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Chronic fatigue and immune dysfunction syndrome: its relationship to underlying emotional and psychological issues

Terri Lynn Alberts

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CHRONIC FATIGUE AND IMMUNE DYSFUNCTION SYNDROME:
ITS RELATIONSHIP TO UNDERLYING EMOTIONAL
AND PSYCHOLOGICAL ISSUES

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Terri Lynn Alberts
June 1997
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Approved by:

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ABSTRACT

This post-positivist research study explored the possible relationship between Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and the presence of underlying psychological and emotional issues. An exploratory design with naturalistic methods of inquiry was utilized to investigate whether the presence, or absence, of these issues had any impact on the overall disease process. Data gathered from interviews with CFIDS patients was analyzed utilizing qualitative methods into categories of information which provide new knowledge pertaining to the CFIDS disease process. Participants reported a variety of emotional and psychological issues both prior to and after their CFIDS diagnosis, particularly in the areas of family of origin/childhood experiences, significant life events/experiences, and living with the disease after diagnosis. While definitive answers could not be derived from this exploration, information gathered provided many possibilities for future studies and important implications for the social work profession. Of primary concern was the recurring theme of stress and its impact both prior to and after diagnosis. It is hoped results of this study will not only stimulate continued research, but also inspire practitioners to develop better advocacy, resources, and services for CFIDS clients.
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INTRODUCTION

Medical technology, over the course of this century, has greatly increased. Yet modern medicine continues to struggle to keep up with the growing demands of the ever-increasing number of viral and immune deficient diseases that continue to affect human populations throughout the world. With this in mind, the nature and cure of these illnesses continues to be a priority for research institutions, such as the Centers for Disease Control in Atlanta, Georgia. While much of the research has focused on the identification of new viral ailments, current research trends are taking more interest in the causes and conditions involved with the many viral diseases already discovered.

Problem Definition

Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), a disease affecting the immune system which mimics symptoms of many other debilitating illnesses, has held great interest in the medical community for the past two decades. It is a complex illness characterized by incapacitating fatigue (experienced as exhaustion and extremely poor stamina), neurological problems, and a constellation of symptoms that can resemble mononucleosis, multiple sclerosis, fibromyalgia, AIDS-related complex
(ARC), Lyme disease, and autoimmune diseases such as lupus. These symptoms tend to wax and wane but are often severely debilitating and may last for many months or years. As cited by the CFIDS Association of America (1995), when clinically evaluated,

CFIDS is diagnosed when the patient meets the following criteria:
A. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (i.e., not lifelong), is not the result of ongoing exertion, is not substantially alleviated by rest, and results in substantial reduction in previous levels of occupational, educational, social, or personal activities.
B. The concurrent occurrence of four or more of the following symptoms: substantial impairment in short-term memory or concentration; sore throat; tender lymph nodes; muscle pain; multi-joint pain without joint swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and post-exertional malaise lasting more than 24 hours. These symptoms must have persisted or recurred during six or more consecutive months of illness and must not have pre-dated the fatigue.

The case definition also describes several medical conditions which, if present, exclude the patient from a CFIDS diagnosis. Physicians perform "rule-out" testing, eliminating each of these conditions, thus leaving CFIDS as the diagnosis. Among these conditions are a primary psychiatric diagnosis, current or past, of a major depressive disorder with psychotic or melancholic features. Doctors must be cautious not to confuse this with the secondary depression that often accompanies the CFIDS illness.(p. 1)

All segments of the population, including children, are at risk, but women under the age of 45 seem to be the most susceptible (Cheney, Lapp & Bell, 1993).

Since it was first identified in the late 1970’s, CFIDS
has had an ongoing struggle with legitimization. Recent scientific discoveries which sought to isolate and identify the viral cause of the disease have had a great impact on the scientific community, yet many researchers continue to search for its underlying causes. Now that the primary medical factor, viral in nature, has been identified, what are the underlying causes that permit this virus to infect and debilitate the many people who suffer from its chronic symptoms? Answers to this, and other significant questions regarding CFIDS, continue to perplex medical researchers (Lapp, 1992; Buchwald, Cheney, Peterson, et al., 1992).

**Problem Focus**

With these questions in mind, this study sought to explore the underlying causes of CFIDS from a different frame of reference. While much of the current research into the nature and cause of this illness has been based on standard medical research designs, empirically founded and positivist in their approach, it is possible that psychological and emotional factors may have some impact on the CFIDS disease process. To study CFIDS from this perspective, this study performed research done from a qualitative frame of reference, focusing on the possibility that while empirical evidence has been helpful in determining the medical truths about CFIDS, there may be
knowledge about the illness that can never be fully understood using strictly an empirical framework. Utilizing a qualitative perspective enabled the researcher to study the causal factors of the disease from a frame of reference that takes into account the concept that while objectivity may be ideal, it may not always be possible to achieve, especially when dealing with the emotional and psychological factors of an illness such as CFIDS. Exploring new ideas about the nature of CFIDS and its underlying causes enabled the researcher to begin developing new theories pertaining to the illness. With this information, new treatment and possible cures for this disease may become more readily available.

While much of the current knowledge regarding CFIDS has been geared toward medically understanding the problem, this study suggested that emotional and psychological issues be explored as possible factors of the illness. It is feasible to assume, due to the recent literature linking the mind to physiological processes such as the immune system (Klimas, Salvato, Morgan, et al., 1990), that much of the disease processes occurring in the human body can be linked to emotional and psychological problems. It is interesting to note that CFIDS is characterized by depression, related to both the chronicity of the problem as well as to
physiological factors (Krupp, Mendelson, & Friedman, 1991). The purpose of this study was to explore and describe some of the underlying emotional and psychological issues suffered by CFIDS patients. In so doing, it is hoped that the information obtained is relevant in helping to produce new theories pertaining to the CFIDS disease process, and that a better understanding of the emotional and psychological components of the illness will result.

It is important that social work practitioners understand the role they may play in serving clients who suffer from CFIDS. What causes or adds to the depression and other emotional problems that current research indicates CFIDS patients suffer (CFIDS Association of America, 1995)? While definitive answers may continue to elude researchers, it is important that practitioners be educated and informed regarding the possibilities that CFIDS patients may have underlying emotional problems that need to be resolved. In the direct practice arena, seeing clients in a clinical setting for emotional and psychological problems are matters that practitioners must constantly face. Due to the fact that many CFIDS clients present with physiological symptoms when dealing with emotional and psychological issues, it is important for practitioners to understand how these affect the CFIDS client. Underlying emotional and psychological
problems can often manifest as somatic symptoms, thus practitioners must learn to delineate between typical physiological symptomatology and treating the client's emotional and psychological issues.

Other factors regarding the significance of research into the causes of CFIDS include mezzo and macro practice arenas. Many CFIDS patients become debilitated to the point of being unable to perform at jobs on a consistent basis. This renders many of these patients incapable of providing for their own well-being, and many have ended up on welfare, state and federally subsidized medical assistance programs such as Medi-Cal and Medi-Care, and for those who are unable to work for extended periods of time, Social Security Disability. Knowing that CFIDS patients may at one time or another become recipients of social services, it is imperative that practitioners understand the nature of the disease and the consequences it has on individuals who are afflicted by it, both mentally and emotionally, as well as physically.

**LITERATURE REVIEW**

A review of the literature pertaining to CFIDS research reveals that few studies have been done regarding the emotional and psychological aspects of the illness. Kruesi, Dale, and Straus, in their 1989 study, found that the rates
of psychiatric illness in patients with CFIDS was higher than that of non-CFIDS control subjects. Friedberg & Krupp (1994) did a comparative study utilizing cognitive behavioral techniques to treat CFIDS and primary depression. Quality of life in CFIDS patients was studied by Schweitzer, Kelly, Foran, Terry, and Whiting (1995), where it was determined that patients were significantly impaired, both mentally and physically, by the CFIDS virus. There have also been many medical model studies done regarding the physiological aspects of the disease, but most have dealt with efforts to identify and isolate a causal virus (Bell, 1989; Bell, 1992; Briggs & Levine, 1994; Cheney, Lapp, & Bell, 1993; Levy, 1994).

Are there CFIDS patients who present with underlying, unresolved emotional and psychological issues? While significant research has been done regarding the degree to which patients are physically impaired by the illness, there has been little, if any, research done regarding the nature of underlying emotional and psychological issues for CFIDS patients (Niebuhr & Marion, 1987; Goldstein, Mena, & Lesser, 1993; Hickie, Lloyd, Wakefield, et al., 1990). Because of the nature of the illness, and the physiological depression that accompanies it, it is feasible that underlying emotional and psychological factors in CFIDS
clients will continue to go unnoticed simply because they are masked by the general physical symptoms of the disease. Possibly, to some degree, this has already occurred. It is vital that practitioners begin to explore the emotional and psychological aspects of CFIDS clients from a perspective that encompasses the possibility that family of origin or other underlying issues may confront these clients. Without this perspective, clients may continue to suffer for years from emotional and psychological issues that go untreated simply because they are labelled under the umbrella of physiological symptoms. For this reason, this study sought to explore CFIDS based on the following preconceived perspective: the possibility that CFIDS clients may suffer from underlying emotional and psychological issues that exist separate from those experienced due to the nature of the disease, such as the physiological depression experienced by many CFIDS clients. It is from this foundation that this current study was based, and it is hoped that new knowledge and theories will be generated as a result of its findings.

