised Wallston scale was called the Multidimensional Health Locus of Control scale (MHLC). Many other HLOC measures have been developed over the years, some of which have been specifically designed to assess HLOC for certain health conditions, such as cancer (see Furnham & Steele, 1993 for a comprehensive review).

One of the difficulties with the MHLC forms was that they were designed for use with people who were relatively healthy or who had an acute illness, and were not sensitive to the concerns of people suffering from a chronic illness (Watson et al., 1990). Many researchers addressed this issue by developing their own MHLC scales targeted to specific health conditions (Wallston et al.,
1994). Unfortunately, while many of these researchers chose to simply alter items from the MHLC Forms A and B, no two researchers chose the same items, and comparison of the newly designed scales for research purposes was not possible (Wallston et al., 1994). In response to the need for a locus of control scale that could be easily adapted for use with persons with any medical or health-related condition, Wallston et al. (1994) designed a "Form C" of the MHLC scale, altering the wording of some items to reflect the unique experiences of individuals who had a chronic illness (Wallston et al., 1994, p.537). The MHLC-Form C contains four subscales: Internality, Chance, Doctors, and Other (powerful) People, and has been shown to be effective in assessing HLOC in many illness populations (Wallston et al., 1994). This was especially beneficial given that HLOC was used extensively in both health-related research and treatment planning. It is this form of the MHLC scale that was used in the present research to assess HLOC.

Purpose and Hypotheses

The main purpose of this study was to examine the relationships among a variety of factors that could contribute to adjustment and quality of life in a group of CFS patients. Variables studied included: adjustment to illness, quality of life, social support, coping style, and health locus of control. Specific hypotheses were as follows:

1. Problem-focussed coping style would be associated with better quality of life and better adjustment to illness in the various domains of the PAIS-SR.

Emotion-focussed coping strategies would have opposite associations.
2. Each social support subscale as well as the overall support score on the DSSI and positive support on the SSIS would be associated with better quality of life and better adjustment to illness in the various domains of the PAIS-SR. Negative support on the SSIS would have the opposite associations.

3. An internal health locus of control would be associated with better quality of life and better adjustment to illness in the various domains of the PAIS-SR.

4. Problem-focussed coping style, the various social support subscales with the exception of negative support, and an internal health locus of control would each be positive predictors of both good quality of life and good adjustment to illness, contributing unique variance to the prediction of each of these criterion variables.

The research also assessed which of the independent variables (coping style, social support, locus of control) were most predictive of quality of life and adjustment, and what combination of factors produced an optimal prediction for quality of life and adjustment to illness.
Chapter III

Method

Participants

This study involved a group of 40 participants who had been diagnosed with CFS. Participants were primarily recruited through general practitioners in the Toronto area who treat CFS patients (68%). Additional participants were recruited through CFS support groups in Toronto, Peterborough, and Winnipeg (12%), as well as through postings on CFS research internet sites (20%). Participation was on a voluntary basis. There were no significant differences between groups recruited via different means with respect to demographic variables or scores on the various measures. Of note is that approximately 25 additional people expressed an interest in participating in the study but withdrew for various reasons, including: familial problems (separation/divorce, death, illness of other family members); loss of energy and/or motivation due to exacerbation of symptomatology; or, the energy level required to complete the questionnaires was too demanding.

Of the 40 people who participated, 25% (10) were men and 75% (30) were women. The mean age of the sample was 45.6 years, with ages ranging from 24 to 59. With respect to race, 95% (38) of the participants were Caucasian, and 5% (2) were Oriental. Twenty percent (2) of the men were single or living alone as compared to 50% (15) of the women. Of the participants, 92.5% had an education beyond grade 13. On average, participants had been ill for 8.6 years, with a range of 1.5 to 27 years. T-tests
comparing genders on the demographic variables showed no significant differences. The high proportion of females in this sample, as well as the participants’ high education level and length of illness are consistent with reported demographic features of CFS populations in other studies (Blakely et al., 1991; Miller Iger, 1992; Ray et al., 1992; Freidberg & Jason, 1998). Given the difficulties surrounding the diagnosis of CFS, it was required that all participants had received a diagnosis of CFS by a medical doctor following the Centre for Disease Control (CDC) criteria (see Appendix A for diagnostic criteria). Individuals whose diagnosis was not independently confirmed by a physician were not included in this study.

Measures

The Quality of Life Scale. The Quality of Life Scale (QOLS) designed by Flannigan (1978) was used to assess participants’ overall perception of QOL (see Appendix B for the complete questionnaire). The QOLS is a 16 item measure designed to assess people’s perceived satisfaction with the quality of their lives in 16 areas: material well-being, health, relations with a significant other, having and raising children, relations with relatives, relations with friends, helping others, activities related to local and national governments, intellectual development, personal understanding and planning, occupational role, creativity and personal expression, socializing, passive recreational activities, active recreational activities, and independence (Burckhardt et al., 1989; Flannigan, 1978). Respondents were asked to rate their satisfaction with each of the 16 domains on a 7-point Likert scale ranging from "terrible" to "delighted".
The QOLS was chosen to assess QOL because of its previous use with chronically ill populations and its established reliability and validity. Internal consistency (as measured by Cronbach's alpha) was reported to range from .82 to .92 for a variety of patients, including those suffering from arthritis, or diabetes (Burckhardt et al., 1989). The QOLS has also been shown to have adequate construct validity (Burckhardt et al., 1989).

The Psychosocial Adjustment to Illness Scale-Self Report. The Psychosocial Adjustment to Illness Scale-Self Report (PAIS-SR) designed by Derogatis in 1978 was used in this study to assess participants' overall adjustment to illness, as well as their adjustment in a number of domains (see Appendix C for sample of complete questionnaire). The PAIS-SR consists of 46 items that assess adjustment in the following seven domains: Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationships, Extended Family Relationships, Social Environment, and Psychological Distress (Derogatis, 1986). Respondents were asked to rate each item by choosing one of four responses. Each item was scored on a 4-point Likert scale, with higher scores indicating better adjustment. Scores can be obtained for adjustment in each of the seven domains, and for overall adjustment (see Appendix D for description of the subscales).

The PAIS-SR was chosen as a measure of adjustment to illness for several reasons. In keeping with current research and conceptualization of ADJ, the PAIS-SR is a multidimensional scale, allowing for an assessment of adjustment in a number of different domains. In addition, the PAIS-SR is a
relatively short, easy questionnaire to complete, which was important given a CFS population. Finally, the PAIS-SR has established reliability and validity. Internal reliability coefficients for each of the seven domains and for the PAIS-SR total score have been reported between .63 and .94 in a variety of patients, such as dialysis, cardiac, and pain patients (Derogatis & Fleming, 1996). In addition, Derogatis and Fleming (1996), in their review of several studies investigating the validity of the PAIS-SR, found significant correlations with external criteria for PAIS-SR domain and total scores (see article for complete review).

Social Support Scales. Two scales were chosen to assess social support in this study: a short form of the Duke Social Support Inventory (DSSI: Koenig et al., 1993), and the Social Support in Illness Scale (SSIS: Ray, 1992). The DSSI-short form is comprised of 23 items examining three major dimensions of social support: instrumental support, subjective support, and social interaction (see Appendix E for sample items from the scale). As noted by Koenig et al. (1993), the DSSI is reliable, having an internal consistency (as measured by Cronbach's alpha) of .75. Validity of the DSSI has also been established, with the scale being significantly related to measures of health outcomes such as mental distress and use of health services (Koenig et al. 1993). As such, the DSSI provides us with a relatively short, reliable, valid measure of several dimensions of social support, as is recommended (Depner et al., 1984).

The SSIS was also used to assess social support in this study (see Appendix F for complete scale). The SSIS is a 23-item scale designed to assess both positive and negative aspects of social support in a CFS population (Ray,
Respondents were asked to rate the frequency with which each item applies on a 6-point Likert scale, ranging from "never" to "always". The SSIS was chosen as a complement to the DSSI, as it assessed negative social support, a factor that is receiving increasing attention in the literature. In addition, using the SSIS allowed us to further examine its utility with the population for which it was designed. Principal components analysis on the items of the SSIS has been reported to yield two factors accounting for 58% of the variance, with the 14 positive items having a reported alpha of .96, and the nine negative items having a reported alpha of .89 (Ray, 1992). In addition, positive social support was found to have a significant negative relationship with anxiety, and negative social support was found to have a significant positive relationship with both anxiety and depression (Ray, 1992).

**Ways of Coping Questionnaire.** The Ways of Coping Questionnaire (WOCQ) designed by Folkman and Lazarus (1988) was chosen as a measure of coping style in this study (see Appendix G for sample of complete scale). The WOCQ is a 66-item scale designed to assess how people cope with stressful events. Respondents were asked to think of a specific stressful event (one related to CFS for this study) that occurred in the past week, and respond to items with this event in mind. Responses are arranged in a 4-point Likert scale, ranging from "does not apply/not used" to "used a great deal". Items are arranged in eight scales, five of which are considered emotion-focussed coping, and three of which are considered problem-focussed coping (Taylor, 1999). Examples of emotion-focussed scales include distancing, self-controlling,
accepting responsibility, escape-avoidance, and positive reappraisal. Problem-focused coping strategies include confrontive, planful problem-solving, and seeking social support.

