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WOMEN'S EXPERIENCES OF MYALGIC ENCEPHALOMYELITIS / CHRONIC
FATIGUE SYNDROME

by

C. Ingrid Deringer

B.A.Hon., University of Regina, 1990

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS

in the Department
of
Women's Studies

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ABSTRACT

Myalgic Encephalomyelitis (ME) is a disease whose etiology is unknown. The symptoms are sporadic and vary in degree among individuals. Research has focused on treatments, causes, and cures of ME but has largely ignored what it means to experience this disease. Women with chronic illnesses are often neglected and devalued by society, and by the medical, disabled, and feminist communities.

To understand what it means to experience ME, I interviewed eight women extensively using a feminist method called experiential analysis. The women came from various backgrounds and all had been ill for more than two years.

They participated in the research process by helping me formulate a list of questions, by telling their stories in their own words, and by validating the results. My assumptions and expectations, as well as my own experiences of having ME, and of doing the research, were incorporated into the thesis.

Many patterns emerged from the co-researchers' stories. They all had many negative experiences with health professionals. They reported being verbally and medically abused, receiving incorrect diagnoses, and not taken seriously. Positive medical experiences were few and usually of short duration. A wide range of treatments and

behavior changes were tried with little success. Financial difficulties resulting from inability to work were a major problem. Friends and family had difficulty dealing with the women's changes in roles and abilities, and often neglected or abandoned them. The women also had difficulty accepting that they had a chronic illness and that they were disabled. However, for most of the women, the longer they had the disease the more they seemed to incorporate the illness into their self-images and as a consequence, their lives became more rewarding.

DEDICATION

To my co-researchers

ACKNOWLEDGEMENTS

This thesis depended on the cooperation of eight women, who because of confidential reasons, cannot be identified. I wish to express my gratitude to these women with whom I worked, for their cooperation and patience, as well as for their trust and honesty.

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CHAPTER ONE

INTRODUCTION

Myalgic Encephalomyelitis (M.E.), also known as Chronic Fatigue Syndrome (CFS), is a chronic illness that is suspected to be viral in nature. It causes severe physical and mental fatigue, and a variety of other symptoms, primarily involving the muscles and nervous system. (Hyde, 1989, p. 1) Although some people recover fully from this disease, many remain significantly disabled by it.

It is important to address the specific experiences of women who have M.E. for several reasons. Women, [including those that are disabled] and their experiences are devalued by society (Asch & Fine, 1988, p. ix; French, 1985, p. 18; Hannaford, 1985, p. 75-76; Mackie, 1983, p. 102; Ridington, 1989, p. 34); women as patients are frequently mistreated by the medical profession (Anderson, 1981; Asch & Fine, 1988; Lexchin, 1984; Penfold, 1986; Roberts, 1985; Seidenberg, 1971; Saskatchewan Alcohol Commission, 1978); disabled women are often forgotten by the feminist community (Asch & Fine, 1988, p. 3-4; Hannaford, 1985); and women with M.E. do not fit the usual image of disabled people and thus may be overlooked by the disabled community. (Jeffreys, 1982, p. 85) In addition, M.E. research to date has focused on the medical aspects of M.E. (i.e., cause, cure, treatments),

largely ignoring what it means to experience this hidden disabling disease.

The immediate purpose of this study was to understand the meaning of the M.E. experience for women, with emphasis on their experience with the medical profession and how they cope day to day. From that understanding I hoped to identify fruitful directions for further research on people with M.E., especially research to help them live with it.

OVERVIEW OF CHAPTERS

In chapter one I will review the literature that pertains to ME, to women with ME, and to women with chronic illnesses. In chapter two I will outline the method I used to conduct the research. The results of the study are in chapter three, and finally, in chapter four I offer a discussion and conclusion.

LITERATURE REVIEW

WHAT IS ME?

ME is not a new disease. Evidence of its existence dates back to 1869, when George M. Beard documented a disorder with similar symptoms which he called "nervous exhaustion" or "neurasthenia." (Levine et al, 1989, p. 3) Epidemic outbreaks of ME have been documented in medical journals all over the world ever since. In Canada, cases of people with ME have been identified since 1984. (Parish, 1991, p. 20 - 30)

Regardless of its long history, ME is not a well known disease. One of the reasons for this is that ME has been known by close to a hundred different names throughout its history. (Parish, Bell, & Hyde, 1991, p. 19) The most common names are Iceland disease, Royal Free Disease, Lake Tahoe Disease, Chronic Fatigue Syndrome, Chronic Fatigue Immune Dysfunction Syndrome, Chronic Active Epstein-Barr Virus Infection, Benign Myalgic Encephalomyelitis, the Yuppie Flu, (Parish, Bell, Hyde, 1991, p. 19) and in many cases, Fibromyalgia (Hyde, 1989, p. 37).

In Canada the medical profession is beginning to steer away from using the term Chronic Fatigue Syndrome (CFS) and to use the name ME. The attractions of using ME rather than CFS are many. For one, there are several more symptoms than just profound "fatigue." As well, "fatigue" is a misnomer.

The fatigue described by people with ME is more like "exhaustion" according to Karpati. (1991, p. 14) Calling ME a "syndrome" is also problematic. ME is a disease, not a syndrome. (Hyde, 1990, p. 2) Disease, according to the Oxford Dictionary is "a condition of the body, or some part or organ of the body, in which its functions are disturbed or deranged." As Hyde states, "ME is a disease that involves elements of the sensory, cognitive, motor and midbrain functions; the entire body and its many interrelated functions are affected" (1990, p. 2). "Syndrome" simply refers to the set of signs and symptoms that characterize a certain disease or disorder (Rothenberg & Chapman, 1989, p. 428) Another attraction of using the name "ME" is that "ME" is already used to describe this disease in many countries, including England, Australia, and New Zealand. (Hyde, 1989, p. 37)

It is worth mentioning that, unfortunately, the Canadian media still insist on using the term "Yuppie Flu" to describe ME. Fortunately, they seem to be adopting the term "CFS" more and more, although they rarely use "ME."

WHO GETS ME?

The ages of people with ME range from young children to senior citizens. The typical ME patient, according to Shepherd, "is a young adult (with females predominating) in the age group of late teens to early forties" (1989, p. 4). In the United Kingdom they report "10% of patients are

pubertal [at puberty] and 20% over the age of 40" (1989, p. 5) However, the proportions may not be accurate for Canada. Many patients may be diagnosed as suffering from other diseases and disorders, such as depression, hypochondriasis, attention deficient disorder, old age, and even schizophrenia. (Hyde, 1989, p. 2) It seems the medical community is still far from recognizing the symptoms quickly and accurately, partly because practitioners have not been educated about ME and partly because there is no one test to determine the existence of ME. Diagnosis of ME is done by the clinical evaluation of symptoms plus the elimination (by testing) of other possible causes. (see Hyde, 1989, p. 2)

RESEARCH ON ME

Most of the research that has been conducted on ME is centred around finding a cure, a cause, and treatment. For example, the recent workshop on Canadian Research Directions for ME \ CFS funded by Health and Welfare Canada and held at University of British Columbia in May, 1991, focused on such areas as diagnosis, treatment, and medical research. There was a definite absence of information about how people with ME cope with this illness financially, emotionally, or physically. Nor were there any discussions of the experiences people with ME have with the medical establishment. The only people invited to participate in the workshop were medical researchers and doctors. This workshop exemplifies a continuing neglect in Canadian

research concerning what people with ME have to say about their illness.

This same flaw is found in most medical research and is not peculiar to research on ME. The medical community is overwhelmed with "controlled" "objective," "cause and effect" research and rarely looks at the whole person. Jeffreys (a woman with ME) describes what she discovered while she laboured through a book on auto immune diseases trying to understand what was happening to her:

In an entire work devoted to one of the most horrendous things that can befall a human being, there was no word to indicate how a person with these problems might feel It isn't there, the reader sees the disease as a detached entity, a label fastened onto a human being and it is the label that comes alive not the patient. (1982, p. 173)

This flaw is also reflected in the way doctors are trained to diagnose people's ailments. Oliver Sacks, an outstanding physician and author of Awakenings, contends that patients are:

subjected to forms of interrogation and examination ... questions of the form: 'do you have this' ... 'do you have that'? Which by their categorical nature demand categorical answers Such an approach forecloses the possibility of learning anything new, and prevents the possibility of forming a picture, or pictures, of what it is like to be as one is. (1990, p. 225)

I strongly believe that including research on people's experiences of disease and disability in medical literature would bring us [and I include the medical profession] closer

to understanding the disease process, and closer to eventual cures and treatments.

Women's lives and experiences have been neglected by mainstream science and social science. In many cases the "scientific fact" or "knowledge" we have come to accept as "truth" has been nothing more than the myths and beliefs of the dominant culture. Feminist scholars are trying to change that. (Dubois, 1983, p. 105-106) Dubois points out that:

feminist scholars are engaged in almost an archaeological endeavor - that of discovering and uncovering the actual facts of women's lives and experience, facts that have been hidden, inaccessible, suppressed, distorted, misunderstood, ignored [For] we must first, quite literally, learn to see. To see what is there; not what we've been taught is there, not even what we might wish to find, but what is there. (1983, p. 109-110)

RESEARCH ON WOMEN'S EXPERIENCES OF ME AND DISABILITY

As a feminist scholar I could see that to understand what ME is, what ME means to women, and how they cope with it, I had to go beyond the male dominated medical realm. I turned my attention to what had already been written about women's experiences of ME. There are a few instances where women with ME have written about their own experiences, such as Jeffreys', The Mile High Staircase, and various articles in the CFIDS chronicles (a newsletter put out by the Chronic Fatigue Immune Dysfunction Syndrome Society in Portland Oregon). However, since there were such limited resources

specifically on ME, I included relevant literature on disability, specifically literature on women with chronic illnesses.

I have divided the remainder of the review into several sections dealing with different aspects of being a woman with a chronic illness. I begin with the problems of treating chronic illnesses.

DIAGNOSIS

Medical doctors in our society are powerful people. They are taught in medical school and encouraged by society to act superior and omnipotent. They have the power to label people sane or insane, able or disabled, healthy or ill, and competent or incompetent. They have the power to invade our bodies through surgery and to alter our bodies with drugs. For people who are chronically ill, the power doctors have can be a serious threat to their well-being.