RESEARCH DESIGN

This study adopted the post-positivist paradigm, which allows the researcher to discover theory about the research topic. The project utilized a research design known as
Grounded Theory Approach, which is based on inductively building theory through the qualitative collection and analysis of data. Unlike positivism, where literature review, data gathering, and analysis take place in a structured manner, grounded theory incorporates and intertwines these processes. Rather than focusing on a stringent design that involves a step by step process, this post-positivist design focuses more on the data collection and analysis involved in doing research. This allows the foundation of knowledge to broaden and expand as more information is collected, and is one of the greatest strengths of grounded theory design. The fact that research is viewed as an opportunity to create new knowledge, and that this knowledge may be utilized immediately, even by the project that generates it, is the essence of creative research. This feature of grounded theory challenges researchers to consider the prospect of discovering new information that could be transforming in its acquisition. Information gathered from each participant influences the collection of data with the next participant. This type of study has the ability to change focus during the course of data collection, and lends itself well to exploratory studies. It attempts to synthesize social theory, practice, and research, utilizing research as the lead agent. Rather
than viewing them as separate enterprises, it emphasizes the link between research and practice.

While this type of design is creative in its process, it can also present difficulties for researchers who choose to utilize it. Data collection, qualitative in nature, is exciting to compile, but often difficult to organize and analyze. With this in mind, all data collected in this study was done via interviews, with information organized through use of the methods described in the analysis section. Organization of collected information occurred after each interview was completed to ensure that data analysis was ongoing and complete.

**Characteristics And Size of Sample Population**

The population studied was taken from the general population in the Riverside and San Bernardino County areas. The sample population included 18 persons who had been diagnosed as having CFIDS, and were either currently or have previously suffered from the standard criteria of symptoms utilized in the diagnosis process. Utilizing field research as the primary source of information, the life events, roles, relationships, group participation, and general psychosocial histories of participants were the foci of the design. Who was affected, where they are living, what has changed or altered their lifestyle patterns, and how these
may have been impacted by family of origin issues, were all pertinent in the population study. The sample population of CFIDS patients was obtained from local CFIDS support group meetings, as well as by snowball sample techniques. They were contacted directly at CFIDS support group meetings, as well as by phone, to set up interviews. The CFIDS patients were studied to explore the relationship, if any, unresolved emotional and psychological issues have for persons diagnosed with this disease.

While the qualitative design described above is suitable for this study, it is not without limitations. Due to the fact that both physiological, as well as extenuating emotional and psychological factors may affect the outcome, it may have been difficult to tease out which variables had the greatest effect on study results. It is also possible that the population chosen may have had some limitations: as mentioned earlier in the problem definition, CFIDS is a disease that is difficult to diagnose. The symptomatology associated with CFIDS tends to mimic that of other related illnesses, and as a result, many patients are misdiagnosed or go undiagnosed (CFIDS Association of America, 1995). To prevent complications of this nature in the course of this study, patients were screened by asking for date of diagnosis and the name of the diagnosing primary care
physician. For the purpose of this study, it was presumed this medical information was valid for verification of diagnosis.

**Sampling, Data Gathering, and Measurement**

In an exploratory, qualitative design, the approach used for sampling, data gathering and measurement is not as easily explained as methods used in quantitative studies. Strategies involve the use of life events, as described by the participants: practices or behaviors, roles, and relationships experienced by these individuals. This type of information does not lend itself to a probability approach. Thus, the sampling techniques chosen for this CFIDS study were based on a non-probability sampling method known as convenience sampling, as well as that of snowball sampling, which relies on participants to lead researchers to others who may qualify for the study. The sample population was derived as a convenience population from individuals attending CFIDS support group meetings, as well as a snowball population obtained by asking members of the support group to identify any other CFIDS patients who might be willing to participate. In this manner, respondents were drawn from the general population for data collection.

The study was designed around an exploratory method, using qualitative data gathered by face-to-face interviews.
Each interview was conducted individually, consisting of the participant and researcher only. In order to ensure confidentiality and to reduce the possibility of restraint on the part of the participant, the interviews took place in a private location with no external observers present. Data gathering techniques for this study involved the use of an inductive approach utilizing open-ended questions, thus enabling the researcher to gather information that may not otherwise have been readily accessible with a standard questionnaire format. The following questions are examples of the style and type of questions that were standard for each interview:

1. Tell me a little about the circumstances surrounding your diagnosis: how you first came to realize you had CFIDS, when you were diagnosed (and by whom), and any treatments you may have tried.

2. What have some of your symptoms been like since you were diagnosed? (May refer to some of the current symptomology as listed by the AMA) Physical symptoms? Emotional effects? Any changes in lifestyle?

3. What do you consider to be the most difficult thing about living with CFIDS? Have you had to
make any major changes in your life since your diagnosis? Any changes in work, relationships, social activities, etc?

4. Have you experienced any psychological or emotional problems since your diagnosis? Any problems with depression, anxiety, or mood swings? If so, did any of these exist prior to your diagnosis with CFIDS?

5. Tell me a little about what your life was like prior to your CFIDS diagnosis. Were you more active physically? Better able to concentrate? Did any of your primary relationships change as a result of your diagnosis?

6. Tell me about your childhood experiences. Any physical or medical problems you may have experienced as a child? Did you have typical childhood illnesses, such as chicken pox, etc. Were there any specific family, social, or emotional difficulties during childhood?

7. Describe your family constellation: Brothers, sisters, extended family members, etc. Describe your relationship with each of these family members, whether you were close, etc.

8. Describe the life events surrounding your
diagnosis, and any other life experiences that may have seemed significant.

These are examples of the types of questions in a semistructured format that were utilized by the researcher to encourage conversation with the respondent regarding their illness and the circumstances surrounding their diagnosis. By engaging participants in an interactive process, the interview allowed respondents to expand on or share additional information as necessary. The questions were asked by the researcher according to the qualitative approach, and questions were asked, changed, or omitted as the interview required.

Interviews with CFIDS patients were arranged in advance via contacts made through CFIDS support group members willing to participate. Basic questions were asked, and observations were organized and analyzed as the data was collected. Careful notes were journaled during the interviews, along with audio-taping sessions, when permitted by the participant, to ensure collected information was recorded correctly.

**Protection of Human Subjects**

Prior to each interview, participants were asked to sign informed consent statements. These forms, upon completion, were removed from the interview process, thus
leaving no connection between the participants and their interview. The individuals were assured of confidentiality and anonymity. Prior to the interview, each participant was informed of the purpose of the research, the voluntary nature of their participation, and the promise that the interview could be terminated at any time if the participant should so desire.

**Analysis**

Data collected through the process of interviewing was analyzed utilizing qualitative methods. Procedures included "open coding" techniques and the use of "categories" to implement inductive analysis. Data was first conceptually processed by labeling phenomena that occurred during the interviews. This information was then further grouped into categories, and initial proposed relationships begin to take shape. As indicated, this phase of the open coding process was further processed by dividing categories into subcategories. Once coded and named, categories and their related subcategories were developed in terms of their properties. Once these characteristics, or properties, were identified, they were further processed by dimensionalizing them along a continuum. As information from the interviews ranged from specific to general, coding interview questions, answers, and observations was done in a line-by-line format.
This enabled the researcher to utilize the maximum amount of data collected.

The specific method utilized for the process involved a style similar to the one described by Lincoln & Guba (1985) in *Naturalistic Inquiry*. In this "constant comparison" method, the process advocated by Glaser and Strauss (1967) is utilized in a strategy that combines inductive category coding with a simultaneous comparison of all the social incidents observed during the course of data collection. As various social phenomenon are recorded, they are at the same time compared across categories to other recorded phenomenon. The discovery of relationships between these units of information is primary to the generation of hypotheses regarding the data collected. With this type of analysis, the process of generating hypotheses involves an on-going and continuous process throughout the entire time of data collection. As new information is received and coded, new categories may appear that will then affect the next attempt at data gathering. Thus, new information continually feeds back into the process of category coding, and as new events or information are recorded, new relationships may also be discovered, thus it is a means for deriving (grounding) theory, as well as analyzing data. In this fashion, data collection and analysis become a
simultaneous process in which each new unit of recorded data affects future data collection and analysis.

For the purpose of this study, the researcher began with a line-by-line analysis of interview information. Each concept was transferred to index cards and filed into categories based on the similarity of content. Each file of index cards was labeled and all new index cards were compared to previous cards and categories. As cards were coded and categorized, the researcher also kept notes regarding the properties of the categories: how they related to each other and how they might be utilized to develop theory. This second phase, involving the integration of categories and their properties, began the process of explanatory theory. Next, the researcher sought to delimit the theory, reducing the number of categories and limiting the focus to include only what was relevant to the established categories. The final phase involved the actual development of theory based on the findings of collected and categorized data.

It is important to note that all participants were given an identification number, and their responses were matched with their given number. This system ensured that coding could be tracked for an audit trail to the participant who gave the response, and also guaranteed
Efforts were made to maintain a theoretical sensitivity during the coding process. Questioning was utilized to ensure that information derived during data collection and analysis was free of biases, assumptions, and previously established patterns of thinking. As previously mentioned, inductive reasoning was encouraged by ensuring information was processed through the use of comparisons, especially the comparison of categories. This stimulated locating and identifying relational aspects of the gathered data.