This measure was chosen to assess coping style because of its extensive use in the health-related literature, and its established reliability and validity. Internal consistency, as measured by Cronbach's alpha, has been reported between .61 and .79 for the eight scales (Lazarus, 1988). The WOCQ has also been shown to have both face and construct validity (Lazarus, 1988).

The Multidimensional Health Locus of Control Scale-Form C. The Multidimensional Health Locus of Control Scale-Form C (MHLC) was chosen as a measure of health locus of control in this study (see Appendix H for complete scale). The MHLC is an 18-item scale, with respondents being asked to indicate their level of agreement to each item on a 6-point Likert scale, ranging from "strongly disagree" to "strongly agree". The MHLC comes in three forms, the first two of which are considered general HLOC scales which can be used for repeated-measures designs. Form C of the MHLC is a newer version of the scale designed in 1987 for use as a condition-specific scale (Wallston et al., 1994). The MHLC contains three subscales: Internal, Chance, and Powerful Others, with Form C of the MHLC further subdividing Powerful Others into Doctors and Other People. Higher scores on subscales indicate higher tendencies toward that particular HLOC orientation.

The MHLC was chosen for use in this study because of its extensive use in health literature as a measure of HLOC, and its established reliability and
validity. For example, internal consistency as measured by Cronbach's alpha has been reported to range from .67 to .77 (Wallston et al., 1978). The scale has also been demonstrated to have adequate construct validity (Marshall, Collins, & Crooks, 1990; Wallston et al., 1978).

Procedure

Recruitment. Participants recruited through physicians were approached first by the general practitioner and asked if they were willing to participate in a study investigating coping and adjustment to CFS. Each CFS patient was given a copy of a description of this study to take home and peruse. (See Appendix I for the complete form). Participants from support groups were recruited at support group meetings. An announcement was made at meetings and interested members were provided with the study description, and asked to leave their names and phone numbers with the researcher, or the co-ordinator of the group if they were interested in participating. The study description was also posted on CPAR, an internet website for professionals conducting research on CFS. Interested people responded by telephone or email. Individuals who were willing to participate were then contacted by the researcher to discuss further details of the study, and to arrange for measures to be completed.

Completion of Measures. The majority of participants in this study met personally with the researcher to complete the measures. Other participants were too fatigued to complete the measures in one sitting, or lived too far away for a personal meeting to be arranged. In such cases, the consent forms and measures were mailed to participants for completion. A self-addressed,
stamped envelope was provided for participants to return the questionnaires by mail. A follow-up phone call was done within two weeks to ask participants if they had any questions or concerns. Those participants who received assistance completing the measures did not differ significantly in terms of how impaired they perceived themselves to be as compared to those who did not receive assistance. All participants were asked to sign a consent form describing the study and assuring them of confidentiality (see Appendix J). Each participant was assigned a number to enable the data to be recorded anonymously. Data collection consisted of the collection of basic demographic data such as age, gender, education level, and length and severity of CFS, and the completion of the various questionnaire measures.

Data Analysis. Once the data were collected, measures were scored according to the procedures outlined in the manuals and the data were analysed to explore the hypotheses. Data analysis was done using SPSS, and consisted of the following stages:

1. Descriptive statistics including means and standard deviations for the demographic data, as well as the scores on all of the various tests were calculated to provide a description of the subject sample and data obtained.

2. The Cronbach alpha coefficients of all measures were calculated to provide a measure of internal consistency. Cronbach's alpha greater than .65 were considered adequate for present research purposes.

3. The Pearson correlation coefficients between the scores for each of the variables were calculated to determine if there were relationships among the
variables. It was expected that higher scores on the internal health locus of control, problem-focussed coping, and social support scales would be positively correlated with higher scores on the quality of life and adjustment to illness scales.

4. A series of standard multiple regression analyses were performed to determine the relative contribution of each of the independent variables (health locus of control, social support, and coping) to the prediction of both dependent variables (quality of life and adjustment to illness). It was expected that the independent variables would emerge as significant predictors of the dependent variables.
Chapter IV

Results

Descriptive Statistics

Descriptive statistics including means, standard deviations, minimum and maximum scores and Cronbach’s alpha coefficients of the various scales and subscales are presented in Table 1. The majority of scales and subscales were found to have adequate internal consistency reliability, with the exception of the Other People subscale of the MHLC-Form C, and the Planful Problem-Solving subscale of the WOCQ. These two subscales were not used in subsequent analyses. Scores for the MHLC-C and the WOCQ were also consistent with those found for chronic illness and CFS populations in other studies (Capuano Sgambati, 1998; Wallston et al., 1994; Unger, 1997). Participants also reported poor ADJ in many areas of the PAIS-SR, which is consistent with other studies on CFS patients (Anderson & Estwing Ferrans, 1997).

In general, participants in this study reported moderate levels of Social Interaction, Instrumental Support, and Subjective Support on the DSSI. They also reported moderate levels of both Positive and Negative Support on the SSIS. In terms of health locus of control (HLOC), participants reported a stronger belief in their own ability to control their illness than their belief that the course of their illness was a result of chance or fate, or in the control of doctors. With respect to coping strategies, participants employed a variety of strategies in coping with situations that arose from their illness. Self-Controlling,
Table 1
Descriptive Statistics for Measures and their Subscales

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<th>Actual Max</th>
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</table>
Key for Table 1

**WOCQ:**  
Prob = Planful Problem-Solving  
Con = Confrontive  
Dis = Distancing  
Self = Self-Controlling  
Acc = Accepting Responsibility  
Pos = Positive Reappraisal  
Esc = Escape-Avoidance  
Socs = Seeking Social Support

**PAIS-SR:**  
HCO = Health Care Orientation  
VE = Vocational Environment  
DE = Domestic Environment  
SR = Sexual Relationships  
EFR = Extended Family Relationships  
SE = Social Environment  
PD = Psychological Distress  
OA = Overall Adjustment
Seeking Social Support, and Positive Reappraisal appeared to be the most commonly used strategies, with Accepting Responsibility and Escape-Avoidance being used only rarely. In terms of ADJ, as expected, participants reported ADJ difficulties across many domains. Specifically, difficulties were reported in Health Care Orientation, Vocational Environment, Domestic Environment, and Social Environment. Adjustment in terms of Sexual Relationships and Extended Family Relationships was less affected.

Gender Differences Across Variables

Comparisons between genders on all scale and subscale scores were conducted using t-tests. There were no significant differences between male and female participants on the locus of control orientation or coping styles. Differences were found on Subjective Support on the DSSI and ADJ in two domains of the PAIS-SR (see Table 2). Specifically, males reported more Subjective Support than females in this study, while females reported significantly more ADJ problems in Extended Family Relationships and in Domestic Environment. Of note is that there was considerable variability within the female group for these subscales, which presents a problem for the equality of variance. Thus, the t-test results for these subscales should be interpreted with caution.

Intercorrelations of Demographic with Dependent Variables

Pearson correlation coefficients showing the association of the demographic variables with quality of life and the various PAIS-SR domains are
Table 2
T-tests Comparing Males and Females on Various Subscales

<table>
<thead>
<tr>
<th>Measure</th>
<th>Males</th>
<th>Females</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
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<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
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<td></td>
<td></td>
</tr>
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<td>16.7</td>
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<td>5.17</td>
<td>4.18</td>
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<td>1.69</td>
<td>13.13</td>
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</tr>
</tbody>
</table>

*p<.05  **p<.01  ***p<.001

EFR = Extended Family Relationships
DE = Domestic Environment
shown in Table 3. Of note is that the relationships with the PAIS-SR domains are inverse relationships, with higher scores on the PAIS-SR indicating more adjustment difficulties. Thus, a positive correlation between a demographic variable and a PAIS-SR domain indicates that the variable is associated with poor adjustment. This should be kept in mind when interpreting the correlations.

Results from this study indicated that an increase in age and perceived impairment in the form of percent debilitation were significantly associated with poor adjustment in Vocational Environment. More education was significantly associated with better quality of life but poor adjustment in Health Care Orientation. A higher income level was significantly associated with better Overall Adjustment, as well as adjustment in several areas, including Health Care Orientation, Domestic Environment, and Extended Family Relationships. Also, those participants who reported feeling better as compared to one year ago reported better quality of life.