People with disabilities are at the mercy of physicians to give them a diagnosis. It is only a medical doctor who can give a person a medical label, and if for some reason the person cannot get a label (e.g., if the illness is uncommon or has unusual symptoms), that person, as well as others, may end up doubting her / his sanity. A diagnosis not only confirms for the ill person that she / he is not imagining her / his experience, it also confirms for others, such as family and friends) that she / he is ill. The physician's stamp of authenticity is crucial in the society

we live in, because doctors are viewed as authoritative when it comes to our bodies and psyches (Boston Women's Health Collective, 1984, p. 556-562). To demonstrate this point I will give an extreme example. Toni, a woman with ME, tells of her experience of having no diagnosis. A veterinarian friend came to see her sick cat (misdiagnosing the cat, incidentally). The veterinarian friend then went to see the woman's mother and informed her that Toni's illness was psychosomatic. Toni writes: "as he was peripherally medical, and male, the family was happier to accept his dogmatic assessment, rather than my own tentative and puzzling version" (Jeffreys, 1982, p. 106).

A diagnosis is important for disabled people because it carries legal and moral weight. If ill people do not have a diagnosis, they cannot apply for disability benefits, they cannot receive handicapped parking stickers, they cannot quit work or receive sick pay. Even if they do get a diagnosis, they still require physicians' continued diagnostic approval to go back to work or school, to continue disability benefits or simply to increase their workload.

There are added problems if the person who has a disability happens to be a woman. It has been well documented that the medical establishment is sexist (Anderson, 1981; Armitage, 1979; Harding, 1987; Howell, 1974; Lexchin, 1984; Penfold & Walker, 1985; Saskatchewan Alcohol Commission, 1978; Weaver & Garrett, 1983). Sexism

can drastically affect the quality of care a disabled woman receives (Fine & Asch, 1988, p. 74).

When women with chronic illnesses first come in contact with their doctors, symptoms can be vague, ambiguous, or strange. It is not uncommon for women to report that initially they were not believed or not taken seriously. (see Register, 1987, p. 6-8) It is also not uncommon to hear that women can wait literally years for a correct diagnosis, and in the meanwhile be given any number of incorrect diagnoses. Many times these incorrect diagnosis are physical in nature, such as when a woman on the verge of kidney failure was told by her gynecologist that she needed an emergency hysterectomy (Register, 1987, p. 6). However, more often physicians over-attribute women's symptoms to psychogenic causes (Fine & Asch, 1988, p. 74), as in the following examples: a woman with MS was told that she had 'housewife syndrome' and that if she "just got busy and away from [her] children, all of [her symptoms] would clear up by themselves" (Register, 1987, p. 3); a woman with ME was told by her doctor "she wasn't really ill, that she was just afraid of exerting herself he wrote his final diagnosis in bold letters across her chart: DEPRESSION" (Fisher, 1989, p. 6).

When women are told over and over that what they are experiencing is not "real" (in the sense that it is not physical), or that what they have is something other than what it really is, they often begin to doubt if they are

really ill or just imagining it. Register believes that people fall prey to this because it is easier to live with self-doubt than to surrender the confidence we have in the medical profession to heal us (1987, p. 7). In a sense that is true, but more importantly, and specifically in the case of women, they doubt their own sanity because in a patriarchal culture women are often not taken seriously in any aspect of their lives and therefore do not possess much self-confidence. In addition, women have often been socialized to believe that physicians are the authority on their bodies and minds (Boston Women's Health Collective, 1984).

Having a name to validate one's experience is extremely important. No diagnosis meant for one woman with ME that her "enemy was faceless, sinister, terrifying" (Jeffreys, 1982, p. 37). How can one fight something that has no name? It also means that the experience is not validated. One man described feeling "almost glad" when he received an incorrect diagnosis of cancer because now "no one could doubt that [he] was truly ill" (Fisher, 1989, p. 9).

For those people who have never had the experience of having no name to describe their experience, it may be difficult to understand how someone can feel glad about a diagnosis of cancer. However, many people report feeling euphoric after receiving a name. A woman who after five years finally received a diagnosis of MS writes:

And with that [diagnosis] came this wonderful sense of relief. I giggled and laughed. I was joyous. My husband was the same. We were just like two kids running through a park. We had a name to something. We could deal with it. I was not a neurotic lady. It was ok to slow down, to quit work. It was ok to say no to things. (Register, 1987, p. 5)

Instead of being a source of grief, as many people would expect, a diagnosis after a long wait can be a blessing, especially if the diagnosis confirms your sanity.

How one deals with the new name can depend on what the name is. Some illnesses are not unanimously recognized as legitimate illnesses. For example, both ME and Environmental Illness (EI) are not always seen as legitimate illnesses by the medical authorities, or society in general. This can create problems. There are still some people who question whether or not ME and EI are actual physical diseases or people's imaginations gone awry. It is difficult for people to accept something they cannot easily see or that does not have a known etiology. Living with an illness such as EI or ME may mean not everyone believes you are sick. A woman with EI writes:

Like other environmentally ill people, I am deeply affected by what seems to be the prevailing notion that I am not really sick. A local newspaper recently ran an article on environmental illness, announced by a blurb on the front page which began, 'Are These People Truly Ill or Merely Crazy?' Many would label us as 'mentally ill' and forget us as quickly as possible. (Browne, Connors, & Stern, 1985, p. 31)

TREATMENT

Chronicity and disablement pose particular problems to modern medicine. Physicians are not taught how to deal with chronicity. Roberts points out that doctors are taught in medical school how to treat and cure "well-defined pathological conditions," and when they are faced with a patient who is experiencing vague and / or ambiguous symptoms, as is the case with many chronic illnesses, they "feel frustrated and annoyed" (1985, p. 31). Mairs states that an intransigent chronic illness such as multiple sclerosis (MS) "defeats ... [physicians'] aims and mocks their skills" (1986, p. 20). Physicians do not like to treat people who are not "fixable." A physician who is disabled states, "[c]hronic patients and the crippled are awkward for the health care system, and so many physicians prefer not to deal with these 'failures'" (Beisser, 1990, p. 177). It seems that chronicity and disablement challenge the image of physicians as all-powerful and call into question their abilities to heal.

BEING "DISABLED"

People who are diagnosed with a chronic illness may or may not identify themselves as "disabled." The term "disabled" conjures up in most of us pictures of people in wheelchairs, or blind people walking with their white canes. It is difficult for many chronically ill people to see how they fit into such an image. For example, some people who

have cyclical chronic illnesses may feel they fit the image of the disabled only when they are in a bad relapse, or when they require an aid.

The term "disabled" ignores the diversity of people in the group. To lump together people who are paraplegic, with those that have EI or are blind seems to make no sense. What could they possibly have in common? For Asch and Fine the commonality for women is that " they share ... similar treatment by a sexist and disability-phobic society" (1988, p. 6). For Campling the commonality is in that "they all involve a limitation of ordinary activity" (1979, p. 2). However, as Wendell points out, it may be that the only commonality among disabled people is social oppression. (1989, p. 6)

If it is the case that the disabled share social oppression as Wendell suggests, then there needs to be a word of caution. Such an argument may result in comparisons being made with other oppressed groups such as racial or class groups. Although there are similarities with these groups, often there is a major difference. Disabled women are much more isolated from other members of the group. As disabled people, Saxton and Howe point out, they "are often the only disabled person in the family" (1987, p. 2) and for that matter, in the neighborhood. As opposed to other oppressed groups who have family, friends, or community to share their experience, there are few others around who can understand their day-to-day experiences; who can say "I

know" (Saxton & Howe, 1987, p. 2). Even when the disabled person joins a group of disabled people, there is a good chance that within that diverse community there will still be only a few who really understand her / his experiences. If the disabled person happens to be a woman, the isolation may be compounded, because as a woman she may be encouraged to live in the private realm, and as a woman she may not be encouraged to build up her self confidence and self-esteem.

Now that I have identified some of the problems people, and in particular women, face when identifying themselves as ill and as disabled, I turn to a critique of the disabled community.

THE DISABLED COMMUNITY

The two most prevalent barriers within the disabled community that disabled women write about, are hierarchies and sexism. The hierarchies seem to be structured on how disabled one looks and on how long one has been disabled. Superimposed over the hierarchies is sexism, where men are seen as the norm, and gender differences are not acknowledged.

Many women comment on the "rarely acknowledged but very real" hierarchy that exists within the disabled community. (Thompson, 1985, p. 82-84, Ridington, 1989, p. 44-45) Thompson contends that the hierarchy "ranks people according to ... how well that person fits into society's 'norm'"

(1985, p. 82). The more normal one appears, the higher the rank. Thompson argues that the phenomenon is similar to the hierarchy in the able-bodied community, in that the closer to the ideal one is, the higher the rank. In our society it is not difficult for a woman to veer from the norm since the image of a normal woman is so narrow (i.e., she must be a housewife, sex object, mother, wife, caregiver and nurturer, AND be pretty, slim, healthy, and able-bodied). Disabled women who cannot pass as "normal" women, often feel and are treated as if they are not real women. (see Hannaford, 1985, p. 78) It seems that those ranking at the top of the hierarchy are those like Rick Hansen, who look very close to normal, are physically strong, healthy, and have plenty of stamina. (see Ridington, 1989)

Although I believe that there is such a hierarchy for some people, I also believe and can identify with a hierarchy that is the complete opposite. In other words, I see a hierarchy where the more *abnormal* one looks, the higher up the hierarchy one is. To illustrate, here is a quotation from a woman who is describing her experience as a young girl of 12. She had just won the swimming award at the Lions Camp for Crippled Children:

[I was] overcome with remorse I wanted to have something more visibly wrong with me. I wanted to be in the same league as the girl who'd lost her right leg in a car accident: her artificial leg attracted a bevy of awestruck campers. I, on the other hand, wore an unwieldy box hearing aid buckled to my body like a dog halter. It attracted no one. Deafness wasn't, in my eyes, a blue ribbon handicap. (Galloway, 1987, p. 5)

For those women who have invisible or less visible disabilities, as do many women with chronic illnesses, their problems are often not addressed within the disabled community. Wheelchair accessibility, for example, is a big issue, but "passing for healthy" is not. That is not to say that wheelchair accessibility is not important; it is. But the problems some people have with passing for healthy are equally important. Register writes about some of them:

Other people may see your shortcomings and make judgements about your character, without knowing that illness is the cause. (1987, p. 30)

'You'd never know it to look at you', is a phrase familiar to many of us. Yet if it leaves no visible marks, the illness is a constant presence in the consciousness of the one who lives with it. It has a profound impact on emotional health, self-image, relationships, work habits, aspirations, and overall outlook on life. (1987, p. ix-x)

For disabled women, passing as healthy is a particular problem, because of the stereotyped view of women as "natural" malingerers and complainers, and as weak and sickly. The stereotype makes it difficult for others to believe women when they say they are sick. At the same time, women may be reluctant to articulate how they feel because they may be afraid of not being believed. It is often simpler to pass as healthy rather than face the possibility of not being believed.