The basic concepts obtained through open-coding analysis help to provide the researcher with information regarding possible underlying causes for CFIDS. By utilizing this qualitative approach, the researcher sought to develop preliminary theories regarding the presence of CFIDS and unresolved emotional and psychological issues. While correlation is not possible, the information obtained regarding these issues and their relationship indicate that findings from this study will hopefully stimulate further research into the impact of emotional issues on human health, and also help to reveal new possibilities for diagnosing and treating CFIDS patients. The implications of these findings could help medical professionals expand their resources for treatment to mental health professionals. The
reverse could also be implied in that mental health professionals could become better educated in understanding that many of their clients may be experiencing symptoms that could be directly linked to medical problems such as CFIDS.

The possibilities for further research, based on the findings of this exploratory design, are extensive. Establishing the nature of relationship between CFIDS and the presence of unresolved emotional and psychological issues, or uncovering some of the underlying emotional and psychological components of the illness itself, could prove helpful in developing improved diagnostic and treatment practices. It is hoped that the information obtained from this research project will create additional knowledge and stimulate further interest in the possibility of such a relationship.

RESULTS

Demographics

Research study participants ranged from 18 to 67 years of age, with a mean of 48.77 years, and a mode of 53 years. One third of all participants (33.3%) fell between the ages of 49 and 58 years of age, with approximately one fourth (27.8%) between the ages of 39 and 48 years of age. The next largest proportion of participants were between the ages of 59 and 68 years of age, with the remaining
participants ranging between 18 to 38 years of age. Refer to Table I for specific statistical information based on age.

### TABLE I

<table>
<thead>
<tr>
<th>Age</th>
<th># of Participants in Range</th>
<th>% of Participants in Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 - 28</td>
<td>1</td>
<td>5.6%</td>
</tr>
<tr>
<td>29 - 38</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>39 - 48</td>
<td>5</td>
<td>27.8%</td>
</tr>
<tr>
<td>49 - 58</td>
<td>6</td>
<td>33.3%</td>
</tr>
<tr>
<td>59 - 68</td>
<td>4</td>
<td>22.2%</td>
</tr>
<tr>
<td>Totals :</td>
<td>18</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Gender was noted by a significant trend, in which 16 of the 18 participants (88.9%) were women, with only two men (11.1%) represented in the sample population. Of the eighteen participants interviewed, five mentioned they knew of males who had been diagnosed, but they were not currently attending support group meetings at the time of this study.

### TABLE II

<table>
<thead>
<tr>
<th>Gender</th>
<th># of Participants</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>16</td>
<td>88.9%</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>Totals</td>
<td>18</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Ethnic groups represented in the sample population included Caucasian, Hispanic, African-American, and Asian.
The majority of participants were Caucasian (66.6%), followed by Hispanic (22.2%), with the remaining groups, African-American (5.6%) and Asian (5.6%), each represented similarly in the sample population.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th># of Participants</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>12</td>
<td>66.6%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>4</td>
<td>22.2%</td>
</tr>
<tr>
<td>African-American</td>
<td>1</td>
<td>5.6%</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>5.6%</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>18</strong></td>
<td><strong>100.0%</strong></td>
</tr>
</tbody>
</table>

Most of the participants had been diagnosed within the last two years. The mean length of time since diagnosis was 4.7 years, with a mode of 2 years. All participants (100%) noted that symptoms and related illness had been problematic for quite some time prior to diagnosis.

Occupation and current work status showed a significant trend in the number of participants who were unable to perform in jobs that required full-time status (40 or more hours per week.) Only two of the participants (11.1%) were currently working in full-time positions. One participant (5.6%) worked part-time, two (11.1%) were retired, and four (22.2%) were not employed, a decision made by personal
choice. A total of nine participants (50%) were completely unable to work due to their CFIDS illness. Of these individuals, six (33.3%) were currently on long-term Social Security Disability and three of the participants (16.7%) had claims pending.

<table>
<thead>
<tr>
<th>Hours Worked</th>
<th># of Participants</th>
<th>% of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Time (40 hrs)</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>Part Time (10-20 hrs)</td>
<td>1</td>
<td>5.6%</td>
</tr>
<tr>
<td>Retired (0 hrs)</td>
<td>2</td>
<td>11.1%</td>
</tr>
<tr>
<td>Unemployed (0 hrs)</td>
<td>4</td>
<td>22.2%</td>
</tr>
<tr>
<td>Disabled due to CFIDS</td>
<td>9</td>
<td>50.0%</td>
</tr>
<tr>
<td>Totals</td>
<td>18</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Based on the sample population studied, a typical participant profile would be a forty-eight year old female Caucasian, currently disabled due to CFIDS, who has been diagnosed within the past two years, with symptoms in existence for some time prior to diagnosis.

**Living with CFIDS**

Information gathered regarding the effect of CFIDS on the participant’s lifestyle was based on questions regarding diagnosis of the disease, the participant’s experiences both prior to and after diagnosis, and the overall effect of the illness on the participant’s ability to function.

Participants provided a wealth of information regarding
the circumstances surrounding their diagnosis. Many indicated the problem of finding doctors who would "take them seriously," indicating the struggle many CFIDS patients face in trying to determine what was wrong. Two respondents (11.1%) noted that they had sought medical help for nearly five years prior to receiving the CFIDS diagnosis. A long wait prior to diagnosis is not uncommon among CFIDS patients, and results from this study indicate that while some participants (four) were diagnosed within several months, many (12) went from doctor to doctor in an effort to determine what was wrong and/or understand the deterioration in their physical health. Six respondents (33.3%) indicated they had been diagnosed with other illnesses, such as fibromyalgia, multiple sclerosis, Lyme disease, and autoimmune disorders such as lupus, prior to receiving a final diagnosis of CFIDS.

Participants reported symptoms prior to and after diagnosis that reflect the current diagnostic criteria established in 1994 by the Centers for Disease Control and published in the December 15, 1994 issue of the Annals of Internal Medicine (See criteria list under Problem Focus heading). While there is still no definitive diagnostic test for CFIDS, diagnosing the illness requires a thorough medical history, physical and mental status examination, and
laboratory tests to identify underlying or contributing conditions that require treatment. Refer to literature review for a detailed description of the diagnostic criteria for CFIDS.

Participants in this study described symptoms consistent with those of the current diagnostic criteria, including persistent and debilitating fatigue, short-term memory loss, difficulties in concentration, tender or enlarged lymph nodes, sore throat, muscle and joint pain, sleep disorders such as insomnia, dizziness, unusual headaches, increased sensitivity to light, increased sensitivity to extremes of temperature, both very warm or very cold climates, and a general "flu-like" feeling that never seemed to improve, regardless of rest, medication, or other standard treatments. One participant stated, "No matter how much I rested, I always felt exhausted. There were times when I could not even take care of myself, much less my children. It was as if I constantly had the flu, without the vomiting or diarrhea problems. Everything else was the same: headache, low-grade fever, sore throat, and aching muscles."

Another respondent reported increased difficulty concentrating, stating that, "...I felt like I was losing my mind. Everything was so easily forgotten. My family teased
me, saying I was getting senile, yet I am only thirty-five years old." One of the male participants indicated that he would still be working, regardless of the fact that he is retired, but difficulty in concentrating made it nearly impossible for him to perform his job. He reported, "I would be leading an important (work-related) meeting, and couldn't even remember what the meeting was about." It was at this point that he made the decision to stop working. Several other participants reported similar job-related problems, and stated that cognitive functioning problems, such as memory loss and lack of ability to concentrate, were the reason they were unable to function in employment situations. One female stated, "It's one thing to make a mistake at home, like forgetting where I put my mail. It's another thing when bosses and co-workers are counting on you and you forget where you put their mail."

When asked what was the most difficult aspect of living with CFIDS, participants responded with a variety of answers which centered around three main areas: work/school related problems, personal relationship problems, and difficulties in dealing with changes in social activities. Ten of the participants (55.5%) stated that work-related problems were the most difficult aspect of living with the disease. Of these ten, only one was currently working part-time. The
remaining nine, as previously mentioned, were unable to work
due to CFIDS. Eight of these ten respondents indicated that
cognitive difficulties had created serious incidents in the
workplace. One female respondent stated that lowered
cognition prevented her from reading, a vital aspect of her
job in the field of public relations. Another female was
forced to leave a long-time career due to the fact that she
could no longer keep up with the deadlines, meeting
schedules, and other demands of a fast-paced publication
business. One male participant reported that his lack of
ability to work had created serious financial difficulties
for his family, and although his wife was able to support
the family on her income alone, he felt it had, "... become
a burden for her at times."

Similar statements were made by participants regarding
difficulties in their personal relationships. Five women
and one man indicated that they felt like a burden on their
spouses, and wished they could be less dependent on them for
help. Eight participants (44.5%) mentioned they experienced
marital problems since receiving their diagnosis, and two of
these stated they also experienced marital problems prior to
diagnosis. One female responded by stating that her
marriage had been difficult prior to diagnosis, but that,
"... it has become increasingly troubled since I became
Thirteen participants (72.2%) described strained relationships with siblings, in-laws, or other extended family members since they were diagnosed with CFIDS. In most of these cases, strain resulted from misunderstanding or lack of understanding regarding the nature of CFIDS and its impact on the patient. Ten of these thirteen participants expressed a desire for family members to become educated regarding the illness, thus alleviating the "unrealistic expectations" these family members placed on them. A primary trend among extended family members was the expectation that patients continue to function at the same level they had maintained prior to becoming ill. Misunderstanding regarding the debilitating effects of the illness was the number one reason 17 participants (94.4%) stated for strained personal relationships.