**Intercorrelations of Social Support with Dependent Variables**

It was hypothesized that more social support on the DSSI subscales and more Positive Support on the SSIS would be associated with better QOL and better ADJ across the various domains of the PAIS-SR. Pearson correlation coefficients showing the association of social support with QOL and psychosocial ADJ are shown in Table 4.
Table 3
Pearson Correlation Coefficients of Demographic Variables with Quality of Life and PAIS-SR Domains

<table>
<thead>
<tr>
<th>Demo</th>
<th>QOL</th>
<th>HCO</th>
<th>VE</th>
<th>DE</th>
<th>SR</th>
<th>EFR</th>
<th>SE</th>
<th>PD</th>
<th>OA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
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<td>.39*</td>
<td>.03</td>
<td>-.08</td>
<td>-.12</td>
<td>.22</td>
<td>-.29</td>
<td>.07</td>
</tr>
<tr>
<td>Edu</td>
<td>.33*</td>
<td>.36*</td>
<td>-.14</td>
<td>.14</td>
<td>.02</td>
<td>.11</td>
<td>-.00</td>
<td>-.26</td>
<td>.06</td>
</tr>
<tr>
<td>Incm</td>
<td>.16</td>
<td>-.34*</td>
<td>-.20</td>
<td>-.40*</td>
<td>-.03</td>
<td>-.34*</td>
<td>-.21</td>
<td>-.16</td>
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<tr>
<td>Mnths</td>
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<td>.32*</td>
<td>.07</td>
<td>.06</td>
<td>-.06</td>
<td>.01</td>
<td>-.29</td>
<td>.05</td>
</tr>
<tr>
<td>Debil</td>
<td>.10</td>
<td>.03</td>
<td>.32*</td>
<td>.24</td>
<td>.10</td>
<td>.23</td>
<td>.14</td>
<td>.02</td>
<td>.22</td>
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<tr>
<td>Feel</td>
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<td>-.14</td>
<td>-.15</td>
<td>.22</td>
<td>.00</td>
<td>.07</td>
<td>-.16</td>
<td>-.09</td>
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</table>

*p<.05

QOL = Quality of Life
Demo = Demographic Variables
Edu = Years of education
Incmm = income level
Mnths = number of months since onset of illness
Debil = percent debilitated
Feel = worse, same or better than a year ago

PAIS-SR:   HCO = Health Care Orientation
           VE = Vocational Environment
           DE = Domestic Environment
           SR = Sexual Relationships
           EFR = Extended Family Relationships
           SE = Social Environment
           PD = Psychological Distress
           OA = Overall Adjustment
Table 4
Pearson Correlation Coefficients of Support Measures with Quality of Life and PAIS-SR Domains

<table>
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<th>DE</th>
<th>SR</th>
<th>EFR</th>
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<td>-.43**</td>
<td>-.11</td>
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<td>.36*</td>
<td>.10</td>
<td>.66***</td>
<td>.42**</td>
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</table>

*p<.05  **p<.01  ***p<.001

DSSI:  
OV= Overall Support  
IS= Instrumental Support  
SI= Social Interaction  
SS= Subjective Support

SSIS:  
PS= Positive Support  
NS= Negative Support

PAIS-SR:  
HCO= Health Care Orientation  
VE= Vocational Environment  
DE= Domestic Environment  
SR= Sexual Relationships  
EFR= Extended Family Relationships  
SE= Social Environment  
PD= Psychological Distress  
OA= Overall Adjustment
On the DSSI, both Subjective Support and Overall Support were significantly associated with better QOL, and better ADJ in the following domains: Vocational Environment, Domestic Environment, Extended Family Relationships, Psychological Distress, and Overall Adjustment. Overall Support was also significantly associated with better ADJ in Sexual Relationships, as was Instrumental Support. On the SSIS, Positive Support was significantly associated with better QOL, and better ADJ in Health Care Orientation, Domestic Environment, Psychological Distress, and Overall Adjustment. Negative Support was significantly associated with poor QOL and poor ADJ in Domestic Environment, Sexual Relationships, Extended Family Relationships, Psychological Distress, and Overall Adjustment.

**Intercorrelations of Coping Style with Dependent Variables**

It was hypothesized that the use of problem-focussed coping strategies such as Planful Problem-Solving, Confrontive coping and Seeking Social Support would be significantly associated with better QOL and better ADJ across the various domains of the PAIS-SR, while emotion-focussed coping strategies would have opposite associations. Since Planful Problem Solving was not found to be a reliable scale in this study, it could not be used in these analyses. Pearson correlation coefficients showing the associations between other coping strategies and quality of life and psychosocial adjustment are shown in Table 5.

Results show that a number of large magnitude and significant associations existed. As expected, Confrontive coping was associated with better QOL and better ADJ in Vocational and Social Environment.
Table 5
Pearson Correlation Coefficients of Coping Style with Quality of Life and PAIS-SR Domains

<table>
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<th>VE</th>
<th>DE</th>
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<th>EFR</th>
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<td>.05</td>
<td>.36*</td>
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<tr>
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<td>-.26</td>
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<td>.06</td>
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<td>.19</td>
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<td>.08</td>
<td>.06</td>
<td>.25</td>
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<td>-.12</td>
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<td>.33*</td>
<td>.38*</td>
<td>.35*</td>
<td>.22</td>
<td>.72***</td>
<td>.42**</td>
</tr>
</tbody>
</table>

*p<.05   **p<.01   ***p<.001

WOCQ:  Con= Confrontive  Socs= Seeking Social Support  Dis= Distancing  Self= Self-Controlling  Acc= Accepting Responsibility  Pos= Positive Reappraisal  Esc= Escape-Avoidance

Contrary to what was expected, Seeking Social Support was significantly associated with poor ADJ in Domestic Environment. The emotion-focussed coping styles revealed associations in the predicted directions. For example, Self-Controlling was found to be significantly associated with poor Overall Adjustment as well as poor ADJ in Sexual Relationships, Extended Family Relationships, and Social Environment. Accepting Responsibility was significantly associated with poor ADJ in Extended Family Relationships and Psychological Distress. Escape-Avoidance was significantly associated with poor Overall Adjustment and poor ADJ in Domestic Environment, Sexual Relationships, Extended Family Relationships, and Psychological Distress.

**Intercorrelations of Health Locus of Control with Dependent Variables**

It was hypothesized that an Internal HLOC would be associated with better QOL and better ADJ in the domains of the PAIS-SR. Pearson correlation coefficients for these associations are shown in Table 6.

As expected, Internal HLOC was found to be significantly associated with better ADJ in all domains of the PAIS-SR, with the exception of Psychological Distress. Internal HLOC was not significantly associated with better QOL as expected. Instead, Chance HLOC was found to be significantly associated with better QOL as well as better ADJ in Vocational Environment. Both Doctor and Powerful Others HLOC were significantly associated with better ADJ in Health Care Orientation and Vocational Environment.
Table 6
Pearson Correlation Coefficients of Health Locus of Control with Quality of Life and PAIS-SR Domains

<table>
<thead>
<tr>
<th></th>
<th>QOL</th>
<th>HCO</th>
<th>VE</th>
<th>DE</th>
<th>SR</th>
<th>EFR</th>
<th>SE</th>
<th>PD</th>
<th>OA</th>
</tr>
</thead>
<tbody>
<tr>
<td>IHLOC</td>
<td>.16</td>
<td>-.50**</td>
<td>-.40*</td>
<td>-.57***</td>
<td>-.38*</td>
<td>-.39*</td>
<td>-.40*</td>
<td>-.15</td>
<td>-.57***</td>
</tr>
<tr>
<td>CHLOC</td>
<td>.58***</td>
<td>-.22</td>
<td>-.51**</td>
<td>.03</td>
<td>.12</td>
<td>.02</td>
<td>.01</td>
<td>.18</td>
<td>-.05</td>
</tr>
<tr>
<td>POHLOC</td>
<td>.19</td>
<td>-.52**</td>
<td>-.33*</td>
<td>-.10</td>
<td>-.06</td>
<td>.10</td>
<td>-.12</td>
<td>.00</td>
<td>-.16</td>
</tr>
<tr>
<td>DCHLOC</td>
<td>.14</td>
<td>-.59***</td>
<td>-.37*</td>
<td>-.17</td>
<td>-.10</td>
<td>.05</td>
<td>-.21</td>
<td>.08</td>
<td>-.24</td>
</tr>
</tbody>
</table>

*p<.05  ** p<.01  ***p<.001

MHLC:  
IHLOC = Internal Health Locus of Control  
CHLOC = Chance Health Locus of Control  
POHLOC = Powerful Others Health Locus of Control  
DCHLOC = Doctor Health Locus of Control

PAIS-SR:  
HCO = Health Care Orientation  
VE = Vocational Environment  
DE = Domestic Environment  
SR = Sexual Relationships  
EFR = Extended Family Relationships  
SE = Social Environment  
PD = Psychological Distress  
OA = Overall Adjustment
Multiple Regression Analyses

Standard multiple regression analyses were conducted to assess which of the variables accounted for most of the variance in the measures of QOL and psychosocial ADJ. Amongst the correlates of the outcome variables in Tables 4 through 6, up to four variables were chosen as possible predictors. Thus there were 10 subjects per predictor, allowing for greater statistical power, as recommended by Harris (1985). In general, predictors were chosen based on the strength of the correlation they had with the outcome variable; that is, those with stronger correlations were chosen over those with weaker correlations. Where a choice had to be made between two subscales of similar measures, the more specific subscale was chosen for inclusion as a predictor. For example, Subjective Support was chosen over Overall Support on the DSSI as it provided a more specific measure of social support on that particular scale. Despite a number of significant correlations amongst the independent variables chosen for inclusion as predictors, their size was not of such a magnitude as to result in multicollinearity.