Another type of hierarchy seems to exist where people are ranked by the length of time they are disabled, newly disabled people ranking lowest. (see Ridington, 1989, p. 44; Thompson, 1985, p. 81) The problems of those that the lower end of the hierarchy are not addressed. Someone who is newly disabled faces different types of problems and goes through different stages than does a person who is born disabled or was disabled long ago. For example, Thompson writes about newly disabled women's anger:

Sometimes it's hard for birth-disabled women to understand the often out-of-control anger and frustration newly-disabled women feel newly disabled women often find their previously well-ordered lives have suddenly been turned upside down. They not only have to deal with their new limitations, but often also with the emotional losses caused by sudden and often drastic changes in self-image, feelings of independence, and their relationships with almost everyone around them. (1985, p. 81)

Some disabled people feel there is a hierarchy in which the newly disabled are at the top and the birth disabled at the bottom. Ridington, for example, points out that women born disabled may "have so many unmet needs, many are ignorant of the feminist movement, many have an extremely poor self image, many lack education and independence" (1989, p. 45). Women who become disabled as adults already have had the advantage of developing in an able-bodied world. With more education and a stronger self-image, the newly disabled might have more power within the community and may use that power to their advantage.

It seems that hierarchies depend on the perspective of the perceiver. It may be that what people are describing are dynamics of their particular group. This would help explain why the hierarchies cannot be seen as universal within the disabled community. It may also be that "disabled" is too vague a word to describe the diverse and complex experiences among this group of people, and that in our attempt to organize and make sense of our world, we oversimplify the nature of the disabling experience, and thus miss the unique experiences of specific groups of people (e.g., those that have invisible disabilities, limb deficiencies, chronic illnesses, quadriplegia, paraplegia).

Sexism within the disabled community has been acknowledged by several authors within the last decade (Fine & Asch, 1988; Hannaford, 1985; Matthews, 1983; Ridington, 1989; Saxton & Howe, 1987). It has become common knowledge among disabled feminist authors that women and men experience disability differently, and, as in mainstream society, women's experiences are not acknowledged and are rarely discussed.

Disabled women have begun reporting that an area that has been neglected by the disabled community is women's role in the nuclear family. For example, Hannaford, Matthews, and Saxton and Howe all point out that there are different expectations in heterosexual relationships if it is a woman who is the disabled partner. Matthews reports that "[n]ational statistics inform us that when men become

disabled, 50 per cent of marriages break up; for women, that figure is 99 per cent" (1983, p. 87). Hannaford states that "three to four times as many disabled men as disabled women enter or maintain nuclear family relationships" (1985, p. 76). One of the reasons given to explain these statistics is that a woman's primary role in society is as nurturer / caregiver. Women are socialized to identify with this role. The result is, women 'naturally' fall into the role as caregiver of the disabled male (Hannaford, 1985, p. 76; see also Saxton & Howe, 1987, p. 82), while men 'naturally' fall into the role of receiver of care. Another reason that may explain the statistics is that male partners cannot accept the reverse of the 'natural' order. It may be difficult for a man to accept a woman who cannot fulfil the role of caregiver, or accept that he may have to be a caregiver.

Disabled women are also beginning to point out that there are different work experiences and expectations for women than for men. For example, Matthews points out that "women with disabilities are guided into secretarial or menial work positions. Disabled men, on the other hand, are guided into more challenging careers." She goes on to say that there is an assumption that disabled women can stay at home and be homemakers" (1983, p. 18, see also Hannaford, 1985, p. 77).

It seems to be a common assumption in rehabilitative literature on disability that women should continue as

homemakers regardless of how disabled they are. For example, Davis points out that "[t]here is a growing body of knowledge concerning the disabled housewife, particularly focusing on methods to facilitate her mobility and general functioning in the home so that she may continue in her homemaking tasks" [my italics](1973, p. 28). He goes on to give an account of what I would describe as a horrifying situation where a woman is playing out the role of homemaker to the bitter end:

... the patient could turn from the sink, to which she was strapped with a device designed to hold her upright, to a work table immediately behind her. This arrangement had to be altered when the patient became still weaker, and when she grew progressively sensitive to heat and found the steam from the hot water in the sink increasingly uncomfortable. Consequently, strapping her to the sink, which had been extremely useful up to this point, was now very uncomfortable for her.(Davis, 1973, p. 31)

I suspect that many disabled women hang on to the bitter end, for reasons of sanity. No one wants to feel useless and totally dependent, especially women, because women are socialized to believe they are to be *depended on* not to be *dependent on others*, for care and nurturing. When disabled women can no longer do menial work or work in the home, or if they never were able to do this work, they may be awarded "child-like status" (Hannaford, 1985, p. 83) and begin to feel like children. These "roleless" women are seen as useless by society and not even identified with the role of homemaker or menial worker.

There are numerous other issues besides work and the nuclear family pertaining to women with disabilities specifically, that have hitherto been ignored by the mainstream disabled community. I will mention those that disabled women have separately and collectively begun to draw attention to in the last decade. Researchers, authors, and organizations such as DAWN (Disabled Women's Network) have begun to direct themselves to the issues of sexuality (e.g., birth control, education)(see Hannaford, 1985; Matthews, 1983; Ridington, 1989), over-prescription of drugs to disabled women (see Hannaford, 1985; Jeffreys, 1982; Register, 1987), mothering (Asch & Fine, 1988; Matthews, 1983), media images (see Ridington, 1988), research funding (see Stoppard, 1988), sexual, verbal and psychological abuse (Ridington, 1989); and premenstrual magnification (PMM) (symptoms are often worse for women with chronic illnesses when they are premenstrual)(see Harrison, 1985). Disabled women have begun to organize support groups and lobby groups around the country. However, it is always those women who are most vocal, most educated, most physically able, who speak, write and attend groups. Many disabled women who are living in remote areas or institutions, who have severe disabilities, who are elderly or young, who are poor, who belong to a racial minority group, who are uneducated, who do not write, who do not speak out, or who do not attend groups are very isolated.

The male-dominated disabled community has failed disabled women. The unique experiences of women are not recognized or addressed, and women must contend with a male dominated perspective.

THE FEMINIST COMMUNITY

Feminists say they value all women's experiences and believe that women must actively try to fight those social structures that oppress them. However, disabled women have criticized the feminist community, especially in the last decade, for neglecting disabled women's experiences and concerns. Asch and Fine point out that "[e]ven the feminist scholars to whom we owe great intellectual and political debts have perpetuated ... neglect [of women with disabilities]" (1988, p. 3-4). The neglect is demonstrated by the lack of literature on women with disabilities, and by the lack of inclusion of disabled women in the feminist movement as a whole (See Ridington, 1989, p. 47-49). Although it can be postulated that feminists are just not aware of the issues that the disabled women have, there are others who claim the neglect is intentional. Whatever the case, the result is that the experiences of women with disabilities are frequently not valorized or validated by the feminist community.

One reason for the neglect, put forth by Asch and Fine, is that "perceiving disabled women as childlike, helpless,

and victimized, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent, and appealing icons" (1988, p. 4). Many feminists within the movement have been struggling to rid society of the stereotyped view of woman as passive, dependent and sickly. It seems that able-bodied feminists may fear that by focusing on disabled women, the feminist movement will move backward rather than forward.

Another reason that feminists may neglect disabled women is that women are the nurturers in our society and, as Miller contends, "[p]erhaps the conviction that disabled people are inevitably burdensome and that women will be so burdened accounts for feminist resistance to involvement in the disability rights movement" (Asch & Fine, 1988, p. 4; see also Fisher, 1988, p. 176). Women have historically been the actual care givers of people. When able-bodied women become aware of the needs of the disabled, they may be afraid they will feel responsible for caring for the disabled. Burdening themselves with this responsibility may seem counter-productive.

Feminists have also been criticized by disabled women because of their lack of concern for four specific issues. Firstly, while there is no doubt that, in the literature and at a grass roots level, feminists have begun to address the abusive nature of the medical establishment, there is no mention of how that abuse can take different forms and, in some cases, be more compelling for disabled women. For

example, there is feminist literature on how women are used and abused by gynecologists and obstetricians when they give birth, go through menopause, have hysterectomies, etc. (Boston Women's Health Collective, 1984; Ehrenreich & English, 1973; O'Leary Cobb, 1986; Mitchinson, 1988; Scully, 1980; Weaver & Garrett, 1983; Yawney, 1981) There is also a growing body of literature on psychiatric issues such as over-prescription of drugs to women, and over-diagnosing depression. (Feminist Therapy Support Group, 1982; Hannaford, 1985; Penfold & Walker, 1985) There are places women can go to for support and non-sexist information and treatment of their bodies, such as the Vancouver Women's Health Information Centre, community women's centres, and feminist therapists. However, feminist writers hardly ever mention how issues surrounding birth, birth control, menopause, hysterectomy, over-prescriptions of drugs, sex education, over-diagnosing of depression and hypochondria are "accentuated and compounded," or just different, for the woman who is disabled (Hannaford, 1985, p. 78). It seems that the diversity of women's experiences is not taken into consideration and that the norm for feminists is able-bodied.

Secondly, feminist literature fails to address how heterosexual relationships and mothering are viewed differently by disabled women. For example, Hannaford points out that:

[w]hile feminist analysis has highlighted the difficulties of women placed within nuclear relationships, the disabled woman faces a paradox. A nuclear relationship for her is seen as a triumph; how lucky she is to have a husband \ lover \ children. This feat of 'normality' is seen as a piece of good fortune for her, the other person involved in the relationship (if a man) being seen as a saint \ martyr sacrificing his life to 'care' for her. (Hannaford, 1985, p. 76-77; see also Campling, 1985, p. 50)

Whereas able-bodied women may be striving to rid themselves of stereotypical roles, disabled women may be striving to fit the same roles in order to feel accepted by society and to appear 'normal'. Furthermore, it may be beneficial for a disabled woman to be in a relationship where she is supported financially, as opposed to living an independent life in poverty.

In some cases, the basic freedoms that able-bodied women take for granted are fundamental issues for disabled women. For instance, while an able-bodied woman is fighting for her right to choose not to have a child, a woman who has a disability may be fighting simply to have a child or not to be sterilized. (Davis & Marshall, 1987)

Thirdly, disabled women have criticized able-bodied feminists for the attitudinal barriers that exist within the feminist community. For example, I have heard some feminists at conferences call disabled women "difficult," claiming that they demanded too much. I have heard able-bodied women argue that there are not enough funds, or that the agenda is already too full to be able to handle all the

demands of disabled women. Thompson criticizes able-bodied women for shunning the anger felt by disabled women:

Even non-disabled women willing to acknowledge our disabilities and even, perhaps, our right to be angry caution us not to express our anger because most able-bodied persons cannot handle it.... [She goes on to say that it is] okay to be angry about rape, pornography ... it does not seem to be okay to get mad because your peers refuse to acknowledge the barriers they constantly help erect to shut out their disabled sisters.(Browne, Connors, & Stern, 1985, p. 79).