Participants also reported changes in social activity as a difficult aspect of living with CFIDS. Three females and one male stated that fatigue and chronic health problems, such as muscle and joint pain, prevented them from participating in social activities that they had enjoyed prior to diagnosis. One female had played a great deal of sports prior to diagnosis, and it was difficult to adjust to a sedentary lifestyle. She reported, "I miss playing sports
because a great deal of my social life rotated around my sports activities. I no longer can keep up with my golf buddies, and as a result, I tend to miss out on other things, such as lunch afterwards or breakfast on the weekends." Another female indicated that changes in her ability to function physically had also affected her social network. She stated that, "Several of my friends just stopped calling because I was always too sick to do anything."

Participants also discussed the emotional and psychological problems resulting from CFIDS. Some of these difficulties were often related to the previous section discussing changes in social activities. Depression due to long-term or chronic illness is not uncommon, and many CFIDS patients have reported it as a feature of the illness. Fourteen participants (77.8%) reported difficulties with depression after diagnosis, with two (11.1%) stating that depression had been problematic prior to diagnosis. Of the fourteen, twelve reported that lifestyle changes, especially a decrease in social activities due to the debilitating effects of the disease, left them feeling "isolated," and depressed. Changes in social functioning and activity, such as the loss of ability to work, inability to show up for social engagements, inability to keep up with family and
friends, and a lack of social contact were all described by participants as factors relating to depression. One female stated, “I was depressed about my total inability to show up for life. Every aspect of my life changed when I got CFIDS: work, school, friends, family, church, and community interests were all different because I couldn’t show up.”

Anxiety was also mentioned by several participants as a feature of the illness. Twelve of the eighteen participants (66.7%) described feelings of anxiety during the course of their illness. Four of these used the term “panic attacks” in relation to their anxiety, stating that much of what they feared was that they were dying. Six responded by stating that anxiety was the result of the long process they endured in order to obtain an accurate diagnosis. “I was scared because none of the doctors could tell me what was wrong,” reported one female. Another described feeling anxious because, “...none of these so-called experts (doctors) had any answers.” Two of the respondents related financial difficulties as the source of their anxiety. One female described laying in bed, wondering how she was going to pay her rent, saying, “I was terrified I would be thrown out on the street. I couldn’t work and my disability application was still not approved.”

The primary post-diagnosis psychological problem
reported by respondents was that of lowered cognitive functioning. All of the participants (100%) reported difficulty living with the effects of cognitive disabilities, either memory loss, lowered comprehension abilities, or a general "foggy headed" sensation. This concurs with previous CFIDS research in which lowered cognitive ability was discovered by researchers in medical model studies. Studies utilizing brain scans have revealed that many CFIDS patients have lesions in certain areas of the brain. Patients also manifest a lowered ability to perform on cognitive tests, as well as have difficulty with short-term memory loss (CFIDS Association of America, 1995; Cheney, Lapp & Bell, 1993).

Twelve of the eighteen participants (66.7%) reported having sought help for psychological or emotional problems prior to diagnosis. Of these twelve participants, eleven had received counseling at some point for marital problems. One male and one female each reported depression had been an issue at some point prior to diagnosis, but that the depression had been related to other circumstances. The male, a Vietnam Veteran, had been diagnosed with Post-Traumatic Stress Disorder due to service-related incidents. The female stated her depression was related to postpartum issues. Five participants sought professional help prior to
diagnosis due to some specific crisis situation in their life: two had been raped, another had difficulty adjusting to the pain resulting from a severe back injury, the fourth stated she sought counseling due to racial discrimination, and the fifth, a female, reported having received counseling after learning that her mother had shot and killed her father when he tried to end their marriage.

Four participants (22.2%) had received counseling prior to diagnosis due to childhood abuse issues: two females reported sexual abuse and another reported being physically abused as a child. The remaining participant, a female, reported severe verbal abuse as the reason she sought counseling prior to her CFIDS diagnosis, stating that both parents had been critical and verbally put her down for most of her childhood.

**Family of Origin/Childhood Experience**

Data regarding family of origin and childhood experiences of the sample population was primarily gathered through the use of genograms. Each participant was asked to describe or discuss their family constellation while the researcher utilized the information to construct a genogram depicting their family background.

Of the total sample population, sixteen (88.9%) stated that difficulties in their family of origin had caused
problems at some point in their adult lives. These individuals described their family life as being "troubled," and all of them utilized the term "dysfunctional" when referring to their family's interpersonal relationships. The remaining two participants (11.1%) described their family life as, "...a good childhood, it was very happy," and as, "My parents provided us kids with a loving family life." As mentioned previously, twelve of the sixteen who described problems in their family environments did seek professional help prior to diagnosis, either for these family of origin problems or for other issues. The remaining four reported that family of origin issues had been discussed in counseling they received after they were diagnosed with CFIDS.

In describing their family of origin experiences, data obtained from the participants fell into four main subcategories: parental marital problems; parental, sibling, or relative substance abuse problems; physical or mental disability in one or both parents; and the presence of physical, sexual, or emotional abuse in the home. In the category of parental marital problems, four participants stated that problems stemmed from their father's alcohol abuse. Five mentioned they were witness to many arguments in which one or both parents were verbally abusive to the
other. Six participants reported their parents divorced during their childhood, and the remaining three reported their parents' marriage was marked by domestic violence.

Parental, sibling, or relative substance abuse was listed by twelve of the participants as the primary family of origin problem. Four reported having alcoholic fathers, and eight mentioned either a sibling or close relative, such as an aunt, uncle or grandparent, was abusing a substance, primarily alcohol. Two of these participants from substance abusing homes also stated they later married alcoholic husbands. Of the twelve who stated substance abuse was a problem, three indicated that drugs were also abused by the addicted individual: one was a parent, one was a brother, and the third had an uncle who was abusing substances.

Seven participants (38.9%) stated that family of origin issues stemmed from the fact that one parent suffered from either physical or mental disabilities. Six of these seven respondents reported having a parent who suffered from depression, with one female stating that, "...basically my mother was depressed the whole time I was growing up." Another female responded by saying that her father had been physically disabled due to a work-related accident, and much of their family difficulties developed as a result of his inability to adjust to life in a wheelchair. "He became
angry, resentful...and took it out on us kids all the time."

Four of the eighteen participants (22.2%) described incidents of child abuse. Two females stated that they had been sexually abused, one by a relative, the other by a family friend. One described severe physical beatings she received from her father, usually when he was angry or drunk, stating, "He would beat me until I was bloody and all bruised up, then keep me home from school by telling the teacher I had fallen down the stairs." The fourth participant discussed severe emotional trauma she incurred as the result of being constantly put down by both her father and mother. She reported, "...my parents would tell me that I was a mistake, and that they wished they had never had me. They constantly told me I wasn't wanted, and often said that I was a waste of their time." She went on to report that as an adult she continues to suffer from a sense of inadequacy, low self-esteem, and general feelings of worthlessness which she feels stem from the self-perceptions she learned from her parents.

Participants descriptions of their family relationships fell into five specific groupings: their relationship with mother; relationship with father; relationship with siblings; relationship with extended family members; and the role they played within the family unit. Four stated their
mothers were critical, perfectionistic, controlling, or difficult to please. One female participant described her mother as, "...someone who was impossible to please. No matter how hard I tried to earn her approval, I always seemed to fall short." Another woman reported, "My mother expected so much of me. It seemed I could never do anything that satisfied her. I felt like I was trying to live up to her expectations, but just as I seemed to reach them, she'd change them." Three participants, all female, reported having very close, loving relationships with their mother. "My mom is my best friend," stated one female. Another said, "My mother and I are very close, and have always been there for each other." Two participants reported their mothers were verbally abusive, one of whom stated, "...she would compare me to other girls and say, "What do we have to be proud of in you?'" indicating her mother felt she had done nothing to make her parents proud of her.

Participants described several types of relational difficulties with their father. Ten (55.5%) reported their fathers were "cut off" from the rest of the family, a sort of emotional disengagement in which their father was present in the home, but emotionally uninvolved. All ten used the term "not really there" when describing their father's role in the family, and four of the ten reported having mothers
who tried to make up for their father’s lack of involvement. Four of the participants stated they had alcoholic fathers, three stated their father worked excessively and was rarely home, and five reported being afraid of their father due to his angry temper or abusive manner. One participant stated, “I was always afraid my dad would kill me one day. He used to get so angry over the least little thing.” She described her father’s temperament as, “explosive,” and said she felt frightened whenever he was home.

Five participants (27.8%) described relational problems among siblings. One stated that she had difficulty with her older sister because, “I always felt like I had to measure up to her.” Two described feelings of envy or jealousy with regards to a brother or sister. Another reported she felt she had always been in competition with her sister, and that her parents seemed to compare them to each other. Of the five participants with difficult sibling relationships, three stated that they still had a difficult relationship with that brother or sister.

Relationships with extended family members were also mentioned as sources of family of origin problems. Three female participants (16.7%) described having strained relationships with their in-laws, and four (22.2%) reported having problematic relationships with their grandparents.
Two (11.1%) mentioned they were currently not speaking to an aunt or uncle due to issues regarding care of their elderly parents. Of the total sample population, fourteen (77.8%) reported that difficult relationships with extended family members was largely due to lack of understanding regarding their illness. Of these fourteen, six indicated that relatives felt they were over-reacting or were not truly sick, especially since the onset of symptoms occurred several years prior to their diagnosis. Of these six, all six reported that these relatives still had difficulty accepting their illness.