Predictors of Quality of Life. A standard multiple regression analysis was performed with Subjective Support on the DSSI, Chance HLOC, Confrontive Coping and Positive Support on the SSIS as predictors of QOL. The final regression model that resulted from this analysis is displayed in Table 7. The overall model was significant (R = .88, p < .001), with the predictors collectively
Table 7  
Standard Regression Analysis of Subjective Support, Chance Health Locus of Control, Confrontive Coping and Positive Support on Quality of Life

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>(sr^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Support</td>
<td>.53</td>
<td>.13***</td>
</tr>
<tr>
<td>Chance Health Locus of Control</td>
<td>.39</td>
<td>.10***</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>.12</td>
<td>.01</td>
</tr>
<tr>
<td>Positive Support</td>
<td>.15</td>
<td>.01</td>
</tr>
</tbody>
</table>

*p<.05  
**p<.01  
***p<.001  

\(R^2\) model = .77***  
R model = .88***
accounting for 77% of the variance in quality of life. Examination of the squared semipartial correlations indicates that both Subjective Support ($sr^2 = .13$, $p<.001$) and Chance HLOC ($sr^2 = .10$, $p<.001$) but not Positive Support and Confrontive Coping made unique contributions to the prediction of QOL, accounting for 13% and 10% of the variance in this variable, respectively.

**Predictors of Adjustment in Health Care Orientation.** A standard multiple regression analysis was performed with Positive Support on the SSIS, Internal HLOC, and Doctor HLOC as predictors of ADJ in Health Care Orientation. The final regression model that resulted from this analysis is displayed in Table 8. The overall model was significant ($R = .74$, $p<.001$), with the predictors collectively accounting for 54% of the variance in ADJ in Health Care Orientation. Examination of the squared semipartial correlations indicates that both Positive Support ($sr^2 = .11$, $p<.01$) and Doctor HLOC ($sr^2 = .16$, $p<.01$) but not Internal HLOC made unique contributions to the prediction of ADJ in Health Care Orientation, accounting for 11% and 16% of the variance in this variable, respectively.

**Predictors of Adjustment in Vocational Environment.** A standard multiple regression analysis was performed with Subjective Support on the DSSI, Internal HLOC, Chance HLOC, and Confrontive coping as predictors of ADJ in Vocational Environment. The final regression model that resulted from this analysis is displayed in Table 9. The overall model was significant ($R = .77$, $p<.001$), with the predictors collectively accounting for 60% of the variance in
Table 8
Standard Regression Analysis of Positive Support, Internal Health Locus of Control, and Doctor Health Locus of Control on Adjustment in Health Care Orientation

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>sr²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Support</td>
<td>-.34</td>
<td>.11 **</td>
</tr>
<tr>
<td>Internal Health Locus of Control</td>
<td>.37</td>
<td>.04</td>
</tr>
<tr>
<td>Doctor Health Locus of Control</td>
<td>-.46</td>
<td>.16 **</td>
</tr>
</tbody>
</table>

*p<.05
**p<.01
***p<.001

R² model = .54***
R model = .74***
Table 9
Standard Regression Analysis of Subjective Support, Internal Health Locus of Control, Chance Health Locus of Control, and Confrontive Coping on Adjustment in Vocational Environment

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>sr²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Support</td>
<td>-.10</td>
<td>.01</td>
</tr>
<tr>
<td>Internal Health Locus of Control</td>
<td>-.41</td>
<td>.16**</td>
</tr>
<tr>
<td>Chance Health Locus of Control</td>
<td>-.27</td>
<td>.06*</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>-.45</td>
<td>.15**</td>
</tr>
</tbody>
</table>

*p<.05
***p<.001

R² model = .60***
R model = .77***
ADJ in Vocational Environment. Examination of the squared semipartial correlations indicates that Internal HLOC (sr² = .16, p < .001), Chance HLOC (sr² = .06, p < .05), and Confrontive Coping (sr² = .15, p < .01), but not Subjective Support made unique contributions to the prediction of ADJ in Vocational Environment, accounting for 16%, 6% and 15% of the variance in this variable, respectively.

**Predictors of Adjustment in Domestic Environment.** A standard multiple regression analysis was performed with Negative Support on the SSIS, Internal HLOC, Escape-Avoidance, and Seeking Social Support as predictors of ADJ in Domestic Environment. For this regression analysis, Negative Support was chosen over Subjective Support as this model allowed for the unique contribution of the other predictors to emerge more strongly. The final regression model that resulted from this analysis is displayed in Table 10. The overall model was significant (R = .74, p < .001), with the predictors collectively accounting for 55% of the variance in ADJ in Domestic Environment. Examination of the squared semipartial correlations indicates that Negative Support (sr² = .12, p < .01), Internal HLOC (sr² = .28, p < .001), and Seeking Social Support (sr² = .07, p < .05), but not Escape-Avoidance made unique contributions to the prediction of ADJ in Domestic Environment, accounting for 12%, 28% and 7% of the variance in this variable, respectively.

**Predictors of Adjustment in Sexual Relationships.** A standard multiple regression analysis was performed with Instrumental Support, Internal HLOC,
Table 10
Standard Regression Analysis of Negative Support, Internal Health Locus of Control, Escape-Avoidance, and Seeking Social Support on Adjustment in Domestic Environment.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>sr^2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative Support</td>
<td>.44</td>
<td>.12**</td>
</tr>
<tr>
<td>Internal Health Locus of Control</td>
<td>-.54</td>
<td>.28***</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>-.27</td>
<td>.01</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>.27</td>
<td>.07*</td>
</tr>
</tbody>
</table>

*p<.05  
**p<.01  
***p<.001  

R^2 model = .55***  
R model = .74***
Escape-Avoidance, and Self Controlling as predictors of ADJ in Sexual Relationships. The final regression model that resulted from this analysis is displayed in Table 11. The overall model was significant \( (R = .64, p < .01) \), with the predictors collectively accounting for 41% of the variance in ADJ in Sexual Relationships. Examination of the squared semipartial correlations indicates that Instrumental Support \( (sr^2 = .14, p < .01) \) and Escape-Avoidance \( (sr^2 = .10, p < .05) \) but not Internal HLOC or Self-Controlling made unique contributions to the prediction of ADJ in Sexual Relationships, accounting for 14% and 10% of the variance in this variable, respectively.

**Predictors of Adjustment in Extended Family Relationships.** A standard multiple regression analysis was performed with Subjective Support, Internal HLOC, Accepting Responsibility, and Escape-Avoidance as predictors of ADJ in Extended Family Relationships. For this regression analysis, Escape-Avoidance was chosen over Self-Controlling as this model allowed for the unique contribution of the other predictors to emerge more strongly. The final regression model that resulted from this analysis is displayed in Table 12. The overall model was significant \( (R = .67, p < .001) \), with the predictors collectively accounting for 45% of the variance in ADJ in Extended Family Relationships. Examination of the squared semipartial correlations indicates that Subjective Support \( (sr^2 = .11, p < .05) \), Internal HLOC \( (sr^2 = .15, p < .01) \), and Accepting Responsibility \( (sr^2 = .15, p < .01) \), but not Escape-Avoidance made unique contributions to the prediction of ADJ in Extended Family Relationships,
### Table 11
**Standard Regression Analysis of Instrumental Support, Internal Locus of Control, Escape-Avoidance, and Self-Controlling on Adjustment in Sexual Relationships**

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>sr²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrumental Support</td>
<td>-.39</td>
<td>.14**</td>
</tr>
<tr>
<td>Internal Health Locus of Control</td>
<td>-.18</td>
<td>.03</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>.35</td>
<td>.10*</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>.14</td>
<td>.02</td>
</tr>
</tbody>
</table>

*p<.05  
**p<.01  
***p<.001  

R² model = .41**  
R model = .64**
Table 12
Standard Regression Analysis of Subjective Support, Internal Health Locus of Control, Accepting Responsibility, and Escape-Avoidance on Adjustment in Extended Family Relationships

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>$r^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Support</td>
<td>-.39</td>
<td>.11*</td>
</tr>
<tr>
<td>Internal Health Locus of Control</td>
<td>-.42</td>
<td>.15**</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.58</td>
<td>.15*</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>-.29</td>
<td>.03</td>
</tr>
</tbody>
</table>

*p<.05  
**p<.01  
***p<.001

$R^2_{	ext{model}} = .45^{***}$  
$R_{	ext{model}} = .67^{***}$
accounting for 11%, 15% and 15% of the variance in this variable, respectively.

**Predictors of Adjustment in Social Environment.** A standard multiple regression analysis was performed with Internal HLOC, Confrontive Coping, and Self Controlling as predictors of ADJ in Social Environment. The final regression model that resulted from this analysis is displayed in Table 13. The overall model was significant (R = .63, p < .001), with the predictors collectively accounting for 40% of the variance in ADJ in Social Environment. Examination of the squared semipartial correlations indicates that Internal HLOC (sr² = .09, p < .05), Confrontive Coping (sr² = .14, p < .01), and Self-Controlling (sr² = .10, p < .05) all made unique contributions to the prediction of ADJ in Social Environment, accounting for 9%, 14%, and 10% of the variance in this variable, respectively.