Lastly, probably the most vocal criticism disabled women have of able-bodied feminists, is that physical barriers do not allow disabled women even the opportunity to belong to the feminist community. Matthews states that "many of the services and meetings are held in inaccessible houses or offices without accessible facilities, materials, and communication, women in wheelchairs and blind and deaf women are effectively barred from participating" (Matthews, 1983, p. 20). At a conference I attended on *Women and Therapy* in 1989, the majority of the functions and lectures were not accessible by wheelchair, even though it was advertised as "wheelchair accessible." As well, the cost of the conference was so high that women living in poverty (many of whom are disabled) could not afford to come to the conference. A few women from the disabled community stressed that by having a conference for only able-bodied, middle class woman, a large number of women were being excluded.

The feminist movement underestimates the power of disability and the isolation it causes. Disability influences all aspects of a woman's life: from the basic day to day survival to how she views the world around her. This is not to say there are not similarities between able-bodied women and disabled women; there are many. However, the differences that exist between able-bodied women and disabled women need to be addressed if feminism wants to represent *all* women.

CHAPTER 2

METHOD

The method of research I employed for this project is experiential analysis, which is a relatively new method of researching in the social sciences. Shulamit Reinharz, the creator, synthesized out of existing methods of research an effective method of analysis congruent with my feminist principles. (1981) For interviewing techniques I turned to Ann Oakley, (1981) a social science researcher, and to the basic principles of feminist counselling set forth by Mary Russell (1984). Some ideas about analysis and format came from a thesis on the experience of breast cancer written by Sheila Campbell (1984).

Experiential analysis is based on a sociology of knowledge perspective. It involves viewing the world dialectically. For example, instead of seeing events as cumulative or in terms of cause and effect, they are seen as processes that are understood in terms of relationships. These processes are dynamic, both influencing and being influenced, and continually exhibiting conflicts and contradictions. Thus, the "truth" in research comes from "balancing and weighing the accounts of reality presented ... by a variety of [sources]" (Ritzer, 1983, p. 431). Insofar as the "truth" or "reality" ultimately can be

discovered, it will emerge from within the varying viewpoints, despite contradictory opinions and evidence.

Variations of experiential analysis have been in existence for a long time. Phenomenology and existentialism, for example, have always valued personal experience and acknowledged their influence on research methods. However, Reinharz has gone a step further than phenomenology and existentialism by developing a new type of method that takes into account the basic feminist principles of valuing experience and acknowledging subjectivity.

Reinharz does not claim that by doing experiential analysis one comprehends the whole picture. In addition, she does not claim that her discoveries are true for all time and in all situations. In fact, she sees the results as a small picture, her picture and the other participants' pictures.

Experiential analysis allows the researcher to acknowledge people's experiences, feelings, thoughts, and beliefs, and by doing so she places value on them. This is an important point, since often the social sciences neglect feelings, thoughts and beliefs in an attempt to appear "more objective." Experiential analysis calls into question the traditional underlying assumptions of the social sciences, that is, that the social sciences are objective and scientific, in particular when dealing with human beings.

Reinharz advocates a non-authoritarian, non-hierarchical relationship between researcher and

participant. Thus, one of the main proponents of experiential analysis is to have a collaborative relation between researcher and subject. Reinharz points out that the "use of the terms 'researcher' and 'subject' is awkward" (1983, p. 180). The conventional term 'subject' in research alludes to the passivity of the person being interviewed and in a sense objectifies her\him. Reinharz believes that it is important to have an interactive relationship between researcher and subject, where subjects are involved in the research and have a sense of commitment to seeing the research through, and where they share the fate of the research. (1983, p. 171) For instance, according to Reinharz, the researcher and the participants should formulate the problem together. In this way, it is more likely that the participants will see the research through to the end and that the results will benefit both researcher and participants. As well, Reinharz suggests having a subsequent meeting after a period of time to ensure that all has been said and that the researcher adequately understands what the participants have related.

Ann Oakley offers valuable information on interviewing techniques. Through her experiences of interviewing several hundred women, Oakley discovered that traditional interviewing techniques did not allow her to validate women's subjective experience (1981). In order to do that, she believes traditional techniques had to be discarded.

For example, Oakley supports a non-hierarchical relationship between interviewer and interviewee, and in order to achieve this, she states it is important for the interviewer not to try to appear objective. (1981, p. 41) In Oakley's approach, as in Reinharz's, the interviews are interactive processes.

In the master's thesis entitled "The Meaning of the Breast Cancer \ Mastectomy Experience," Campbell did several things both in her procedure and in her analysis that I felt were valuable.¹ For example, she wrote out her own story of her experience of breast cancer and mastectomy, and her assumptions and expectations of her research, and incorporated them into the body of the thesis. Furthermore, she referred to her participants as "co-researchers" to reflect the egalitarian relationship between herself and the women she interviewed. (1984)

During the second set of interviews I conducted, I was taking a class in feminist counselling at University of British Columbia under the direction of Dr. Mary Russell, author of Skills in Counseling Women: The Feminist Approach (1984). Although I did not "counsel" the co-researchers at any time, I did incorporate some aspects of feminist counselling, such as listening skills, into the interviews and into the way I handled the co-researcher's problems.

¹ I would like to thank Dr. Sue Wendell for directing me to Sheila Campbell's master's thesis.

What follows is a detailed explanation of how I did my research.

My Assumptions and Expectations

Before I began interviewing, I wrote out my own story about my experience with ME. I wanted to be clear about what was influencing the types of questions I would be asking and what was of interest to me as a result of my experience. For instance, I had negative experiences with the medical establishment that changed the way I viewed the whole medical model of healing, so I was curious to know if other women had similar experiences. On the other hand, I did not have any really negative financial experiences, so I had not really thought about the importance of asking questions about the women's financial situations. Foremost, I saw that writing my story was a way of identifying with my co-researchers. For instance, after writing my story I felt that I had a clearer picture of what happened to me. It was, in a sense, therapeutic. I felt cleansed when I was finished. At the same time, however, I felt anger and sorrow and shame about things that had happened. I realized that many of the women, if not all, might feel the same way after their interviews with me.

After writing my story, I began to write my own assumptions and expectations about the research. Doing this made it clear to me why I was doing the research. It was also a useful tool for analysis, as I could then revert

back to those assumptions and expectations during the analysis and compare them to the actual results.

Most of my assumptions were based on past research about women in general, and about women and men with disabilities. Some assumptions are based on my own life experience. My assumptions are as follows. Based on past research: women are often disbelieved and \ or patronized by medical practitioners; women are often over-prescribed mood altering drugs; women's symptoms are often trivialized and \ or attributed to psychogenic causes; many disabled women feel alienated from mainstream society, family, friends, the disabled community, and the feminist community; people who become ill go through stages of acceptance; people often find ways to make disasters in their lives meaningful or even beneficial to them; poverty or financial strain is a reality for disabled people; and women's primary role is as caregivers to others. Based on my own life experience: most people place high value on health and fitness; most people try to make the best out of a bad situation; and most people are afraid of death, dying, and illness.

Out of these basic assumptions, came my expectations. I expected to find that: most women had a lengthy and intense relationship with the medical establishment and the relationship was not always a good one; many women felt bitter and angry about the way the medical establishment treated them personally and treated the illness itself. I expected that most women went through stages of acceptance

of their disease, beginning with euphoria, joy, or relief at having the diagnosis, to depression and eventually to acceptance. I also expected that most women, if not all, had experienced significant lifestyle changes: changes in their relationships with everyone around them, changes in their self-concept, and changes in how they viewed the world around them. I also expected some women to change how they viewed the meaning of life and death, and of health and illness. I expected that: most women, if not all, tried a wide variety of medical and non-medical treatments, some of which were harmful, to alleviate their symptoms; most if not all, changed their behavior in several different ways in an attempt to alleviate their symptoms or cure their illness. I expected that: women's roles as wife, mother, partner, friend, and sister changed since they became ill, and these role changes (especially if they experienced going from nurturer of others to nurturing oneself and having others nurture them) were the most difficult things for them to cope with. I expected that most women felt extremely isolated, alone, and misunderstood by family, friends, partners, co-workers, and doctors at some point in the illness. Finally, I expected that most women felt they grew in some way from their experience, and that they learned something important.

During this process of writing out my assumptions and expectations, I realized I had to change my way of thinking about research, my way of doing research and my way of

writing about research. For instance, instead of expecting consistent, sequential stories about which I would discover the ultimate truth, I had to accept that people do not always remember things in sequential order, and it is human nature to have many contradictions in our lives. Consequently, I should expect that there would be many contradictions in the stories. Ultimately, the end product was going to be a result of the cumulative efforts of all involved.

At this time I also realized the need to evaluate and modify the format that I had been trained to write in and that I wanted to continue to use because of its useful organizational quality - the format and guidelines set out by the American Psychological Association. The need to modify arose because the framework was too rigid and had underlying assumptions that were not compatible with my feminist principles. For instance, the American Psychological Association (APA) does not encourage authors to describe the relationship between the researcher and participant. (Walsh, 1989, p. 434) As well, the relationship between researcher and participant is assumed to be hierarchical. For instance, Welsh points out that traditionally "[i]nvestigators retain power and control over conceiving, designing, administering, and reporting the research" (1989, p. 434). Furthermore, when writing the report, the APA manual dictates an "objectivist, decontextualized style" (Walsh, 1989, p. 434). For example,

usually the passive voice is used, implying that the researcher is "objective," and participants are referred to as "subjects," implying they are passive objects from which researchers can extract pieces of information. In such a framework, there is no room for reporting ambiguities, feelings, or interactions between researcher and participants. In addition, there is no place for the researcher's voice or point of view. The APA clearly defines what can and cannot be included in each section. For example, under the methods section there are the following subheadings: "subjects," "instrument," and "procedure." I found this to be too constricting. For example, I had no place to fit my experience of finding women to participate in the study. I realized that to know and write about "the truth" of the ME experience for these women, and to incorporate the relationship these women had to the research and to me, required me to combine objectivity, subjectivity and creativity. The result is that I adhere somewhat to the APA style in basic format: I have a literature review, followed by a methods section, followed by a results section, followed by discussion and conclusion. There are many ways I do not follow either the style of writing or the basic principles and assumptions set out by the APA.

Finding Co-researchers

I contacted several ME support groups in Vancouver and surrounding area to find women to interview. I went to support group meetings and gave brief descriptions of the type of research I was doing and asked women who were interested in participating to sign up. It is interesting to note that while talking to the ME support groups, I found that there were certain women who felt they could participate and some women who felt they were not suited to do the research. The reasons given by the latter were "I'm not articulate enough to be in a study" or "my experiences are not very interesting," or "I'm too busy." Three women stated that their memories and concentration were "too bad" to be able to be interviewed over a long stretch of time. I realized that my research would most likely be about women who were outgoing, assertive, confident, unemployed, well educated, and not too ill.