When questioned regarding the role they played in their family of origin, three participants (16.7%) reported they had been "scapegoated" by their families, singled out as the constant problem child or blamed for many of the family's difficulties. Four of the female participants (22.2%) stated they had played a "fix-it" role in their family, where family members, parents as well as siblings, would turn to them for help, advice, or assistance. Of the total population, eleven of the participants (61.1%) indicated they had been "parentified" as a child, taking on the role of parent in caring for their other siblings. Four stated they had resented filling this role, and felt they had missed out on their own childhood by having to take on adult
responsibilities.

Respondents information regarding their childhood medical histories revealed that all of the participants (100%) reported having had the usual childhood illnesses, such as measles, chicken pox, mumps, etc. Four (22.2%) reported having had chronic asthma during childhood, and one (5.6%) reported that chronic bronchitis had been a problem. Two (11.1%) stated they had difficulties with allergies, and two of the females (11.1%) mentioned that menstrual problems had onset early in their development. One (5.6%) reported childhood medical bills had been high due to her exposure to chemical toxins. Another mentioned that she had been hospitalized frequently during childhood due to a kidney transplant she received at an early age. The most significant trend among participants involved the experience of frequent sinus infections during childhood: twelve of the 18 participants (66.7%) mentioned that they frequently suffered from sinus infections and had taken a great deal of antibiotics during childhood.

Significant Life Events/Experiences

When asked to describe any significant life events or experiences, participants offered a variety of responses. The data collected fell into the following sub-categories: deaths/losses of significant people, life-changing or
traumatic events, and life-stressors prior to and at the time of diagnosis of CFIDS.

Of the total population, sixteen participants (88.9%) reported they had been impacted by the death/loss of a significant individual at some point in their life. Seven participants mentioned the loss of their mother, with one male reporting that his mother had died when he was three months old. Five reported the death of their father, and one female indicated her father had been shot by her mother over divorce issues. Three participants mentioned the deaths of grandparents, two mentioned siblings who had died at an early age, and four stated they had been impacted by the death of an extended family member or friend. Regarding losses, twelve participants (66.7%) reported that significant losses occurred when they became estranged from friends or family members who could not cope with their CFIDS illness. Five (27.8%) reported that the divorce of their parents had been a major loss, and six (33.3%) reported their own divorce had resulted in feelings of loss. One female, who’s mother spent time in prison, indicated the absence of her mother had created a loss in her life.

Fourteen of the respondents (77.8%) indicated their lives had been impacted by the presence of a life-changing or traumatic event. One respondent reported having an auto
accident while driving under the influence of alcohol. Two friends were injured, and as a result of this, he chose never to drink alcohol again. Another male participant reported incidents that occurred during his service duty in Vietnam. He indicated these experiences changed his life dramatically, and as a result, he continues to suffer from problematic feelings of anxiety, depression, and panic attacks. Two females reported sexual abuse, and two reported incidents of rape: all four of these women stated these events had greatly impacted their lives, and each described feelings of anxiety and fear. One female stated, “I doubt I will ever forget the terror I felt when I was raped.”

One female indicated the death of her younger sister in a drowning accident had been traumatic, and another reported that her mother’s struggle with cancer had greatly changed her own life. Both described these incidents had left them feeling helpless, powerless, and afraid. One female reported her father’s extra-marital affair, and the resulting divorce of her parents, had greatly changed her life. One male respondent stated he had been traumatized during his Naval service when it appeared his submarine would not be able to resurface. He reported, “The fear I saw in the officers (in authority) over me made me feel even more afraid, because no
one seemed to know what to do.” One woman reported the loss of her business had been traumatic, leaving her with feelings of, “…helplessness and insecurity.” Another stated that her husband’s recovery from alcoholism had a life-changing effect for her, giving her a sense of hope in life that she had lost. Five participants indicated that spiritual experiences, both prior to and after their CFIDS diagnosis, had life-changing effects, filling them with the strength they needed to cope successfully with the disease.

To encourage participant reports of the various circumstances surrounding their lives, both prior to and during the time of their CFIDS diagnosis, the researcher utilized eco maps. The use of this format enabled participants to visualize their life situations just prior to and at the time they were diagnosed, with particular emphasis on various stressors. Analysis of this information resulted in sub-categories which described interaction with various components of their lives: family, extended family, friends; work/school; community groups; religious organizations; social supports/resources; and particular life-events.

The sub-category pertaining to family, extended family, and friends dealt with identifying stressful relational issues in each of these areas. Of the eighteen
participants, sixteen (88.9%) stated they had stressed or difficult relations with a particular family member or friend since they became ill. As many as twelve (66.7%) reported they were completely estranged from at least one individual.

With regards to work/school, ten participants (55.5%) described stress-related issues. Of these ten, the most common stressor was dealing with the ability to perform, which all ten stated created stress in their life, regardless of whether or not they were currently employed. One male participant represented the others fairly well when he stated, "The inability to perform in a job at the same capacity I had enjoyed prior to becoming ill was very difficult, and created a great deal of stress for me."

Responses in sub-categories pertaining to community groups and religious organizations were not as frequently cited. Five (27.8%) reported having to drop out of certain groups they had previously participated in. One participant (5.6%) was forced to drop out of a writer’s group that had been very important in her life. Two (11.1%) mentioned difficulty with members of their particular religious denomination, stating that people seemed cold and distant, and that they had expected more comfort and support. Another woman (5.6%) indicated this same experience, stating
that the lack of emotional support she had received from her religion had created a great deal of stress. One participant (5.6%) indicated she had gone through a "spiritual crisis" as a result of stress regarding her religious beliefs.

Participants reported similar stressors in the subcategory of social supports/resources. Four (22.2%) indicated that previous support networks, such as a women's group, or resources such as a counselor or therapist, became stressed during the course of their diagnosis and illness. One (5.6%) stated her women's group avoided her, and did not include her in their functions. Two (11.1%) stated that therapists they had been seeing prior to becoming ill had difficulty dealing with their illness and tended to minimize or doubt the reality of CFIDS. One participant (5.6%) reported that she terminated therapy as a result of this issue, stating that trying to explain or verify her poor physical health created more stress.

Participants provided a variety of responses regarding particular life events, all of which are covered under previous categories, such as family of origin issues, traumatic events, and living with CFIDS. It is important to note that while these responses were previously mentioned, the researcher found them significant enough to warrant
specific mention in this separate sub-category. Incidents such as having her father killed by her mother, the drowning accident of a sibling, the death of a close relative due to AIDS, rape, sexual abuse, auto accidents due to intoxication, and living with an alcoholic spouse, were reported by study participants. In addition, one participant mentioned that the death of his mother when he was three months old had been a particularly difficult life event. Regardless of his age, this man felt that it had, "definitely impacted his life." This same response was indicated by other participants who reported specific life events.

**DISCUSSION**

**Demographics**

In comparison to other CFIDS studies, the statistics on age gathered from this project reflect an age range that is older than that found among participants in previous studies. According to the CFIDS Association of America (1995), most diagnosed cases in the United States are between the ages of 25 and 45 years of age. In this current study, one participant (5.6%) fell below this 25 to 45 year age range, seven (38.9%) fell within this range, and ten (55.5%) were above the range. Thus, participants diagnosed with CFIDS in this study tended to be older than those of
previous studies. Several possibilities exist that may explain this discrepancy. First, participants, or referrals for other participants, were primarily from a support group in a geographic area that tends to attract retired individuals and couples. Second, sample size included a total of eighteen individuals, and it is possible that a broader sample size would have resulted in an age range similar to that indicated in previous studies. It is also possible that due to the use of snowball sampling techniques, participants tended to refer the researcher to individuals who were primarily their peers, thus sampling tended to produce a population that was largely similar in age to the first participants interviewed.

Demographics regarding gender taken from the sample population indicated more women than men had CFIDS. This is typical in comparison with other CFIDS studies, which indicate the majority of persons diagnosed are women (CFIDS Association of America, 1995). It is possible that men are not diagnosed as frequently for several reasons: men may not seek treatment as readily as women, there may be gender differences that render them less susceptible to the illness, and, due to the fact that the illness mimics many other physical ailments, men may be more frequently misdiagnosed. It is important to note that gender
differences may have occurred in this study due to the fact that participants were recruited via a support group network. It is possible fewer men participate in such groups, and thus the population gender may have been skewed.

Statistics in this study regarding ethnicity indicated that the majority of participants were Caucasian, followed by Hispanic, with a lower number of African-American and Asian participants represented. These findings reflect similar statistics from current CFIDS literature which states, "CFIDS strikes people of all ages, ethnic, and socio-economic groups (CFIDS Association of America, 1995)."

Although this study involved no specific controls for this variable, it is interesting to note that while previous findings indicate the disease effects all ethnic groups, the sample in this study included a fairly small representation of minority groups. This is possibly due to minority groups having less access to proper medical care, a lack of education and awareness of the disease among minority groups, or it could be related to the propensity of the disease itself.

The study indicates that statistics regarding duration of illness, or length of time since diagnosis, lend to the development of further questions regarding symptomatology. All participants indicated that symptoms had been present
prior to diagnosis, for some as many as two years or longer. Why is there such difficulty in promptly diagnosing CFIDS, and what can be done to improve the diagnostic process? Why does it take so long for full symptomatology to present, and what effect, both physical and psychological, does this long-term diagnostic process have on CFIDS patients? The feedback gained from individuals in this study indicate there was significant stress as a result of lengthy diagnostic procedures, leaving them both physically weakened and psychologically stressed. It is possible this is medically significant, and that a reevaluation of the current diagnostic criteria would be beneficial in relieving the emotional, psychological, and physical issues faced by individuals with CFIDS.