**Predictors of Psychological Distress.** A standard multiple regression analysis was performed with Subjective Support on the DSSI, Negative Support on the SSIS, Accepting Responsibility, and Escape-Avoidance as predictors of Psychological Distress. The final regression model that resulted from this analysis is displayed in Table 14. The overall model was significant (R = .84, p < .001), with the predictors collectively accounting for 70% of the variance in Psychological Distress. Examination of the squared semipartial correlations indicates that Subjective Support (sr² = .11, p < .01), and Escape-Avoidance (sr² = .04, p < .05), but not Negative Support or Accepting Responsibility made unique contributions to the prediction of Psychological Distress, accounting for 11%, and 4% of the variance in this variable, respectively.
Table 13

**Standard Regression Analysis of Internal Health Locus of Control, Confrontive Coping, and Self-Controlling on Adjustment in Social Environment**

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>sr²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Health Locus of Control</td>
<td>-.32</td>
<td>.09*</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>-.37</td>
<td>.14**</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>-.33</td>
<td>.10*</td>
</tr>
</tbody>
</table>

*p<.05

**p<.01

***p<.001

\[ R^2_{\text{model}} = .40^{***} \]

\[ R_{\text{model}} = .63^{***} \]
Table 14

Standard Regression Analysis of Subjective Support, Negative Support, Accepting Responsibility, and Escape-Avoidance on Psychological Distress.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>sr²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Support</td>
<td>-0.44</td>
<td>0.11**</td>
</tr>
<tr>
<td>Negative Support</td>
<td>0.11</td>
<td>0.01</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>0.20</td>
<td>0.02</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>0.31</td>
<td>0.04*</td>
</tr>
</tbody>
</table>

*p<.05  
**p<.01

R² model = 0.70***  
R model = 0.84***
**Predictors of Overall Adjustment.** A standard multiple regression analysis was performed with Subjective Support, Internal HLOC, Escape-Avoidance, and Self-Controlling as predictors of Overall Adjustment. The final regression model that resulted from this analysis is displayed in Table 15. The overall model was significant \((R = .75, p < .001)\), with the predictors collectively accounting for 56% of the variance in Overall Adjustment. Examination of the squared semipartial correlations indicates that Subjective Support \((sr^2 = .12, p < .01)\) and Internal HLOC \((sr^2 = .13, p < .01)\), but not Escape-Avoidance or Self-Controlling, made unique contributions to the prediction of Overall Adjustment, accounting for 11%, and 13% of the variance in this variable, respectively.
Table 15
Standard Regression Analysis of Subjective Support, Internal Health Locus of Control, Escape-Avoidance, and Self-Controlling on Overall Adjustment

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta</th>
<th>( sr^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Support</td>
<td>-.39</td>
<td>.12**</td>
</tr>
<tr>
<td>Internal Health Locus of Control</td>
<td>-.39</td>
<td>.13**</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>.11</td>
<td>.01</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>.16</td>
<td>.02</td>
</tr>
</tbody>
</table>

\( *p<.05 \) \( **p<.01 \) \( ***p<.001 \)

R\(^2\) model = .56***
R model = .75***
<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Important Predictors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life</td>
<td>Subjective Support</td>
</tr>
<tr>
<td></td>
<td>Chance Health Locus of Control</td>
</tr>
<tr>
<td>Health Care Orientation</td>
<td>Positive Perceived Support</td>
</tr>
<tr>
<td></td>
<td>Doctor Health Locus of Control</td>
</tr>
<tr>
<td>Vocational Environment</td>
<td>Internal Health Locus of Control</td>
</tr>
<tr>
<td></td>
<td>Confrontive Coping</td>
</tr>
<tr>
<td>Domestic Environment</td>
<td>Internal Health Locus of Control</td>
</tr>
<tr>
<td></td>
<td>Negative Perceived Support</td>
</tr>
<tr>
<td>Sexual Relationships</td>
<td>Instrumental Support</td>
</tr>
<tr>
<td></td>
<td>Escape-Avoidance</td>
</tr>
<tr>
<td>Extended Family Relationships</td>
<td>Internal Health Locus of Control</td>
</tr>
<tr>
<td></td>
<td>Accept Responsibility</td>
</tr>
<tr>
<td>Social Environment</td>
<td>Confrontive Coping</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>Subjective Support</td>
</tr>
<tr>
<td>Overall Adjustment</td>
<td>Subjective Support</td>
</tr>
<tr>
<td></td>
<td>Internal Health Locus of Control</td>
</tr>
</tbody>
</table>
Chapter V
Discussion

This study examined social support, coping style and health locus of control and their associations with quality of life and adjustment to illness in a group of CFS patients. Specific hypotheses were as follows:

1. Problem-focussed coping styles would be associated with better quality of life and better adjustment to illness in the various domains of the PAIS-SR. Emotion-focussed coping styles would have opposite associations.

2. Positive social support would be associated with better quality of life and better adjustment to illness in the various domains of the PAIS-SR. Negative support would have the opposite associations.

3. An internal health locus of control would be associated with better quality of life and better adjustment to illness in the various domains of the PAIS-SR.

4. Problem-focussed coping styles, positive social support, and an internal health locus of control would each be positive predictors of both good quality of life and good adjustment to illness, contributing unique variance to the prediction of each of these criterion variables.

In general, the main hypotheses of this study were supported, with problem-focussed coping strategies, positive social support and an internal HLOC being associated with and predictors of better QOL and better adjustment, and emotion-focussed coping and negative social support being associated with and predictors of adjustment difficulties. With respect to demographic variables, individuals with more education tended to be dissatisfied with their health care,
possibly because they had higher expectations from their physicians, or were less willing to rely on the medical community. What follows is a more in-depth discussion of the results in light of relevant literature.

Health Locus of Control

Participants in this study reported a strong belief in their ability to control their illness while maintaining beliefs in the influence of doctors and chance or fate. A belief in personal control was most influential for adjustment, although a belief in external factors such as doctors and luck or fate was also important for adjustment in certain areas. Specifically, an internal HLOC emerged as a strong predictor of adjustment in vocation, domestics, social activities, and relationships with family members. A belief in doctors impacted on satisfaction with health care and adjustment on the job. Overall quality of life was attributed to luck or fate. In general, these results are consistent with prior research that has found an internal HLOC orientation to be related to better adjustment and psychological well-being in various illness groups, including CFS (Enevoldsen Bowsher & Keep, 1995; Karanci, 1988; Kuehn & Winters, 1994; Nada Raja et al., 1994; Ray et al., 1997; Taylor et al., 1991; Unger, 1997; Wallston et al., 1994).

Coping with a chronic illness like CFS can require individuals to find a balance in terms of how controllable they believe their illness to be. Patients who believe that they can assume some control over the illness are often more willing to take active steps to overcome their health problems and tend to adjust better than those who believe they have no such control (Keller, 1988; Watson et al., 1990). Individuals with CFS can gain a sense of control by seeking
information about the disorder, by being willing to try different treatment
regimens, and by taking steps to avoid activities or situations which they know
exacerbate their symptoms. A belief in external forces can also be important in
coping with a chronic illness. Patients with supportive doctors can benefit in
terms of their health care, or by obtaining social assistance with the help of their
physicians to pay for alternative treatments. It is also important for patients to
recognize that CFS is a chronic illness with an unpredictable course that is often
not amenable to personal control. Maintaining a belief in personal control may
actually be maladaptive in the face of such an uncontrollable illness, leading to
frustration, anger, and feelings of helplessness (Taylor et al., 1991). Believing
that the fluctuations in symptoms are due to fate or chance can reduce the sense
of responsibility, and hence the sense of guilt and failure, from the patient.

Coping Style

As with other CFS populations, participants in this study reported using
both problem-focused and emotion-focused coping strategies in dealing with
problems that arose from their illness (Blakely et al., 1991; Capuano Sgambati,
1998; Hynick, 1997; Ray et al., 1995; Ray et al., 1997; Schmell, 1991). Of those
strategies, problem-focused coping emerged as adaptive in some areas and
emotion-focused coping emerged as generally maladaptive. Specifically, the
problem-focused strategy of Confrontive coping was a strong predictor of better
adjustment in terms of vocation and social activities and was associated with
better QOL. Emotion-focused strategies predicted adjustment difficulties in
areas such as domestics, sexual relationships, relationships with family
members, social activities, and emotional health. It is unfortunate that the Planful Problem-Solving subscale was not internally consistent despite its widespread use by participants in this study, as it eliminated a potentially important coping strategy from the data analysis.

In general, these findings are consistent with studies of coping in chronic illness populations (de Ridder et al., 1998; Feifel et al., 1987; Felton et al., 1984; Ray et al., 1993; Schmall, 1991; White et al., 1992). Studies of coping in CFS patients, however, have found contradictory results. Problem-focussed coping strategies have been associated with better mental health (Heijmans, 1998), as well as functional impairment and emotional distress (Capuano Sgambati, 1998; Ray et al., 1995; Ray et al., 1997). Emotion-focussed coping strategies have been associated with functional impairment, emotional distress, and lower perceived competence (Heijmans, 1998; Hynick, 1997; Ray et al., 1995), but also improved functioning (Schmall, 1991). This is consistent with some studies that have suggested that emotion-focussed strategies are effective in the face of relatively uncontrollable illnesses (MacCarthy & Brown, 1989).