Co-researchers

The co-researchers were eight women all of whom had a diagnosis of ME for at least one year but who had been sick between three and ten years. The mean length of illness was 6.2 years. The median was 6 and 7 years, and the mode was 7 years. The women's ages varied between 29 and 60 years of age. The mean age was 45.5, and the median age was 41 and 46. One woman identified herself as lesbian. One woman identified herself as a woman of color.

Five of the women were living alone at the time of the interview. One woman lived with her partner and child, and two women lived only with their children. Five of the women had children. One woman had two special needs children under the age of 11. One woman had a three year old and another had a teenager who also had ME. Two of the women had two grown children living away, and one of them had grandchildren.

The formal education level achieved ranged from grade 12 to three and a half years of post secondary education. The median and mode were three years post secondary.

All the women described themselves as being "spiritual." One identified herself as Anglican, another followed the Alcoholic Anonymous (AA) twelve steps, one said she read the Bible and the others described a more general sense of spirituality.

At the time of the interviews, all the women were unemployed, although three of the women did volunteer work on a regular basis. The women all came from Vancouver or a suburb of Vancouver.

I chose these eight women out of twelve who responded to my request for participants in the research. The eight women were chosen on the following criteria: (1) distance in kilometers from me; (2) ability to devote the time necessary; (3) diagnosed with ME more than one year ago; (4) ability to articulate their experience in English; and (5) willingness to have their interviews taped. I kept the four

remaining women as "back-ups" in case I needed more information or in case any of the women backed out. One woman did back out after the first interview because she was too busy and I replaced her with a back-up. I contacted the eight chosen women by phone, and we set up a convenient time to meet in their homes. I informed the others that they were back-ups.

Instrument

A list of questions was developed specifically for the study (Appendix A). This instrument contains questions relating to the respondents' work, coping strategies, experiences with the medical establishment, relationships, self-concepts and ways of seeing the world. Most of the questions are open ended to allow the women the opportunity to tell their own stories.

For the main interviews I used an audio cassette recorder.

Procedure

I conducted three interviews with the women in their homes. For the first interview, I took the questions I had previously developed (for the research proposal) to each of the co-researchers and asked for their input. All except one added one or more questions to the list. Many of the women suggested rewording or adding to existing questions. I revised the list of questions to incorporate all their

suggestions. The women signed consent forms and we discussed what to expect for the remaining interviews. I assured them of confidentiality at this time.

In the second interview I set up an audio cassette recorder and we began the interview. The women started by identifying who they were. For example, their age, level of education etc. Then the women began to tell their own stories. I used the list of questions as a guide, only asking the questions when they seemed appropriate. I tried not to lead the interview in any way. Most of the stories were in a somewhat chronological order. One woman was having a difficult time concentrating and remembering events sequentially (this is a symptom of ME). For this woman, I asked the questions and she answered them.

At the end of their stories I turned off the tape recorder and went through the list of questions to see if there was anything that was not mentioned in the list of questions. If there was, I would turn on the tape and I would ask those specific questions. The women were told they were free not to answer any of the questions.

The interviews were conducted at the women's convenience and in their homes where they felt comfortable. Thus, there was variation as to the time of day, the place, and the way in which the women were interviewed (e.g., some of the women were lying down to rest during the interview, some were sitting up).

The women invariably asked me many questions during and after the interviews. I found Oakley's in-depth description of her interviews helpful in preparing and conducting my interviews. For example, Oakley believes the interviewer should answer questions honestly when asked by interviewees instead of using strategies to avoid answering interviewees' questions as employed by conventional researchers (Oakley, 1981, p. 35, 42-44). I used Oakley's method. For example, some women asked why I chose to do a study on women's experiences of ME \ CFS; most of the women asked me how I could manage to go to school, do research, and read; many women asked me about my personal experiences of ME, what treatments I was trying, or had tried; and some women asked my advice about treatments, about going to school, and about childrearing. One woman asked me if I thought she was coping well. I answered all their questions as honestly as I could. When they asked me for advice, I told them clearly it was my own experiences on which I was basing my answers. I felt that by answering their questions honestly, I was diminishing the power differential that I sensed most women felt in the beginning stages of our relationships.

Oakley discovered in her research with women and childbirth that the women she interviewed took the initiative in defining their relationship (Oakley, 1981, p. 45). I found this to be true as well. In the first interview, all of the co-researchers offered me tea, coffee or another drink. Six of the women offered me food on at

least one occasion, and all of the women asked me questions about myself. I felt that by the end of the second interview we were on an equal footing and more like friends than researcher and subject.

The skills I learned in my feminist counselling class were helpful during the main interviews. I found myself using the listening and feedback skills I had developed. At one point, I found myself very distressed over the horrendous predicament of one of the co-researchers. I felt the need to "do something for her" to help her get out of her situation. I even felt a sense of responsibility for her being where she was. Because of what I had learned in my feminist counselling class and through reading literature on feminist counselling, I decided that I needed to supply her with information on where she could go for financial assistance and for affordable counselling. That way she could make up her own mind about what avenue she wanted to pursue. I had learned that I had a responsibility to give her information, but that I didn't need to feel responsible for her or to feel I needed to do something "for her." This helped me to deal effectively with the situation.

My goal in the main interviews was to have the women feel they had told me everything there was to know about their experience of ME. I realized during the process that this was not a realistic goal. A few times I felt (although the women did not report) that they had more to tell me. I sensed that, in some cases, the women were too ill to go on,

or that perhaps they felt that they couldn't afford to give me any more of their time. With one woman I felt that the interview had been too much for her. She had confided in me about prostituting, which she had never told anyone before. She was very emotional, and I felt she was not up to many more questions after that. I did not push her or any of the co-researchers to continue once they let me know that they were finished. I did, however, tell them that I was open to having them phone me at home if they thought of anything they might want to add to their story. (Three of the women did phone me and give me more information.)

Many of the women expressed concern about confidentiality at the end of the main interviews. I explained that I would not use any identifying characteristics and that I would not publish anything until they had validated what I had written about them specifically and felt comfortable with what I had written. I informed them that I would bring the results to them for validation as soon as I had finished writing them. Meanwhile, I destroyed the tapes after the interviews were typed. I used only fictitious names in the transcripts. Since the transcripts still have many identifying characteristics, they too will be destroyed upon completion of this thesis. The names and addresses of the eight co-researchers will be kept under lock and key until such time as I will stop all contact. (The women and I have decided to

keep in touch so I can inform them of any further publications that may arise out the study.)

All of the main interviews were typed verbatim. Once the transcripts were finished I read and reread them to try to get a sense of what the common themes were. I extracted categorical statements from all of the transcripts that seemed to be relevant to a particular theme or simply seemed important. I typed out all of the categorical statements and color-coded them by name. So, for instance, Mary's categorical statements were all together and were coded as yellow. All the categorical statements were referenced by page to the original transcript.

After reading and rereading the categorical statements, I began the painstaking task of grouping together the categories. I found that although there were many themes, there were also many unique experiences that were valuable. I didn't want to concentrate just on the common themes, because I felt unique experiences were equally important. Thus, I adopted a framework similar to the list of questions I had developed for the second interview. I broke down the experiences into what I call "clusters." For instance, there are experiences with the medical establishment, work experiences, experiences with friends and family, and so on. Within each of these clusters I had common themes and unique experiences. For instance, under experiences with friends and family, I discuss caregiving, which was a common theme,

and abuse, which was a unique experience for one woman.

Once I had finished writing the results, I did the final interview, the "validation" interview. I presented the results of my analysis in person to the co-researchers and asked them to validate the parts of the results that pertained to them. I had color-coded the areas that pertained to each woman ahead of time. The women were told that they were free to read the whole results section or to address only those areas I had highlighted for them specifically. One woman read the whole results section while the other co-researchers read only the areas that pertained to them. If they wished to add or change any information they did so at this time. Some of the women changed the wording of their quotes and, in a few cases, the women added or subtracted words or phrases from their quotes to adequately reflect their thoughts. The women did not make changes to what other participants had said. Lastly, I made the changes to the results that the co-researchers requested.

CHAPTER III

RESULTS

EXPERIENCES OF THE DISEASE

Typical days

When the co-researchers were asked to describe a typical day, there were many similarities among the women in how they spent their days. Getting twelve hours of sleep a night was common for six of the women. Those with children living at home seemed to get much less than twelve hours. Six of the women felt they usually had to rest during the day. Four of the women rested every day habitually. The others did so when they felt the need. Resting did not always mean sleeping. For some women, this was their time to listen to a favorite radio or television program, read a book, or listen to music. One woman, who rested every day from 3:00 to 7:00 on her floor with her heating pad, saw the resting as a "preventative measure" to avoid a relapse.

Taking care of themselves was a big part of four of the women's days. Strict daily regimes included such things as relaxation, visualization, meditation, treatments with the TENS machine (transcutaneous electronic nerve stimulation machine), light exercise, and rest. Seven of the women also had daily regimes of various combinations of drug therapy, vitamins, herbs, ointments, and teas. This is one woman's typical day:

I get up around noon, take my medication and vitamins, then do my shopping, banking, pruning the roses, whatever. I have a little lunch then go onto the floor with a heating pad at three o'clock. I bolster up my head, take one Demerol [pain killer], play some light music and do some progressive relaxation I stay on the floor until seven. Then I get up and make dinner, take more medicine and receive phone calls and watch television. I stop all phone calls at ten. I take a sleeping pill at eleven and try and wind down until one. I have no social life.

One woman went to a chiropractor and massage therapist at regular weekly intervals. For another woman, shopping for fresh organic food was a daily routine. She lived on a very strict diet, and buying and cooking food took up a large part of her day.

One woman with severe respiratory problems tried to spend the entire day outdoors, as that was the only way she could keep her lungs clear enough to breathe. This certainly was the opposite to the rest of the women, who spent almost the entire day indoors.

Socializing was not a big part of these women's day, although all of them saw socializing as important for their well-being. Five women reported that they hardly ever went out in the evening. When they did socialize, it tended to be in the mornings or afternoons.

Symptoms

I did not specifically ask about my co-researchers' symptoms. I wanted to avoid detailed descriptions of symptoms, as I was more interested in knowing how they coped overall. Since the symptoms did invariably come up during the interviews, I felt that they were important for these women to report, and that therefore the symptoms should be included with the results.

All the women reported experiencing extreme fatigue or exhaustion. Two women described this fatigue identically: "sometimes it is too much to dress and shower in the same day." One woman described how walking her daughter to school across the street was too much for her some days, because there is a slight incline in the street. Consequently, on such days she resorts to driving her daughter across the street. If she does walk to the school on a "bad" day, she is "finished" for the day because she has expended all her energy.