Occupational status among the sample population resulted in statistics indicating a high number of totally disabled individuals. Fifty percent of those interviewed reported a complete inability to work. Of the six who were unemployed by choice, four mentioned they were grateful to have that choice as they were not certain, due to their health, they could show up for a job regularly. The inability to work often creates not only financial issues and/or stress for individuals, but may also create emotional and psychological issues due to the stigma associated with
relying on public aid. This was particularly true for disabled participants who were younger. Those retired or older participants who were drawing Social Security Disability monies were less troubled by this stigma. Overall, the fact that half of the participants were completely disabled by CFIDS raises some interesting questions regarding the impact the resulting stress has on their ability to cope with the illness.

It is interesting to note that the typical respondent from this study fits previous literature profiles of CFIDS patients fairly well. According to the CFIDS Association of America (1995), the typical CFIDS patient diagnosed is female, between the ages of 25 and 45 years of age. Findings from this study indicated that a typical participant profile would be a 48 year old Caucasian female, currently disabled due to CFIDS, who had been diagnosed within the last two years. As previously discussed, age differences may have resulted for a variety of reasons. While current literature trends do not tend to cover demographics specific to ethnicity, socioeconomic status, or employment status, it is important to note that results from this study indicated that each of these areas may provide useful information in the diagnosis and treatment of CFIDS patients.
Living With CFIDS

As previously mentioned, stress created by the long process of diagnosis, as well as frequent misdiagnoses, such as being diagnosed as mentally ill, hypochondriacal, or being told that symptoms are only somaticization, often affect individuals with CFIDS. These findings are conducive with previous CFIDS literature which reports, “CFIDS is often misdiagnosed because it is frequently unrecognized and can resemble many other disorders... (CFIDS Association of America, 1995).”

The problems created by this additional stress may in and of itself create physiological, psychological, and emotional issues for patients, thus establishing a vicious cycle that is perpetually in motion. As mentioned, participants reported that finding doctors who would, “...take me seriously,” was a frequent comment among participants. The stigma of mental health labels or the remarks of “senile” or “losing your mind” can be hurtful to CFIDS patients, especially since many report that prior to diagnosis, they, too, feared they were “losing” their minds. Results from this study indicate that many participants are affected negatively by the long process of getting diagnosed, and the problems of misdiagnosis, that accompany the disease.
Participants described symptoms that were consistent with those cited in current CFIDS literature. As listed in the December, 1994 issue of Annals of Internal Medicine, "...substantial impairment in short-term memory or concentration..." is listed as one of the primary manifestations of CFIDS symptoms. All of the participants in this study reported difficulty with cognitive abilities, especially memory and concentration. Efforts to increase or improve these limitations often led participants to feel frustrated, anxious, and debilitated. Feelings of anxiety were most frequently reported by those who were still in the workplace, indicating that they feared losing their position due to debilitated cognitive functioning. Others stated they were "teased" or became the brunt of jokes due to their memory and concentration problems. Male participants were impacted with the loss of identity, job status, and performance issues due to their impaired cognition. Several participants felt these issues led to stigmatization, or that they were ostracized from previous social activities, such as bridge or chess, due to the cognitive difficulties associated with CFIDS.

Flu-like symptoms, another widely reported manifestation of CFIDS among participants, were also difficult to cope with. Those who suffered from chronic
low-grade fevers, chills, sore muscles and joints, tender lymph nodes, and an all-around sensation of having the flu, indicated that these symptoms were often not validated by the physicians who treated them. This was difficult to cope with, and left participants feeling "crazy" or "frustrated" because no one would "take them seriously." It is difficult enough to cope with the chronicity of the symptoms, let alone being told, "you've just got the flu." It is interesting that most of the participants reported experiencing these difficulties.

In discussing issues surrounding personal relationships, study findings indicate that participants experience a great deal of stress pertaining to marriage, extended family, and social networks. The number of participants who mentioned marital difficulties indicates a need to provide information and support for primary care givers. Those closest to the diagnosed individual often become the primary source of personal and social connections for the patient, and this can result in feelings of stress or a sense of being burdened for the care giver. CFIDS can be a socially isolating disease, as many people are not able to cope with the patient's inability to "show up for life," such as work, school, or social activities. Participants indicated that family members and friends were often
avoidant, stating that they stayed away because they did not know how to deal with their illness.

There were other factors that add to this sense of "alienation" described by participants in the study. The unknown origin of the CFIDS illness lends to the idea that patients are somehow "odd" or "peculiar." Until the Centers for Disease Control (CDC) or other research institutions can discover the cause of CFIDS, patients will more than likely continue to suffer from the questioning, skepticism, and suspicion of others who doubt the existence of the illness. This in turn creates further feelings of inadequacy, self-doubt, and insecurity in the individual with CFIDS. Without adequate care and support, it is possible that this will also result in further emotional and psychological difficulties for CFIDS clients.

Depression, frequently mentioned by participants as an aspect of life with CFIDS, was described as a secondary factor that seemed to manifest for a variety of reasons. Participants reported that loss, primarily losses incurred by their change in lifestyle due to the disease, were the primary cause for feelings of depression. The loss of job, school, professional aspirations, athletic activities, social activities, and the interpersonal contacts that each of these offered, were the reasons cited by many of the
participants that led to their depression. In addition, the disease of CFIDS itself often presents with a physiological depression by the way it affects the brain chemistry. This is difficult to cope with and participants found that the stigma associated with these difficulties were just as hard to live with. Depression and the stigma of taking anti-depressant medications was mentioned by several of the participants as a sort of "double whammy," in which they first feared being labeled as "crazy" due to CFIDS, and then must also cope with the same label in reference to treatments and medications utilized for the illness. Results indicated these issues often overlap in treatment.

Anxiety was also frequently reported by participants as a feature of living with CFIDS. While it is expected that a certain amount of anxiety would be experienced by any individual receiving a diagnosis of a long-term, chronic illness, many of the participants reported anxiety feelings that were more closely related to the ambiguities surrounding CFIDS. Several mentioned the fear they felt when their physicians indicated that medical science had yet to discover the cause of the disease, and that treatment was basically focused on managing symptoms, rather than providing a cure. Participants reported these "unknowns" regarding cause and cure of CFIDS left them feeling anxious
and helpless.

The presence of debilitating cognitive functioning, reported by all participants in the study, indicated that loss of memory and decreased ability to concentrate created both emotional and psychological problems for respondents. Several mentioned feelings of terror and anxiety surrounding the lack of ability to think clearly, inability to find the right words when speaking, or being unable to finish complete sentences, especially when dealing with job-related circumstances. Fearing they were losing their minds, these participants indicated that stress, tension, and avoidance was often the result of knowing they had to perform in work or social situations. These same features of CFIDS are commonly reported among diagnosed individuals, as indicated by previous studies (CFIDS Association of America, 1995). This indicates that chronicity of cognitive functioning, and the problems resulting from this feature of the illness, may need to be addressed early in the diagnostic process. Assuring individuals that they are not “crazy” or “losing their minds” and informing patients of these features early in their illness would greatly reduce the anxiety and stress caused when these conditions are not discussed.

The presence of emotional and psychological problems prior to CFIDS diagnosis reported among participants as an
added difficulty in dealing with the illness stemmed from a variety of causes. Marital difficulties, depression due to Post Traumatic Stress Disorder, the death of a relative from AIDS, or postpartum problems, crisis issues such as rape, adjustment to physical injury, a parent’s murder, and racial discrimination, are examples of the types of issues participants faced prior to diagnosis. It is possible that these issues, compounded by the physical stress each of these may have had on the body, were significant in stressing the immune system and leaving these individuals more susceptible to CFIDS. Results from this explorative study indicate that the presence of these problems may have placed individuals at a higher risk, but further research would be necessary prior to a definitive report. The results of this study did indicate that many of the participants had, at some time prior to their diagnosis, experienced a significant trauma in their life.

Family of Origin/Childhood Experiences

Participants were encouraged to describe and discuss family of origin issues through the use of genograms. Genograms, as explained by Hartman and Laird (1983) in their work, Family-Centered Social Work Practice are an excellent tool in helping both practitioner and client to visualize family ties, generationally as well as interpersonally. It
is a primary tool utilized in the field of social work to assist in understanding the linear relationships among family members, as well as making important patterns and themes visible. The researcher asked questions surrounding family relationships, including both past and present relations. In the course of developing genograms, each participant was also encouraged, via open-ended questions, to discuss and describe family patterns of interaction.

The analysis of this information pertaining to dynamics within the family of origin began to fall into certain patterns of family functioning. The following five subcategories materialized: the participant’s perspective of their childhood, whether positive or negative; the marital relationship between participant’s parents; the presence of one or more substance abusing parents or relatives; a history of mental/physical illness in one or both parents; and the presence of child abuse within family unit.

This study indicated that a participant’s perspective of their family or childhood experience may be significant in their learning to live with CFIDS. Of the sixteen who responded by stating that difficulties were present in their family and/or that childhood experiences had in some way affected them, all sixteen utilized the term “dysfunctional” when describing their family of origin. When questioned
regarding their interpretation of this word, the most common response was that they felt that their family's pattern of functioning was somewhat unusual or abnormal. Is this perspective significant later in their lives, and if so, to what degree? It is possible that participants, especially those who described these dysfunctional childhood circumstances as stressful, may have developed immune deficiencies resulting from these stressors that later placed them at greater risk for the disease of CFIDS.