Individuals with CFS face a number of complex problems as a result of their illness. Different stages of the illness bring about different problems that may require different coping strategies. In the early stages of the illness, individuals may be searching for information on CFS or trying to find a suitable physician. In later stages, financial concerns may be paramount if the person is unable to work. Across all stages of the illness, individuals continually struggle to cope with particular aspects of the disorder such as fatigue, or consequences of
the disorder such as loss of employment or friendships. Therefore, it makes sense that patients employ multiple strategies, and that no one coping strategy is effective in all situations.

Using several coping strategies is common in chronic illness groups, serving an adaptive function by allowing a person to match strategies to a particular problem or to use new strategies when others become dysfunctional or inappropriate (Badger, 1990; de Ridder & Schreurs, 1996; de Ridder et al., 1998). CFS patients must constantly balance the demands of their illness, assigning priority to the problems they face, and coping as best they can with their limited resources. Unfortunately, as the illness progresses, individuals may feel increasingly hopeless and helpless, and lose their emotional drive to cope with the illness, even if their physical health is improving (Anderson & Estwing Ferrans, 1997). Individuals may continue to use old coping strategies even if they have become maladaptive simply because they do not have the mental energy or desire to try alternative strategies. For example, they may continue to seek support of family members who themselves are unable to provide the necessary support because they are suffering from caregiver burnout.

Of note is that coping with one problem may result in difficulties in other areas. For example, patients may avoid housework in an effort to reduce their fatigue, but may experience difficulties in the home as chores remain undone and other members of the household take on the additional responsibilities. Similarly, confronting problems in interpersonal relationships may give a person a sense of control and relieve emotional distress, but it may also damage the
relationship, increasing the stress level and decreasing available support; as a result, individuals tend to deny such problems and avoid discussing them with significant others. Overall, research seems to suggest that a variety of coping strategies may be appropriate, if not adaptive, in dealing with CFS, depending on the situation or problem that is being addressed. Such an approach allows patients to cope as best they can with the most salient problem facing them.

**Social Support**

Participants in this study reported receiving sufficient support and being reasonably content with the support they received. Of note is that males and females differed with respect to their perception of support, with males reporting that they felt significantly more accepted, understood, and listened to despite equal amounts of social contact. This may be a reflection of differences in expectations for support, or differences in the actual amount of emotional support received. It should be noted that there was considerable variance for female participants for this subscale, and the results for this subscale should be interpreted in light of this. A simple comparison of means masks this variability.

In general, perceived positive support predicted better QOL and better adjustment in many areas, while negative support in the form of expressed frustration, criticism, and irritation predicted poor QOL and adjustment difficulties in many areas. Practical assistance such as helping with household chores or running errands was only relevant for adjustment in sexual relationships. These findings are consistent with literature suggesting that positive social support has beneficial effects on QOL and adjustment while the negative aspects of support
were associated with adjustment difficulties and emotional distress (Connell et al., 1994; Corrigan & Buican, 1995; Dimond, 1979; Dunkel-Schetter, 1984; White et al., 1992). In fact, some studies have shown negative support to be more strongly and consistently related to mental health outcomes than positive support (Dunkel-Schetter, 1984; Shinn et al., 1984). Studies of social support in CFS patients have found positive support to be associated with perceived competence and a reduction in emotional distress, but also negatively related to symptomatic relapse (Hynick, 1997; Friedberg & Jason, 1998; Ray, 1992).

Overall, the quality of social relationships appears more important than the quantity for CFS patients. Feeling understood, accepted and listened to appears more relevant for adjustment and QOL than simply having contact with people and receiving practical aid from them. The general sense that one is loved and cared for, and the belief that others will help when needed likely serves as a buffer against the stress of the illness. In contrast, negative comments result in poor adjustment, likely by increasing stress levels, and exacerbating symptoms (Friedberg & Jason, 1998). Manne and Zautra (1989), in their study of coping with chronic illnesses, noted that negative support led to maladaptive coping strategies such as wishful thinking, which in turn resulted in poor adjustment. This suggests that social support can impact individuals by influencing them to choose appropriate or effective coping strategies.

Contrary to what was expected, practical aid in the form of running errands or helping with chores did not appear to have a significant impact on adjustment. The exception in this study is in the case of sexual relationships,
where such assistance may have communicated understanding and sympathy leading to increased energy and a willingness to maintain intimate relationships. Of note is that some participants reported receiving assistance with household chores from hired help, which was not reflected in the social support scales used in this study. This leaves open the possibility that tangible support may play a role in adjustment. However, other research has indicated that instrumental support is not as relevant for adjustment to illness on a daily basis as perceived or emotional support; rather, it becomes important in crisis situations (Revicki & Mitchell, 1990; Schwarzer & Leppin, 1991; Wortman & Conway, 1985).

Given the high degree of disbelief and lack of acceptance of CFS, it is interesting that the majority of participants were satisfied with the amount of emotional support they received. According to de Ridder & Schreurs (1996), this is not uncommon in chronically ill populations, and may reflect the support that participants were receiving from key people such as doctors or support group members. In fact, a study by Anderson and Estwing-Ferrans (1997) noted that CFS patients typically experience a marked decrease in their social network early on in the illness, but report receiving more support and understanding from those people who remained in contact with them. This support plays a key role in adjustment to life with CFS.

**Overall Results in the Context of the Theoretical Model**

An examination of the theoretical model proposed to explain QOL and adjustment to illness in CFS patients demonstrated that they are multifactorially determined. Participants in this study used both intrapersonal and interpersonal
resources in various ways in their adjustment to CFS, although the importance of these factors depended somewhat on the area of adjustment assessed. Overall, individuals appeared to benefit from gaining control over their illness, whether it be through successfully obtaining assistance from others, or minimizing the impact the illness had on them through the use of problem-focussed coping strategies.

Given that only a small portion of variance in psychosocial adjustment and QOL was explained by the above mentioned variables, it is likely that other factors contributed to adjustment and QOL. Factors such as optimism and hardiness can play key roles in adjustment to illness (Taylor, 1990). In particular, the personality characteristics of optimism and pessimism (defined as generalized expectancies of good versus bad outcomes) have been found to have a direct impact on adjustment, as well as impacting on health outcomes through the differentiated use of coping strategies (Chang, 1998; King, Rowe, Kimble & Zerwic, 1998). In particular, optimists generally use more problem-focussed coping strategies in the face of stressful situations, while pessimists generally use emotion-focussed strategies such as denial or withdrawal (Chang, 1998). In a recent study examining optimism/pessimism in the context of Lazarus and Folkman's stress, appraisal and coping model, Chang proposed that optimists and pessimists differ at the secondary appraisal stage, with optimists taking the time to consider the options and resources available to them and pessimists simply withdrawing from the situation.
Another characteristic that has been found to impact adjustment is Kobasa's concept of hardiness. According to Kobasa, Maddi and Courington (1981), hardiness is comprised of three components: commitment, control, and challenge. Hardy persons are said to have curiosity and find experiences interesting (commitment), they believe that they can change or influence events (control), and they regard change as normal and important for development (challenge). Altogether, such an outlook helps to reduce the stress of situations. As with optimism, hardiness has been found to have a direct impact on health outcomes, as well as influencing a person's appraisal of stressful events and their subsequent use of coping strategies (Manning & Fusilier, 1999). As such, it would be interesting to include them in future studies to assess their contribution to adjustment and QOL in CFS patients.

Limitations

This study is limited in its correlational and between-subjects design rather than a within-subjects approach. Such approaches do not allow for a conclusion of causation. Thus, while the study shows relationships among the variables, cause and effect relationships were not established.

This study is also limited by the nature of the sample used. Although every attempt was made to obtain a representative sample of CFS patients, random sampling was not possible. All participants were volunteers and were likely more motivated than people who were not willing to participate. In addition, many participants were being seen and treated by physicians specializing in CFS. In this respect, this is not a typical sample of patients who were facing the
disbelief of the medical community. Also, participating in this study required a certain level of energy; participants who were fatigued to the point where they were bedridden were not able to participate in this study. This suggests that participants in this study were less ill than a representative CFS population. Although the demographic characteristics of this CFS population were consistent with those of populations in other studies, care should be taken in generalizing the results to all CFS patients.

A further limitation lies in the measures used. In particular, the social support measures did not allow participants to endorse items differently for different social groups. Participants reported difficulty responding to items, stating that their answers differed for friends and family members. For example, they may have received considerable support from family, but almost no support from friends. Some participants reported averaging out their answers, which likely masked their true perception of support had they filled out separate questionnaires for the different people in their social network. Other participants chose either friends or family, and responded accordingly.

Participants also reported difficulty responding to items on the PAIS-SR with respect to the Health Care Orientation domain. Items for this domain address a person's attitudes toward medicine and doctors in general, as well as attitudes towards and expectations regarding the person's own physician, and the treatment and information provided. Better adjustment in this domain was associated with being satisfied with the information and quality of the care received, and with patients' beliefs that the doctors can provide adequate
treatment. This seems to make the assumption that the disorder is treatable and that adequate information is available. Unfortunately, this is not the case with CFS. Many participants in this study commented that the items on this scale did not reflect their views on their health care. Specifically, the majority of participants believed that their doctors were giving them all of the information they had on CFS and were using the most up-to-date treatments available, but they were dissatisfied with the overall lack of information and effective treatments for the disorder. They did not blame the doctor for this, and therefore had difficulty endorsing items.