Seven of the women reported feeling either "disoriented," "spaced out" or "unable to concentrate." Five of these women reported that they were unable to read, watch television, or hold a conversation at times. Six of the women reported memory problems. Lily describes one of her experiences:

I walked to the drug store to get some toilet paper and I walked around for half an hour not knowing where I was or what I was doing there. I got into a panic and left. Half way down the street I remembered. I didn't

have a lot of physical strength but I did go back to the drug store again. By the time I got there, it was gone again. It took me about two hours to get a roll of toilet paper when I should have been laying down on the couch resting.

Two of the women suffered from recurring headaches. Two complained of depression and two women complained of having anxieties and fears that were exaggerated. Three of the women described feeling irritable a lot of the time.

Muscle pain and weakness, especially in the limbs, was reported by five of the women. Walking and carrying anything was sometimes extremely difficult. The pain was described by one as "it hurts when someone touches me." Another women described it as "an ache that goes from my hair to my toenails."

Six of the women reported being "hypersensitive" or "allergic" to many things. All of these women were hypersensitive to drugs. Francine describes her hypersensitivity:

I am very sensitive. I react quickly and strongly. And because I am overweight they give me more [drugs] because they go by body weight and I don't require that.

Another woman who was on an antidepressant said "every side effect there was - I got." Another woman who had been in surgery said she reacted very badly to the anesthetic and found it took a long time to get the anesthetic out of her system.

Five of the women found they could not tolerate second hand smoke at all. In fact, all five of the women felt their sense of smell was so acute that anything that had a strong or toxic smell, (i.e., perfumes, dry-cleaning, new carpet, fresh paint, carbon monoxide) made them ill.

Another allergy reported was to certain foods. Five of the woman felt they were now allergic or sensitive to dairy and wheat products and a variety of other foods. Two of those women also could not tolerate meats and any processed food. They also tried to eat organically grown vegetables as much as possible.

Four of the women complained of having gastrointestinal problems. Recurring diarrhea was experienced by all these women. Two of the women were diagnosed with "irritable bowel syndrome." Another two had recurring abdominal pain. Weight gain was considered a real problem for three of these women.

Four of the women reported having urinary problems. Two women experienced recurring bladder infections. One woman experienced frequent urination and one of the youngest women was incontinent at times.

Three of the women reported that they had "noises" in their heads. One woman described the noises as "a ringing," the other, as "a hollow sound." Two women had blurred vision at times.

Many other diseases and disorders that the women felt might be related to ME were reported. For example, three

women reported having respiratory problems. One of these women suffered to the extreme. Her life was centered around trying to find ways to clear her lungs enough to breathe. Another woman had recurring bronchitis. Two women reported having chronic sinusitis. Another two women had recurring yeast infections. Two women had tumors that had to be removed. One had the tumor in her throat, the other had the tumor in her abdomen and the outer circumference of her breast. Two women had cysts on their ovaries. One woman had recurring staff infections in the eye area.

Changes in Physical and Mental Abilities

The co-researchers reported drastic changes in their everyday lives. Physically, all the women were very active before becoming ill. They all worked outside the home full time before becoming ill. Their occupations were as follows: flight attendant, shiatsu therapist, cook, draftswoman, administrative secretary, owner and operator of landscaping business, psychiatric nurse, and registered nurse. Four women also did volunteer work.

Four of the women said sports had been a big part of their lives. One woman, for example, was an avid hiker, mountain climber, and canoeist. Another woman said she "hiked and swam a lot." Four women were very active in the community. Three women had travelled extensively and regularly. One woman had a very active social life.

Another woman was a single mother to two special needs children, and was also active in the community.

When asked to describe their health before becoming ill, all the women said it was "good" or "excellent." All the women reported that they had no problems with memory or concentration before becoming ill. They reported that they became very ill, very quickly. For instance, when asked to describe their health six months after becoming ill, all the women used words such as "devastating," "debilitating," "horrible," "extremely bad." Only one of the women stopped her paid job right away. Three women took a leave of absence, then tried to return to work several times. Two women worked part-time for a while. Two women tried to keep working full-time. Eventually, all the women stopped working outside the home altogether. All sporting activities also eventually stopped, as the women found they no longer had the physical ability to endure exercise.

Of the four women who were engaged in volunteer work, all of them eventually cut down on their volunteer work. Two women increased it for a period of time because it gave them a "sense of worth." However, these two women, at the time of the interviews, were both retiring from most of their volunteer work.

The women also reported that their social lives changed dramatically since they were not able to "keep up" with their friends. The majority of the women led very secluded,

sedentary lives. However, that was not always negative.

Francine put it this way:

What happened to me and I'm sure what happens to a lot of other people, is that their world gets smaller and smaller and eventually it can make you sane My daughter put some plants on the balcony for Mother's Day and it was so great. So little things have become important I have begun to write - to write some poetry.

Modes of transportation also changed as the women's ability to walk and drive decreased. Two of the women had recently gotten motorized scooters to help them get around. They found that motorized scooters gave them a lot of freedom. Due to visual and concentration problems, five of the women stopped driving either permanently, or temporarily when they were not feeling well. These women relied on public transit, friends and family, and taxicabs to get them to their destinations.

All the women reported having difficulty reading, watching television, studying, or even holding a conversation in the first six months of their illness and later when they were having a relapse. Two women experienced all of these difficulties.

Two of the women's lives are still totally centered on coping with their illness because their health is still very poor. As Lily states, "all I do is cope - there is nothing left over." These two women described their health now as much the same as in the first six months of the illness.

The other women felt their health had improved somewhat since the first six months. They used words such as "passable," "shitty," "up and down" and "bad" to describe their health now.

What is ME?

The women all had their own understanding of what "ME" meant. This picture of ME changed as the illness wore on. All the women reported that at first they simply thought they were sick and that they would go to a doctor and everything would be "fixed up." They saw their illnesses as acute and curable. Once they discovered they had "ME," or "CFS" or "EBV," their views gradually changed and they saw their illness as a chronic disease probably caused by a virus. At the time of the interviews, three women believed their illnesses were curable. One woman gave her rendition of why people have ME:

I believe environmental degradation is responsible for my disability. It is because of environmental degradation that we are not as healthy as we once were and that the immune systems of the planet are breaking down. All the disorders that have become prominent in the last 20 years are immune disorders, herpes, ME, lupus, AIDS, cancers.

All of the co-researchers had read a fair amount of literature on ME. However, from their own personal experiences of the disease, the women had very different thoughts about the nature of ME. One woman felt she would

die soon, maybe within a year, because of complications from ME. Another woman said she was "prepared to die all the time" and it wasn't because she was depressed but because she became so ill at times. Two women felt they would worsen over time. Three women didn't think their health would change, and only one woman said she saw herself as getting "stronger and healthier."

The belief that ME is contagious was a very big issue for one woman. She was afraid to be intimate with anyone or to share food with anyone. Although two other women brought up the fact that they too thought ME was contagious, they did not express a great fear. However, they were still very concerned that they may have given, or might give, ME to other people.

MEDICAL EXPERIENCES

Diagnosis

The time it took for the women to get a diagnosis of ME / CFS / EBV varied greatly. The range was from nine years to four months. The woman who waited nine years for a diagnosis had been ill the longest of the eight women. The woman who waited only four months for a diagnosis, had been ill the shortest time of the eight women.

With the exception of one, all the women were given other diagnoses besides ME / EBV to explain their symptoms.² The other diagnoses were as follows: two women were diagnosed with fibromyalgia (a disorder marked by inflammation of muscles and connective tissues, stiffness, and joint or muscle pain), three with depression, one with pelvic inflammatory disease, one with "the flu, the flu, the flu," one with stress, two with anorexia, One with food allergies, one with a psychosomatic disorder, one as menopausal, and one with dementia.

Their doctors were not usually the ones who finally discovered the women had ME. In five cases the women had heard through the media about ME and recognized the symptoms as the same ones they were experiencing. These women told doctors who then agreed with the diagnoses. The remaining three women were diagnosed as having EBV and gradually realized through reading literature on ME that EBV and ME were the same disease.

Two of the women who had a difficult time getting a diagnosis had been in accidents. The accident in one case seemed to have triggered the ME; in the other case, it made the ME, which had been "manageable" for five years, flare up. (The woman was not aware that her illness was ME all those years). The accidents posed particular problems for the women in that they were not believed by their doctors.

² For confidential reasons, I cannot identify which woman was given which diagnosis(es).

The symptoms always seemed to be "too severe" for the type of injury or "not related" to the injuries. Thus, their symptoms were discounted. One of these women was diagnosed by several doctors as "psychosomatic." The other woman was involved in a court battle over a settlement for the accident and found that her doctor of ten years, whom she trusted, had written in her files several times that he simply "did not believe her." She was not aware of his disbelief until the files were brought out in the court proceedings.

Depression was given as a diagnosis several times. One woman, who had two people she knew (an aunt and a girlfriend's father) die a week apart, was diagnosed with "grief" even though she said she didn't feel depressed about the deaths. She was prescribed Halcion [a tranquilizer] to help her sleep and she was given some literature on grief. Janet said:

Later when I started getting physical signs of fatigue, poor digestion and weight loss, that were reasonable she [the doctor] sent me to the gastroenterologist for tests. But she still felt that it was triggered by grief and that it was going to settle down.

The woman who had a teenager who also had ME said depression was also used as a diagnosis for her daughter. Her mother had this to say:

She [her daughter] came down with acute abdominal pain. The gynecologist said there was nothing wrong with her. Because nothing showed up for PID, the doctor put her

on antidepressants and sent her home with this little sheet of paper describing depression and describing the treatments. It had all these lists of things you could do to help with depression. One of them was ECT [electroshock therapy]. This is for a 16 year old kid who has been hospitalized for seven days with acute abdominal pain The gynecologist said she had a problem with illness and that we both were isolated and devastated about illness.

Once the women did have a diagnosis of ME \ CFS \ EBV six of them reported feeling euphoric. Margaret gave a typical response:

I felt great relief. Not because I was overjoyed at having ME, but because of the validation that there was actually something wrong with me and it wasn't like I had one foot in the psychiatric ward It felt really good to have someone believe me.

For two of the women, the experience was not connected with joy at all. One woman said:

It didn't mean much to me because the doctor never explained it to me. I didn't know if I was going to die or get better or what was going to happen.

For her, understanding that she had ME and accepting what that meant was a process that spanned many years. Another woman felt completely devastated when she was told she had ME. She reported that at one point she felt close to committing suicide.

Supportive and Helpful Health Professionals

All but one woman had one or more experiences in which a health professional was helpful and supportive. Three women reported that they had some support and help from a physician during their illness. Support included the doctor being "understanding," "non judgmental," and "respectful." Helpful meant more tangible help such as filling out insurance forms, or trying new treatments.