What effect do each of these issues present? Does stress in a marital relationship, such as divorce, domestic violence, or substance abuse, place children living in the same environment at a significant risk for developing stress themselves? Does this stress then further place these children at risk for stress-related diseases, such as CFIDS? The same perspective regarding substance abuse among siblings or extended family members was described as stressful for participants. Literature concerning issues faced by children from alcoholic families states that the impact of stress on other family members when one or more parents are abusing alcohol can be damaging to children both at the time and in later years (Anderson & Quast, 1983; Copans, 1989; Sher, 1991).

In addition, participants who lived with parents
suffering from mental illness or a physical handicap described these experiences as stress producing. Research cites that persons who have grown up in the care of a parent suffering from mental illness can produce stress-related issues for other family members (Miklowitz, Goldstein, Huechterlein, Snyder, & Mintz, 1988). Participants who were victims of abuse, either sexual, physical, or emotional, also stated they experienced a great deal of stress as a result of these experiences. Literature reporting the effects of abuse on children states that children living in abusive situations are negatively impacted and prone to high stress levels (Brunk, Henggeler, & Whelan, 1987).

Through the use of genograms, participants also discussed the significance of roles within their family of origin, and the interaction among members as each of them fulfilled their specific role in the family system. Analysis of data collected during these discussions developed the following groups: mother’s role, father’s role, sibling roles, roles of extended family members, and the participant’s role within the family.

In discussing their mother’s, the participants who described their mother as critical, controlling, difficult to please, or perfectionistic stated that this role had a negative affect on their relationship with their mother.
Analysis of their responses indicated that these participants had difficulty feeling close to their mother, and often had feelings of low self-worth or a sense of inadequacy as a result of their mother's high expectations or lack of unconditional acceptance. Of the total sample population, only three female participants reported being close to their mother, and yet of these three, two went on to describe relational patterns that closely resembled enmeshment: a type of suffocating, all-encompassing relationship in which the participants stated they did little thinking for themselves. Similar patterns of maternal interaction were described by participants who reported having poor relationships with their mother. While the participants who felt they had good relationships with their mothers did not perceive the "closeness" as a problem, the enmeshed pattern itself could be seen as problematic, especially as it affected their own growth and development. One adult woman who is currently financially supported by her mother, stated she has difficulty making decisions apart from her mother's influence, and often feels controlled by the closeness she shares with her mother. Thus, while relationships may be perceived as "healthy" by the individual, it is still possible that this mode of interaction may not be optimal, and could possibly cause
stress for both individuals.

The role played by fathers in the family system, described by individuals in a variety of ways, produced a prominent pattern: 55.5% of the participants indicated that their father was somewhat disengaged from the family, stating that he was present physically, but had little to do with the family on an emotional level. These participants all described their fathers as "not really there," indicating his emotional absence in the family. This pattern was fulfilled in the following ways: four had alcoholic fathers, three had fathers who worked excessively, and several had fathers who would isolate at home and did not involve themselves in family matters. It is possible that the presence of a disengaged father within the family unit may have had a stressful impact on these participants.

Only five of the eighteen participants described sibling relationships that were problematic. Feelings of jealousy, envy, the need to compete for approval, and parents who compared siblings to one another were the main focus of sibling-related discussions. Of the five who reported difficulties with a brother or sister, only two had still not resolved these issues, and continue to have a stressful relationship with their sibling. These results do not determine a majority or significant response, thus it is
possible that sibling relationships did not produce any particular childhood stress issues for participants. Discussion of sibling-related issues tended to develop more after diagnosis of CFIDS occurred, such as brothers or sisters who found it difficult to cope with the participants illness and its consequences. All of the participants reported stress pertaining to family and/or friends who could not deal with their illness and its impact on their lives. CFIDS education components, as well as the issue of well-supported networks for family members, may prove helpful in relieving these kinds of stressors.

Analysis of data relating to the participants role in the family system revealed an interesting pattern: parentification. Parentification, as described by Hepworth & Larson (1993), occurs when a child is forced to assume a parental role in meeting the needs of a child-like parent(s) and/or younger siblings at the sacrifice of their own childhood. All of the eleven participants (61.1%) who had been parentified stated that this role created a significant amount of stress in their lives. Of these participants, four continue to suffer from feelings of resentment regarding this role, and its resulting cost to their own childhood. It is possible that fulfilling this role may have caused these individuals to suffer stress that may have
had some impact on both their physical and emotional health.

All of the participants reported having the usual childhood illnesses, such as measles, chicken pox, or mumps. The most frequent response led to the development of a grouping specific to sinus-related illness, such as chronic or recurring sinus infections. Of the twelve participants who reported suffering from this difficulty during childhood, all twelve also stated they took regularly prescribed antibiotic medications.

**Significant Life Events/Experiences**

Analysis of the data relating to this area of questioning led to the development of three sub-categories: death/loss, life-changing or traumatic events, and life stressors prior to and at the time of diagnosis. The results indicated that a significant portion of the sample population (88.9%) had experienced the death/loss of a significant individual at some point in their life. This data lends to the possibility that loss issues, particularly those related to death of a loved one, may somehow impact individuals as a stressor that may later lead to the development of stress-related diseases. With such a large number of participants reporting their lives had been impacted by the loss of a significant individual, it seems possible that factors surrounding loss issues may play a
part in the overall effect CFIDS has on an individual. While this relationship between stress and its impact on the disease process has been well documented in previous studies (Schnurr, 1996; Koss, Koss & Woodruff, 1991), it may be helpful to continue focusing on stress aspects specifically in relation to CFIDS (Lutgendorf, et al., 1995).

Participants reported a variety of life-changing and traumatic events which had impacted their lives. Of the total sample, fourteen (77.8%) responded with descriptions of events or traumas such as rape, childhood sexual abuse, auto accidents, drowning, cancer, extra-marital affairs, divorce, and experiences in Vietnam during combat duty. The fact that these were experienced prior to receiving a CFIDS diagnosis, many of them several years prior, indicates the presence of major stressors in the participant’s life prior to becoming physically ill. While correlation cannot be made based on these results, it indicates that further study of the impact of these events on each of the participants may provide helpful knowledge in determining the role stress may play in the disease process.

As indicated by the development of a third sub-category, life stressors prior to and at the time of diagnosis, the issue of stress and the role of life stressors in the CFIDS disease process became a recurring
theme during the study. As participants described their life experience surrounding their diagnosis, the use of eco maps assisted individuals in visualizing the overall picture of their life’s circumstances. Many participants had a great number of difficult relationships/associations and other stressors just prior to and at the time they were diagnosed with CFIDS. Again, while it is not possible to assume any correlations, it remains interesting to note that so many of the participants were experiencing significant life stressors both during and just prior to diagnosis. Results indicated that life stressors in each of the following areas were problematic for these individuals: family, extended family, friends; work/school; community groups; religious organizations; social supports/resources; and particular life-events.

It is important to note that the area of family, extended family, and friends was reported as the greatest source of stress for most of the participants, and is best explained by the following response from one female: “I was surprised to realize that the people I thought would really be there for me, weren’t, and that people I had not expected to be supportive really came through when I needed them. I was surprised, and hurt, by the number of family members and “close” friends who could not cope with my illness or
doubted its reality." This phenomenon concurs with Ware’s (1992) CFIDS study, in which CFIDS patients described similar experiences and difficulties dealing with the stigma and alienation incurred when other people doubted the reality of their illness. It is possible the additional stress experienced as a result of these life events may play a role in the CFIDS disease process.

**IMPLICATIONS FOR PRACTICE**

A resounding theme throughout this study was the importance of both medical and social work professionals to understand the surrounding life circumstances of CFIDS clients and begin to make efforts to inform themselves about the disease and its consequences. Due to the fact that medical science has yet to produce a cure, it is imperative that CFIDS clients learn to cope with symptoms and manage life stressors in order to deal effectively with this illness. It would benefit both patients and practitioners to utilize concepts and tools such as eco maps in developing treatment for the patient, education components for family and friends, and problem solving strategies to resolve difficulties for all who are impacted by the individual’s illness.

Due to the stigma, alienation, and isolation features of the illness, it is imperative that practitioners and
medical professionals work together to provide CFIDS patients with faster diagnosis, treatment plans that specifically confront these concerns, and educational segments that assist patients in dealing with these aspects of the illness. It is suggested that practitioners seek to establish educational components that include both patients and their significant others. Support for CFIDS clients should focus on normalizing the feelings accompanied by stigma, alienation, and isolation, as well as assertively handling these issues when they arise. Significant other education could focus on sensitizing individuals who do not understand the various effects of CFIDS, as well as assisting support persons in expressing and resolving their own feelings regarding the patient’s illness.

This educational component would also be beneficial for medical and mental health professionals, as the stigma or label of “hypochondriacal” from such individuals is devastating and stress-producing for CFIDS patients. It would also benefit professionals to become educated regarding the impact of long, drawn out diagnoses, and the debilitating stress this creates for patients. It may be necessary to review and renew the diagnostic criteria currently utilized for CFIDS, and/or develop more educational components for medical professionals.
Due to the fact that half of the participants in this study were either on, or pending notification of, disability, a better understanding of the impact this has on patients may assist professionals in providing social services to these individuals. Results also indicate the need for social work practitioners to provide better advocacy for CFIDS clients and increased public awareness of the disease. Advocacy for clients would provide better services and more prompt assistance to individuals who presently must wait an extended period of time to receive much needed financial and medical assistance, thus reducing the undo stress CFIDS clients currently endure in acquiring social services. Advocacy should also include efforts to educate the public, seeking to eliminate the discrimination and stigma surrounding the "invisible" nature of this disease. Public education may help to alleviate the hurtful stereotyping reported by CFIDS patients. Due to the fact that much of the disability suffered by CFIDS clients does not necessarily present as an obvious physical handicap, these clients are often treated avoidantly, or confronted with statements like, "You don't look sick." Education and advocacy would go far in removing these particular stressors associated with CFIDS.