Clinical Implications

Despite its limitations, this study provides valuable information about CFS patients that could be directly applicable to individuals in treatment programs. One of the most salient findings of this study is the impact that perceived negative support has on the QOL and psychosocial adjustment of individuals with CFS. For the majority of people this manifests itself in the form of disbelief in the validity of the illness, and subsequent blaming of the patients for their experienced disabilities. Such attitudes can have a significant impact on a CFS patient's level of emotional distress, their adjustment in a number of areas of their lives, and their willingness to seek assistance from health care professionals. Psychologists have much to offer individuals suffering from chronic illnesses in terms of helping them learn to cope with the illness; unfortunately, many CFS patients are unwilling to seek such assistance for fear they will be blamed for causing their own illness. As such, one of the most
important components of treatment with CFS patients would be the presence of a non-judgemental clinician who is willing to work with the patient to enhance their perception of support. Clinicians can also assist CFS patients in learning how to respond effectively to the lack of understanding and support they encounter in their daily lives. It may also be helpful to include significant others (family, friends) in treatment sessions to educate them on the impact a chronic illness such as CFS can have on not only the patients' lives, but their own lives, and to provide suggestions for coping appropriately with conflicts that may arise as a result.

Results from this study also suggest that an important component to treatment with CFS patients is assisting them in gaining some control over certain aspects of their disorder, in particular through the use of problem-focussed coping strategies. Focussing individuals on practical solutions to certain problems can help them gain a sense of control. For example, teaching CFS patients to prioritize tasks and use time-management skills may alleviate the sense that they are overwhelmed and must complete all tasks when they are feeling somewhat better. Memory strategies such as those used for individuals with head injuries or dementia may be effective in helping CFS patients cope with the cognitive dysfunction they experience. At the same time, individuals with CFS appear to benefit from recognizing that the control they have over their illness is limited, and should be encouraged to implement alternative coping strategies when appropriate.
Future Directions

Results of this study indicate that future research should examine more closely the impact of social support, coping style, and HLOC on QOL and ADJ in CFS patients. Issues such as who is providing what type of support and what types of support are needed at what stages of the illness are important to consider. In addition, it would be beneficial to examine coping strategies used by CFS patients more closely. The Illness Management Questionnaire designed by Ray, Weir, Stewart, Miller & Hyde (1993) is a promising assessment tool that assesses problem-focused ways of coping with CFS across four factors: maintaining activity, accommodating to illness, focusing on symptoms, and information-seeking.

Future research projects would benefit from examining social support, health LOC, and coping strategies utilized across different stages of the illness. In particular, Fennell (cited in Freidberg & Jason, 1998) proposed a 4-stage model of CFS which suggests that such variables differ widely depending upon the stage of the illness. For example, in early stages of the illness, individuals often deny their symptoms; support may or may not be present. In later stages, individuals may reassess their values and priorities and develop new standards of living, possible making new social connections for support (Freidberg & Jason, 1998). A systematic study of the model and how variables such as coping style, social support and health locus of control fit into it would add to the understanding of the CFS experience.
A further consideration for future research projects is method of recruitment of participants. Participants in this study were mainly recruited through general practitioners with a special interest in CFS. As previously discussed, the majority of CFS patients do not have such supportive doctors. Although readily available, research populations recruited through such physicians are therefore not necessarily representative of a typical CFS population as the support and level of medical care they receive may be different from that of other CFS patients.

A further consideration in recruiting participants concerns the diagnosis of CFS. Many medical personnel question the legitimacy of CFS as a medical disorder, and subsequently will not diagnose patients with the illness, even if their symptom pattern fits the CFS diagnostic criteria. Thus, recruitment methods aimed mainly at patients of physicians have a tendency to miss potential participants who have CFS but have not been formally diagnosed.

To address the abovementioned issues, future research projects may benefit from using other sources to recruit participants. In particular, given the lack of acceptance of CFS by the medical community, many CFS patients seek out the assistance of other health care practitioners such as homeopaths, chiropractors, or massage therapists to relieve their symptoms. Such practitioners may be able to refer potential participants for research projects. Another method of recruitment includes advertisements in newspapers and magazines that list the CFS symptoms and ask individuals to respond if they are interested in participating in a study. Such recruitment methods would allow for
a study of patients experiencing CFS symptomatology, but who may have not been formally diagnosed with CFS.
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Appendix A

Summary of Diagnostic Criteria for CFS

1.) Medically unexplained, relapsing fatigue for at least six months, which is of new or definite onset, not the result of ongoing exertion, not relieved by rest, and that results in a substantial decrease in levels of occupational, social, educational, or personal activities.

2.) Concurrent occurrence of 4 or more of the following symptoms, which must be persistent or recurrent during six or more months of the illness and do not predate the fatigue:

   1. Self-reported impairment of memory or concentration that is severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities.

   2. Sore throat.

   3. Tender cervical or axillary lymph nodes.


   5. Arthalgias (joint pain) without redness or swelling.


   7. Unrefreshing sleep.

   8. Post-exertional malaise, lasting 24-hours.
Appendix B

The Quality of Life Scale

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

1. Material comforts-home, food, conveniences, financial security......

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Health-being physically fit and vigourous.....

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3. relationships with parents, siblings & other relatives-communicating, visiting, helping.....

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4. Having and rearing children.....

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5. Close relationships with spouse or significant other....

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6. Close friends....

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7. Helping and encouraging others, volunteering, giving advice.....

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8. Participating in organizations and public affairs.....

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9. Learning-attending school, improving understanding, getting additional knowledge.....

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10. Understanding yourself-knowing your assets and limitations-knowing what life is all about.....

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11. Work-job or in home.....

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12. Expressing yourself creatively.....

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13. Socializing—meeting other people, doing things, parties, etc.…..

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14. Reading, listening to music, or observing entertainment…..

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15. Participating in active recreation…..

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16. Independence, doing for yourself…..

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APPENDIX C & D 122-133

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UMI
Appendix E

The Duke Social Support Index

Below you will find several questions about the people in your life and the support or help that they give you. Please read each question carefully and circle the response that best describes how you feel.

1. Other than members of your family, how many persons within one hour’s travel of your home do you feel you can depend on or feel very close to?

   1
   1-2
   >2

2. (Other than at work) How many times during the past week did you spend some time with someone who does not live with you? (that is, you went to see them, they came to visit you, or you went out together?)

   none
   once
   twice
   three times
   four
   five
   six
   seven or more

3. (Other than at work) How many times did you talk to someone (friends, relatives or others) on the telephone in the past week (either they phoned you or you phoned them)?

   none
   once
   twice
   three times
   four
   five
   six
   seven or more

4. (Other than at work) About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?

   none
   once
   twice
   three times
   four
   five
   six
   seven or more
5. Does it seem that your family and friends (i.e. people who are important to you) understand you most of the time, some of the time, or hardly ever?

   Most of the time   some of the time   hardly ever

6. Do you feel useful to your family and friends (i.e. people who are important to you) most of the time, some of the time, or hardly ever?

   Most of the time   some of the time   hardly ever

7. Do you know what is going on with your family and friends most of the time, some of the time, or hardly ever?

   Most of the time   some of the time   hardly ever

8. When you are talking with your family and friends, do you feel you are being listened to most of the time, some of the time, or hardly ever?

   Most of the time   some of the time   hardly ever

9. Do you feel you have a definite role (place) in your family and among your friends most of the time, some of the time, or hardly ever?

   Most of the time   some of the time   hardly ever

10. Can you talk about your deepest problems with at least some of your family and friends, most of the time, some of the time, or hardly ever?

   Most of the time   some of the time   hardly ever

11. How satisfied are you with the kinds of relationships you have with your family and friends...very dissatisfied, somewhat satisfied, or satisfied?

    very dissatisfied   somewhat dissatisfied   satisfied

(If you have no family of friends, would you say that you are very dissatisfied, somewhat dissatisfied, or satisfied with not having any of these relationships?)

    very dissatisfied   somewhat dissatisfied   satisfied
Now I want to ask you about some of the ways your family and friends help you out. Do your family or friends ever help you in any of the following ways:

<table>
<thead>
<tr>
<th>Do they....</th>
<th>NO</th>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. help out when you are sick?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13. shop or run errands for you?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14. give you gifts (presents)?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15. help you out with money?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16. fix things around your house?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>17. keep house for you or do household chores?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18. give you advice on business or financial matters?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>19. provide companionship to you?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>20. listen to your problems?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>21. give you advice on dealing with life’s problems?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>22. provide transportation?</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>23. prepare or provide meals?</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
Appendix F

The Social Support in Illness Scale

Think of the people in your life who are important to you. The questions below refer to feelings that you might have about them and about the ways that they respond to you now that you are ill. Please say to what extent each description applies, in your view, to the people in your life who are important to you by circling the appropriate number.