Helga reported that one doctor she found was "kind and willing to listen and read any information [she] brought him." Two women had very good experiences with their psychiatrists and one woman with her therapists (all of whom were female). They all reported that their psychiatrists / therapists were the only ones who believed they were truly ill. The psychiatrists / therapists were described as a "key person" and a "saving grace." Two of the women have continued with their therapy. Francine said:

The person who is my therapist is probably the key person that has helped me. She helped me to organize everything, to help me take care of all the things that needed taking care of. She believes her position is as an advocate for me. She is someone who can say 'I have known this person for this period of time and I don't think she is crazy. I believe she is ill'.

One woman found her gastroenterologist helpful because he believed her and was informed about ME. He told her she had Giardiasis [an infection of the intestines] which he said was common in people with ME, and he prescribed Flagyl

[an antiprotozoal]. The recurring diarrhea she had suffered for three years was suddenly gone. Another woman got a diagnosis and continuing support from a friend who was an internal medicine specialist. Two women felt their kinesiologist was supportive and helpful. Meg says this of her kinesiologist:

He took a keen interest in me and was the thread that held me together until my big flare up. He used TENS and acupuncture and he helped me with my [court battles].... He was the one person I could go and talk to. It was more like counselling. The TENS and acupuncture didn't work though.

One woman found ongoing support from her chiropractor, kinesiologist, and massage therapist, all three of whom she educated about ME. This woman also saw a pain management specialist who was supportive and willing to listen and try new things. The eighth woman could think of no experience where she got support or help from a health professional.

The positive experiences the women spoke about were rarely ongoing except with the psychiatrists, therapists, the chiropractor, kinesiologist and the massage therapist. The experiences were usually of short duration. In some cases the helping professional was supportive but not helpful or was supportive and helpful on one occasion and not on another. Lily tells of her latest experience:

After much doctor shopping I settled on this very sweet doctor down the street. He doesn't know a lot about ME but I feel he is emotionally supportive which is a hell of a lot better than what I have been getting (i.e.,

when I burst into tears when I was relapsing, he hugged me and said 'take all the time you need' instead of yelling at me). So that was an improvement. But, he is not supportive about prescribing me Flagyl for my Giardia, which has come back without a positive test result. Unfortunately, getting a positive test result is hard to get at the best of times. He likes to take the natural route. So he is not supportive physically.

Negative Experiences with Health Professionals

Seven of the women reported that many general practitioners and specialists either did not believe they were ill and that they were lying about their illness, and / or the doctors did not believe ME existed. In three cases the women were not aware that their doctors did not believe them. Margaret states:

My doctor was really on the fence in the beginning. One day he would be ok, and the next day he wouldn't be. I finally brought him an article on ME and he read it. I thought he would go along with it but he didn't and he never told me. I had been seeing him for 20 years When I lost all my group life insurance, thanks to the report he sent in, I confronted him and he told me he was still 'on the fence'.

One woman found out about her doctor's disbelief when her files became evidence in a court case:

At one point the doctor had written that I had all this abdominal pain because I worked in a rape crisis centre and I identified with my clients. I also discovered that he wrote in my chart a really awful thing about how I persisted in this morbid fantasy about my rotten insides He kept going on about my psychological quarrel with my insides He often said in his reports that he didn't believe me. I wasn't aware of that. It was very demoralizing to actually read some of that stuff and find out how much power he had over my life.

Two women were told to see a psychiatrist because there were "no physical symptoms." One woman was a psychiatric nurse. She had this to say:

In the beginning, my family physician and later the neurologist, said I should see a psychiatrist. I knew something was happening but I knew it wasn't that. I'd been a psych nurse too long. I can certainly separate what is going on in my head.

The majority of the women said their symptoms were merely dismissed. Helga's doctors thought she was "exaggerating." One of the women who had had an accident, was told "she had pain where she couldn't possibly."

One woman had a myelogram (x-ray used to examine the spinal cord) that was done improperly, which left her completely disorientated for three months. One woman was given an unnecessary hysterectomy to end her abdominal pain. One woman was told by her insurance company to go to a certain doctor. The doctor verbally abused her for five minutes. He kept saying "you are a nurse and you can't remember what pills you were on five years ago?" He did not get a chance to examine her because she walked out on him. From his five minute interview, he proceeded to write a five page letter against her:

He wrote that he was this big person, he was in business for fifty years and a whole bunch of things pointing to his opinion about me and his right to do that. His report had a lot of weight in court All this and he only saw me for a few minutes. He didn't even examine me. He literally didn't do anything and yet he wrote this terrible letter.

Four women said they were discriminated against by their doctors either because they had ME or because they were women. Francine and her daughter went to a physician whom they had heard was quite good. The doctor said she would take the daughter who had ME but not Francine because she was on painkillers. While Janet was seeing a gastroenterologist he repeatedly referred to her as a "pretty white woman who was successful, who looked fine, and was articulate and intelligent, and who had nothing physically wrong with her." He gave her a small bowel biopsy without any anesthetic and left the hose down her throat for half an hour because he had booked several other people with the same procedure at the same time. Later Janet found out from her general practitioner that doing the small biopsy was unnecessary. Finally, he suggested Janet see a psychiatrist because he believed she was anorexic or bulimic. Sue had this to say:

I really feel because I am a woman there is a lot of prejudice. It seems like I have to prove myself to doctors all the time. They don't believe me I find I really have to watch what I say, how I talk to them. I can't tell them what I know because they will say 'she is a hypochondriac - she's been studying'. So I play them now. I say 'you are the doctor, you know what is best, I don't know these kinds of things'. Meanwhile, I know everything, I've read everything.

Lily was suffering from violent hives and needed to see her specialist who was familiar with her ME and her allergies:

I phoned to make the appointment and the receptionist said 'oh, he is not seeing any ME patients till Christmas. And I said, well I have these hives, I'll be dead before Christmas. She said 'oh, you mean it isn't for ME?' I said 'no not exactly'[hives are a symptom of ME]. She said 'well he is seeing non-ME people in October so I'll book you but you have to promise not to say anything about ME or he'll rip your head off.

Lily did go to see this doctor and did not mention her ME.

It was clear that many of the co-researchers' doctors did not understand the nature of ME. Six of the women were told by their doctors to exercise more. For instance, Lily was told to get on a bicycle and ride everyday, and Meg was told to join an aerobics class and to go back to work. Four women were told to lose weight. One woman found out her gynecologist had put in her file that she was "just an obese middle-aged woman." Lily was told by her naturopath that if she quit smoking she would be cured. Margaret was told her symptoms would be gone if she just changed her profession. Janet went to a nutritionist on the insistence of her doctor. Janet knew she was sensitive to certain foods but the nutritionist would not accept that. As far as the nutritionist was concerned, if Janet did not have an actual diagnosis of "celiac," she needed to incorporate wheat into her diet. She refused to take Janet's word on it.

Many of the women expressed that they felt like a nuisance to their doctors. When Meg went in to see a doctor for the second time, he showed her files of a dentist and a

"neurotic separated lady" for whom he had to "waste his time going to court." He then asked her "what the hell" she was doing there in his office, implying she was another patient wasting his time. A few of the women stated that they never got more than a few minutes with their doctors. Lily stated that her doctor began to say sarcastic things to her like "you can't just laze around for the rest of your life." Then one day he "told her off" for taking up more than ten minutes of his time. Another woman had this to say:

I finally found a doctor who was receptive but who books patients every few minutes. So I wait for over an hour to see him and only get a minute or two of his time. I feel really objectified because you are so anonymous.

Negative experiences also occurred with non-traditional doctors. Three of the women reported that visits to, and the remedies and treatments from, naturopaths, herbalists, homeopaths, and massage therapists were costly and often frustrating. If positive results did occur, which was not often, the cost was often too high for them to continue the treatment or remedy. One woman went to see her naturopath. This was her experience:

[The naturopath] started prescribing this really expensive stuff and I said 'excuse me but I am on welfare. I cannot afford this'. She asked me how much I was willing to 'dedicate to my good health.' I told her fifty dollars a month. She completely lost interest. She told me to buy this stuff in her pharmacy on the way out. She didn't tell me that what

she was prescribing was available for a third to a half cheaper in another store.

Changes in the Women's Views of the Medical Establishment

As a result of ME, all of the women had changed their view of the medical establishment and of doctors in particular. Seven women stated that before they became ill they believed in the medical establishment and trusted doctors' judgments. They also expected that medical science would cure them or at least tell them what was the matter with them. One woman, who had had previous negative experiences with the medical establishment, was already suspicious of it and of doctors' judgments.

After becoming ill, four women reported that they lost respect for their medical doctors. Margaret said:

I have lost respect for my doctor because for the length of time I've been seeing him [20 years], he could have credited me with the ability to know that there was something radically wrong with me.

Two women stressed how they have lost faith in medical science. Before they got ME they felt that if they were sick it was just a matter of going to the doctor and the doctor telling them what was wrong and how to fix it. Now they feel that the medical establishment knows very little about the body and that medicine does not have all the answers. One woman, who was a nurse, said she did not trust any doctors anymore now that she realizes how much power they have. She stated:

Now I don't give information I don't expect will be respected. If I do give any information away, I have to expect that it will not be respected. And I only do that in exchange for something else.

The psychiatric nurse had changed her views about the psychiatric profession. She had this to say:

I just wonder how many psych patients are misdiagnosed. How many of these are suffering with other misdiagnosed diseases and then doped up with medication which they are not supposed to be on?

Three of the women stressed how shocked they were to find the prejudice against women that existed within the medical establishment. They did not believe before that there was any discrimination within the medical establishment. One woman discovered this:

We don't have a position as women, as middle-aged fat women. It has become clear to me that I don't get seen, I don't get heard.

Their changes in attitudes led many of the women to take charge actively of their health rather than be passive subjects. Four of the women stated that now they only go to their doctors for "maintenance." Francine said:

I only go for maintenance. I've come to the point where I don't want to see doctors anymore for anything. I go to get my prescriptions filled. In fact, my GP [general practitioner] knows nothing about ME at all.

One woman stated that "now, any doctor I am sent to, I don't care how highly recommended he comes, he has to prove himself."

TREATMENTS

Treatments Tried

The number of treatments these eight women tried ranged from five to sixteen treatments each. I use the word treatment widely, including anything the women used on a regular basis to try to alleviate their symptoms. The types of treatments ranged from medical treatments, such as drugs, to "new age" treatments such as psychic healers, to "natural" treatments such as herbs. There was very little agreement between the women about what was helpful and what was not. It seemed to depend largely on the individual. For example, whereas one woman found Sunryder products (Chinese herbs) helpful, another woman found they made her symptoms worse. Some of the treatments helped to a certain degree, but no treatment eliminated all the symptoms of ME. The following is a summary of what was helpful and not helpful for these women.