Results from this study also indicated the need for
interdisciplinary efforts in helping CFIDS patients. As many CFIDS clients present with both medical and psychological issues as a result of the illness, it is imperative that medical, mental health, and social service providers work together to diagnose, treat, and provide ongoing services to this population. These issues often overlap in treatment planning for CFIDS patients, and it is vital that practitioners become skilled in treating the "dual nature" of the depression that many CFIDS clients manifest. It suggests that referral or recommendation of mental health services may aid patients in normalizing these anxious feelings, as well as with coping with the chronicity of the disease. Results also indicate that this may benefit clients in dealing with family of origin issues that also may present difficulties both prior to and after a CFIDS diagnosis. An interdisciplinary approach would prevent costly replication of services and prevent problems due to a lack of shared information. Cross discipline and interagency treatment approaches would assist providers in delivery of service and ensure patients have access to needed assistance.

Results also implied that prevention and services focused on family of origin issues may eliminate pressures that only add to the already stressful nature of living with
CFIDS. As findings indicated, stressful childhood and family of origin issues were present in some participants, and while it requires further research, dealing with these issues may result in lowering stress levels experienced by these individuals. Emphasis on facing family of origin issues may assist individuals in dealing with CFIDS symptomatology, helping them to sort out the various issues that may create or add stress to patients' lives.

LIMITATIONS

As the study progressed, certain limitations became clear. First, a definite gender bias was apparent, and it would have been beneficial to include more men in the sample population to better determine if gender issues were a factor for CFIDS patients. Second, the small sample size may have possibly skewed results or prevented definitive answers from being obtained. Studying a larger sample size may have generated more specific information regarding emotional and psychological issues, as well as gender, ethnicity/cultural implications, and the overall implications of long-term chronic illness. While the CFIDS Association of America (1995) reports a representation of all ethnic groups, it would be interesting to investigate what proportion of minority populations are actually diagnosed. Controlling this variable in future studies may
lead to important information about the disease itself.

Third, it would have been interesting to control for degree or severity of illness. This could have been accomplished through the use of a self-administered scaling question in which participants were asked to rate the degree to which they felt their symptoms manifested, or to what degree they were ill due to CFIDS. This would have allowed the researcher to determine if the participants who reported a greater amount of family of origin or emotional and/or psychological issues suffered from more severe CFIDS complications. It would have been interesting to track this factor, as more direct implications could have been derived from such findings.

Fourth, a similar limitation occurred by not tracking the impact of counseling or other form of emotional or psychological support received by participants prior to or after their diagnosis. Did seeking help for family of origin issues prior to diagnosis in any way affect the individual in coping with CFIDS? Did those who didn’t get help for family of origin issues suffer greater symptoms once they were diagnosed? Did counseling or other mental health services for these issues received after diagnosis have a positive or negative impact? Controlling for these factors would have generated information useful in
determining more specific findings.

Finally, it would have been interesting to include participants who were located in geographic regions that did not allow them access to CFIDS support groups. Including individuals in the sample population who had not experienced the assistance of a local support group may have generated different results regarding emotional/psychological issues and their impact on CFIDS patients.

SUGGESTIONS FOR FURTHER RESEARCH

Based on the exploratory findings of this current study, many possibilities for future research studies exist. First, as indicated by the limitations of the study, further research that controls for variables such as the severity of illness and its relationship to both pre and post-diagnosis emotional/psychological issues would be beneficial in generating more specific knowledge. A study that explicitly looks at the role of family systems, whether functional or dysfunctional, and the nature of parental/child roles within these systems, would provide interesting information regarding the relationship between specific roles and their impact on the disease process. Roles identified in this current study, such as the disengaged father, the controlling, perfectionistic mother, and the parentified child, could be further researched as to their impact or
relationship to the CFIDS disease process. Future studies may also wish to specifically investigate the relationship between enmeshed/disengaged relational patterns and the diagnosis of CFIDS. Results from this explorative study also indicate that further investigation of the role of a parentified child and its impact on that individual's health, may possibly reveal new information regarding the link, if any, between family of origin issues and the disease process. It is possible that research in this area may provide new ideas and concepts helpful to understanding CFIDS and other immune-deficient diseases.

Also of interest would be further study regarding the impact of loss issues and their influence on the disease process. Further research on both pre and post-diagnosis loss issues may provide useful information for prevention, diagnosis, and treatment of the disease. Also pertinent to such studies would be further research regarding the role played by stressful incidents. A study given specifically to the role of stress and its impact on the disease process would also be beneficial in providing preventive, diagnostic, and treatment services. Specifying the presence of these stressors and their effect on the body is not an issue that could be fully explained within the scope of an exploratory study, but the fact that sixteen of the eighteen
participants all presented with childhood and family of origin stressors, such as abuse, parental/marital problems, substance abusing parents or siblings, and the presence of mental or physical illness in one or both parents, indicates this is an issue for further research. It is recommended that a research model broader in scope than this current study be utilized to fully understand the breadth of these issues.

Similar to the issues of loss are issues of traumatic events. How these affected participants, including a study of the emotions experienced during these traumas and its effect on their bodies, would best be studied using a framework that combines both medical and psychological viewpoints. The fact that so many of the participants reported stress-related factors in their family of origin or childhood environment, indicates that further study regarding the link between stressors and immune-related diseases may prove useful in developing treatment plans, cures, or possible preventive measures. It is hoped the information gained from this study’s exploration of these issues will provide a catalyst for further research in this area.

Data results in the category specific to childhood illnesses may possibly indicate the need for further
research into the link, if any, chronic or recurring sinus conditions may have in relation to CFIDS. While it is a common symptom among CFIDS patients, it is possible that research investigating the presence of sinus conditions prior to diagnosis, particularly those experienced in childhood, may assist in providing information regarding current treatment methods and possible cures for the disease. Such research studies may lend to prevention and/or intervention at an earlier stage in the CFIDS disease process.

Finally, a study specifically geared toward understanding minority and cultural aspects of CFIDS would greatly add to the current body of knowledge regarding this disease. Review of the literature indicated a severe deficiency in research specific to any culturally diverse aspects of this disease. While the CFIDS Association of America reports a representation of all ethnic groups, it would be interesting to investigate what proportion of the minority population actually is diagnosed. Controlling this variable in future studies may lead to important information about the disease itself. All professions that deal with CFIDS clients, whether medical, mental health, or social service, would greatly benefit from knowledge generated by culturally sensitive research.
CONCLUSION

The position of the social work profession affords practitioners a unique opportunity to work with CFIDS clients. How to best identify and provide services to this population are issues that will continue to face practitioners. In this preliminary study, possibilities were explored regarding underlying emotional and psychological issues and their relationship to CFIDS. Further research is clearly indicated, and it is hoped that the findings of this study will be a catalyst for future efforts. Results from this study do substantiate the need for better provision of services to this population. It is not only imperative that medical and mental health professionals understand the long-term complications of CFIDS, but also that social work practitioners understand and seek to provide these individuals with both the medical and psychological support and care they need.
APPENDIX A: INFORMED CONSENT STATEMENT

The study in which you are about to participate is designed to investigate the relationship, if any, between patients suffering from Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and the presence of underlying psychological factors. This study is being conducted by Terri L. Alberts, a student in the Masters in Social Work program at California State University, San Bernardino. All research is being done under the supervision of Dr. Teresa Morris, acting Director of the Department of Social Work, California State University, San Bernardino.

In this study you will be asked questions regarding the circumstances surrounding your diagnosis as a CFIDS patient, and its affect on your life. You will also be questioned regarding any emotional or psychological problems you may have suffered both prior to and after your diagnosis. Questions in the latter portion of the interview will be concerned with childhood experiences and family of origin issues. This interview will be approximately 45 minutes long.

Please be assured that any information you provide will be held in strict confidence by the researcher. At no time will your name be reported along with your responses. All data will be reported by a number system. You may request to receive a report of the results at the conclusion of this study. Your participation in this research is totally voluntary and you are free to withdraw at any time during this study without penalty. You may also remove any data at any time during the study.

I acknowledge that I have been informed of, and understand, the nature and purpose of this study, and I freely consent to participate. I acknowledge that I am at least 18 years of age. I also agree to have this interview tape recorded.

Participant’s Signature ___________________________ Date ______________

Researcher’s Signature ___________________________ Date ______________
APPENDIX B: DEBRIEFING STATEMENT

The purpose of this study was to explore the relationship, if any, between Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) and the presence of underlying psychological factors. To facilitate a thorough collection of information, personal interviews were utilized as the primary source of data.

Should you find that at any time following the interview you have questions, concerns, or reactions concerning the content of the interview, you are encouraged to discuss them with the researcher. It is also possible for you to contact the researcher’s advisor, Ms. Lupe Alle-Corliss, MSW, LCSW, at the Department of Social Work, California State University, San Bernardino. Both may be reached at the following numbers: Department of Social Work, CSUSB office at (909) 880-5501, or directly at (909) 880-7223.

This study could not have been accomplished without your participation, thus your time and efforts are greatly appreciated. It is hoped that the information obtained from this research will create knowledge and stimulate interest in further studies. The results of this study will be available to all participants upon their request.

Sincerely,

Terri L. Alberts, Student
Masters of Social Work Program
California State University, San Bernardino
REFERENCES