1. Can you lean on and turn to them when things are difficult?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

2. Can you get a good feeling about yourself from them?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

3. Do they put pressure on you to do things?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

4. Do they take over your chores when you feel ill?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

5. Do they express concern about how you are?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

6. Do they misunderstand the way you think and feel about things?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

7. Can you trust, talk to frankly, and share your feelings with them?

never   almost never   sometimes   quite often   very often   always
1        2             3             4             5             6

137
8. Can you get practical help from them?

never almost never sometimes quite often very often always
1  2  3  4  5  6

9. Do they argue with you about things?

never almost never sometimes quite often very often always
1  2  3  4  5  6

10. Do you feel they are there when you need them?

never almost never sometimes quite often very often always
1  2  3  4  5  6

11. Do they press you to say that you are feeling better?

never almost never sometimes quite often very often always
1  2  3  4  5  6

12. Do they listen when you want to confide about things that are important to you?

never almost never sometimes quite often very often always
1  2  3  4  5  6

13. Do they express irritation with you?

never almost never sometimes quite often very often always
1  2  3  4  5  6

14. Do they accept you as you are, including your "bad" as well as good points?

never almost never sometimes quite often very often always
1  2  3  4  5  6

15. Do they help out when things need to be done?

never almost never sometimes quite often very often always
1  2  3  4  5  6
16. Do they show you affection?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

17. Do they make helpful suggestions about what you should do?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

18. Are they critical of the way you respond to your illness?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

19. Do they do things that conflict with your own sense of what should be done?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

20. Do they give you useful advice when you want it?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

21. Do they express frustration with you?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

22. Do they treat you with respect?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6

23. Do they disagree with you about what is best for you to do?

never  almost never  sometimes  quite often  very often  always
1       2          3            4            5            6
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APPENDIX G 140-149

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Appendix H

The Multidimensional Health Locus of Control Scale-Form C

Each item below is a belief statement about CFS with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1. If my CFS worsens, it is my own behaviour which determines how soon I feel better again.

   Strongly disagree moderately slightly slightly moderately strongly
disagree disagree disagree agree agree agree
   1  2  3  4  5  6

2. As to my CFS, what will be will be.

   Strongly disagree moderately slightly slightly moderately strongly
disagree disagree disagree agree agree agree
   1  2  3  4  5  6

3. If I see my doctor regularly, I am less likely to have problems with my CFS.

   Strongly disagree moderately slightly slightly moderately strongly
disagree disagree disagree agree agree agree
   1  2  3  4  5  6

4. Most things that affect my CFS happen to me by chance.

   Strongly disagree moderately slightly slightly moderately strongly
disagree disagree disagree agree agree agree
   1  2  3  4  5  6

5. Whenever my CFS worsens, I should consult a medically trained professional.

   Strongly disagree moderately slightly slightly moderately strongly
disagree disagree disagree agree agree agree
   1  2  3  4  5  6

150
6. I am directly responsible for my CFS getting worse or better.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>agree</th>
<th>slightly disagree</th>
<th>moderately disagree</th>
<th>strongly disagree</th>
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<td>5</td>
<td>6</td>
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7. Other people play a big role in whether my CFS improves, stays the same, or gets worse.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>agree</th>
<th>slightly disagree</th>
<th>moderately disagree</th>
<th>strongly disagree</th>
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</table>

8. Whatever goes wrong with my CFS is my own fault.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>agree</th>
<th>slightly disagree</th>
<th>moderately disagree</th>
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</table>

9. Luck plays a big part in determining how my CFS improves.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>agree</th>
<th>slightly disagree</th>
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</table>

10. In order for my CFS to improve, it is up to other people to see that the right things happen.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>agree</th>
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</table>

11. Whatever improvement occurs with my CFS is largely a matter of good fortune.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
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<th>agree</th>
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</table>

12. The main thing which affects my CFS is what I myself do.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>agree</th>
<th>slightly disagree</th>
<th>moderately disagree</th>
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</table>
13. I deserve the credit when my CFS improves and the blame when it gets worse.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>slightly agree</th>
<th>moderately agree</th>
<th>strongly agree</th>
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</table>

14. Following doctor’s orders to the letter is the best way to keep my CFS from getting any worse.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
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<th>slightly disagree</th>
<th>slightly agree</th>
<th>moderately agree</th>
<th>strongly agree</th>
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</table>

15. If my CFS worsens, it's a matter of fate.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
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<th>slightly agree</th>
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</table>

16. If I am lucky, my CFS will get better.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
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<th>slightly agree</th>
<th>moderately agree</th>
<th>strongly agree</th>
</tr>
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</tr>
</tbody>
</table>

17. If my CFS takes a turn for the worse, it is because I have not been taking proper care of myself.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>slightly agree</th>
<th>moderately agree</th>
<th>strongly agree</th>
</tr>
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<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

18. The type of help I receive from other people determines how soon my CFS improves.

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>moderately disagree</th>
<th>slightly disagree</th>
<th>slightly agree</th>
<th>moderately agree</th>
<th>strongly agree</th>
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</table>
19. Is there anything else that I have not asked you about which may have an influence on your experience of CFS?

No ____
Yes ____ (please explain)
Appendix I

Description of Study

COPING AND ADJUSTMENT TO CHRONIC FATIGUE SYNDROME

Researcher: Janette M. Collier, B.Sc., M.A.
Doctoral Student in Adult Clinical Psychology
University of Windsor

Supervised by: Kathryn Lafreniere, Ph.D.
Associate Professor, Psychology Department
University of Windsor

Purpose: to investigate how CFS sufferers are coping with their illness and what they find helps them adjust to life with CFS, with the purpose of sharing this information with other health professionals.

Background: My interest in CFS began about 11 years ago when both of my parents contracted this disease. Over the years, I have noticed that much of the research on CFS has focussed on diagnosis, medical treatment, and cure. In the meantime, you are left to cope with the effects of this illness on your own. As with other chronic illnesses such as chronic pain, Lupus, or Multiple Sclerosis, CFS has a large impact on your life, and can lead to feelings of anger, frustration, sadness, grief, and despair. Family members, friends, and health professionals need to better understand what you are experiencing, and what is helpful to you in coping and adjusting to life with this illness. The present research project will examine the coping strategies that you as a CFS sufferer have found to be effective in adjusting to the illness.

What is Required of Participants: You will be asked to complete questionnaires designed to assess what you, as a CFS patient, find helpful in adjusting to life with CFS. You will also be asked to provide some background information, including age, marital status, duration of illness, and education level. NOTE: Your name WILL NOT appear on ANY forms, thus protecting your identity and assuring confidentiality.

It should take a total of 1-2 hours to complete the questionnaires. They can be completed across a number of days so as to not tire you out. The researcher is willing (and would prefer) to meet with you personally to explain the questionnaires, answer any questions, and provide assistance as needed. You can receive a copy of the results of the study, if you wish.
We would really like you to participate in our study! If you are interested in participating, or have any questions about the study, please leave your name with Dr. (doctor's name)'s office (phone number here) or contact Janette Collier directly at: (905) 883-7874 or e-mail: collier@aracnet.net

THANK-YOU FOR YOUR TIME!
Appendix J

Consent Form

You are invited to participate in a research investigation being conducted by Janette Collier, M.A., under the supervision of Dr. Kathryn Lafreniere of the Psychology Department of the University of Windsor for Dissertation research. The main purpose of this study is to identify some of the factors that help Chronic Fatigue Syndrome (CFS) patients cope with and adjust to their illness.

This study will involve you filling out several short questionnaire measures related to how CFS patients react to and cope with their illness. Some background information about you will also be collected (e.g. your age, education level, and length of illness). Altogether, it is estimated that this should take one to two hours of your time.

Your participation in this study is strictly voluntary. You can stop filling out the questionnaires at any time, and you can refrain from answering any question that you do not wish to answer. We would, however, prefer that you fill out as many of the questionnaire items as possible, as a large number of unanswered items may mean that we will not be able to use your data.

All information gathered in this study is completely confidential. Your name will NOT appear anywhere on the questionnaires. You will be enclosing one copy of this consent form in a sealed envelope separate from your questionnaires, so there will be no way to identify them. The second copy of the consent form is for you to keep for your own records.

If you are interested in the results of this investigation, a copy of the report will be available in the Psychology Department at the University of Windsor by the year Fall, 1999. In addition, please feel free to contact either Janette Collier (905-883-7874), or Dr. Lafreniere (1-519-253-4232 ext. 2233), if you have any questions about this study.

This research investigation has been approved by the Ethics Committee of the Psychology Department, University of Windsor. Any questions or concerns regarding the procedures or ethics of this investigation may be directed to:

Dr. Sylvia Voelker, Chair
Psychology Dept. Ethics Committee
University of Windsor
(519) 253-4232 ext. 2249
I, ________________, (please print name) have read and fully understood the information above, and agree to participate in this research study.

Please sign here: ________________

Date: ___________
VITA AUCTORIS

Janette Marie Collier was born on November 27, 1968 in Scarborough, Ontario. In June, 1987 she graduated from Francis Libermann Catholic High School in Scarborough and in the following September she enrolled at McMaster University in Hamilton, Ontario. She graduated summa cum laude with a Bachelor of Science Degree, Honours in Psychology in May, 1991. In September, 1992, Janette enrolled in the Graduate Program for Clinical Psychology at the University of Windsor. She completed her Master's Degree in August of 1994 and began her doctorate. In May, 1997, Janette married, and while completing her Doctorate gave birth to her first child, Alexander William in December, 1999. She successfully completed her doctorate in July, 2000.