Helpful Treatments

Five women felt that changing their diet was helpful. Changing their diet included excluding wheat, dairy, alcohol and in some cases sugar, yeast and meats from their diets. Four of the women found that relaxation, deep breathing, meditating, and visualizing all helped to some degree, both physically and mentally. Three of the women reported that taking vitamins and minerals on a daily basis was helpful. Two of these women found that "mega" doses of vitamin C were helpful in addition to multivitamins and minerals. Two women found that stretching or yoga was beneficial if they did not overdo it. Two women found that going to a massage therapist was helpful. But, for one of these women, the day after the message she felt "wiped out." Three women found various herbs (Sunryder products, Chinese herbs from Chinatown, and Gingko) to be helpful. Two of the women went to hypnotherapists. One said it was helpful and the other was not sure yet because she was just beginning the sessions. One woman found reishi mushrooms helped her once and CO-Q-10 (enzyme) helped once.

Three women found various painkillers effective. In particular, the two women who had been in accidents found painkillers effective for their various injuries. Taking extra strength Tylenol and Tylenol 3 were useful for three of the women. One of these women, who reported having tried "everything under the sun," found that the best thing for her was simply to rest and take Extra Strength Tylenol. One

woman had a very intense drug therapy program set up which included anti-inflammatories, anabolic steroids, tricyclic antidepressants, painkillers, and tranquilizers. Another woman was on tranquilizers and was very concerned that she was addicted to them. However, her doctor insisted that sleep was the most important thing for her and he recommended she stay on tranquilizers. One woman felt Gamma Globulin (an immune system modulator) was somewhat helpful.

One woman had various things she found helpful but that no one else did. Following are some of the treatments she found helpful that the other women did not mention: TENS machine, Zheng Gu Shui (a Chinese ointment), chiropractic adjustments, naturopathic remedies, swimming, and doing positive affirmations.

Unhelpful Treatments

Many of the women reported adverse effects from drugs. Five women reacted adversely to various pain killers. Three women found that they reacted negatively to antidepressants. One woman had a negative reaction to a muscle relaxant. Another woman had a bad reaction to antibiotics and to cortisone. One woman had a severe reaction to Halcion (a tranquilizer).

Many women found "natural" treatments such as blue green algae, Matol, herbs, vitamin B shots, radio wave devices, naturopathic and homeopathic remedies and acupuncture not helpful. One woman found that physiotherapy

did not help. Another found that the TENS machine did not help. And lastly, one woman found that doing positive affirmations was damaging because it put the blame on her for her illness.

One woman had consulted an Indian Shaman and a psychic healer. She found the experience with the Indian Shaman "nice" but did not report feeling any better afterwards. However, she did report feeling a "bit" better for awhile after seeing a psychic healer.

Cost and Time

Many of the women stressed that they would like to try many treatments, but that due to financial constraint, they could not even consider trying them. Some of the women had found something helpful but had to stop because they could not afford to pay for the treatments. Lily, for example, found that the one thing that had helped her (CO-Q-10) was too expensive to continue on a regular basis. All the women on the restricted diet commented on the additional expense of eating non-dairy, non-wheat, fresh and organic foods.

Time and energy was another barrier to maintaining and trying new treatments. All the women, but especially those with children living at home, expressed how difficult it was to keep up with basic day to day activities. There was often no time or energy to do those "extra" things like meditation, shopping for and cooking healthy and wheat-free, dairy-free meals. As one woman put it:

Many things have helped, but they are hard to do because you have to be organized and on top of things. That is hard when you are sick and have a three-year-old running around.

Anger and Frustration

The women reported feeling frustrated and angry when treatments did not work. One woman in particular who was extremely sick had this to say:

I get angry because doctors don't really learn in school all the side-effects of drugs and I am wondering if I got worse because my body was so loaded with antibiotics I'm angry at my body. I feel why are you not getting better? I am feeding you the right food, I am exercising, I'm treating you good, I'm doing stupid yoga, I'm doing deep breathing, I don't take cigarettes or alcohol or candy. I hate that my whole life is consumed by my health.

WORK AND FINANCES

Previous Work

All the women eventually had to stop working outside the home after they became ill. Six of the women tried to continue their jobs in some way when they became ill (i.e., changed to part-time, took leaves of absence). Two of the women stopped working as soon as they became ill. Of the women who kept working, three reported difficulties with bosses and co-workers who did not understand their illnesses. When Sue, who worked for a man who did not speak

English well, phoned in sick, her boss would say "Sue mentally sick." Janet found her boss understanding once she had a diagnosis. Before her diagnosis, he was often impatient with her. Co-workers were hard to deal with for Francine:

I really let people down. People would be angry with me because I couldn't let them know ahead of time what I could do. I couldn't tell ahead of time what I was able to manage. Everything I took on seemed to fall through. My self esteem was really affected because before my word meant something.

Once the women stopped working outside the home, they reported a loss of pride, confidence and worthiness. Some felt "shameful," "humiliated," and "inadequate." Another woman found not being able to work hard to accept.

It made me feel pretty angry and sad and hopeless because there is no place for me. Working is hugely connected to my self-worth I can't even hold a volunteer job with any consistent responsibility. I feel really robbed of my chance to be productive and predictable.

Similarly, one woman stated that she felt like a "real loser" because she was not "putting her two bits worth into society." Margaret, who had worked since she was sixteen and who had nursed for 30 years lost more than just a job. She lost friends:

There is a lot of pain in leaving my job. I liked the staff, I liked the clients, I just liked the job.

Financial Difficulties

The financial situations of the women before becoming ill varied greatly. Whereas one woman made 40,000 - 55, 000 per year, another woman was living well below the poverty level. Once the women stopped working, their financial situations changed drastically, except for the woman living below the poverty level. As she stated, "I was desperate then, I am desperate now."

When Sue first became ill, she went to unemployment insurance for help. They refused to give her any sickness and illness benefits because she did not have a doctor's note. She was extremely desperate. Sue told the woman at unemployment insurance that if they were not going to give her the money she would have to go out and do something "criminal." Sue stated:

With that I walked out. I was so angry. The woman came running down the street after me and said she would give me the money. It took something desperate like that to get my money.

After sickness and illness benefits ran out, Sue tried a few different jobs and eventually went on welfare. Lily, like Sue, received unemployment insurance sickness and illness benefits and eventually went on welfare. Francine also resorted to welfare. She applied for disability insurance for five years, but because she had no diagnosis, she was turned down. She believes that not being recognized by

Revenue Canada as disabled affected her ability to get other benefits.

One woman remembers two months when she had absolutely no money coming in. She believes the only reason she survived was because she lived in a co-op and she didn't have to pay rent for those months. As well, she had caring neighbors who brought her food from time to time.

One woman, who was quite well-off before her illness, found herself having to move three times in 18 months because of financial difficulties. She now lives in a co-op and gets disability insurance, private insurance and has some savings to fall back on. At one point, her private insurance was cancelled after she had been on it for two years. She said:

Whatever the doctor had told them, it gave them the impression that nothing was wrong with me.

She threatened a lawsuit and after submitting her own case, she won. This woman also had difficulty getting Canada Pension Plan benefits (CPP), because she kept putting on the application that she "hoped" to return to work one day. After four years, she finally realized she had to state that she did not see herself returning to work ever again which is true. She has never been well enough to be able to return to work. Only one woman reported being on GAIN (Guaranteed Available Income For Need) for the handicapped

(social assistance for people with disabilities). Another woman was living entirely on investment income.

When one woman first became ill she was self-employed. As she slowly cut down her workload, she relied on her savings to live. Eventually, she sold her car and declared personal bankruptcy. During a remission she returned to work and took out private insurance. (At the time her only diagnosis had been food allergies, so she had no difficulty being accepted). Unfortunately, the remission did not last, and she was forced to stop working. She now collects private insurance, and CPP benefits. Whereas before she could not get by financially without the help of her mother, now she describes her financial situation as "livable." Another woman had difficulties getting insurance benefits from the company she worked for until her doctor threatened to take them to the media and consumer relations. She is now applying for CPP benefits. Mary stated:

[Before I received insurance benefits] it was difficult because my husband was also out of work. We basically lived off our savings.

Four of the women stated that financial problems were the most difficult thing they had to deal with since becoming ill. Many stressed that without adequate funding they were not able to pursue avenues of treatment they felt might be helpful to them.

One woman who is a single parent had this to say:

Now I get 1200 a month which is really good. But what has happened over the years is that I have accumulated debt. That is what happens after years of having no extra money. I can't get ahead.

One woman stated her basic living expenses equal 600.00 a month. She gets 550.00 from social assistance. A friend of hers (who has a chronic illness) told her about a way to make some extra money. She has now turned to a form of prostitution to pay her bills. She sleeps with the same man once a month and gets paid for it. She states:

[It] is really terrible for me because I am very religious and I know it is morally wrong. But, I am doing this to survive. My conscience really bothers me and I have a lot of guilt. It is such a desperate situation. I am chronically ill and I have no one to lean on. I don't have a family to go home to. I don't have any friends I can go to. Sometimes I think is it really worth it, wouldn't I just rather die?

Housework

Four of the eight co-researchers have a homemaker come to their homes to help with housework. However, there is variation in how much the homemaker does, how often the homemaker comes in, and who pays for the homemaker. For one woman, the homemaker comes in two times a week. She helps with laundry and general cleaning and will even run errands or pick up the children from school if necessary. The homemaker is paid for by GAIN. For another woman, a team of

two cleaning women come to her house once a month. She pays for this service herself. For another woman, a homemaker comes in and does only the vacuuming. Social assistance pays for this.

One of these women commented on how having a homemaker still does not adequately address her needs. She stated:

I have a homemaker who shuffles things around for three hours, once a week. After five years there is dust behind the couch and the walls need to be washed. It needs to be cleaned behind the stove and fridge. There is no way I can do these things. The homemakers won't do it and I don't have enough money to hire someone to do it for me.

Other women also reported that housework had accumulated. It was not as if they wanted their houses to be like they used to be, for they were getting used to "letting things go a little," but that dust and dirt that needed to be looked after accumulated. One woman who lives alone found that the best way to deal with housework was to be very tidy:

I can deal with housework in small amounts so I clean up after myself as I mess.

Another woman found that living alone was beneficial because there is no one around to bother her about a messy house. She cleans only when she is physically able and otherwise leaves it messy.

Volunteer Work

Four of the women found that doing volunteer work was important to them because it gave them a sense of worth. Janet had this to say about the various volunteer jobs she has:

Volunteering keeps me busy and gives me a sense of self-worth and makes me feel like I am doing something worthwhile because I find it frustrating not to do anything at all.

One woman began volunteering after three years of being ill "to build up her activity level." Three of the women were involved with leading ME support groups at one time or another. Other volunteer work included editing and writing for a lesbian newspaper, and working with environmental and peace groups.

EXPERIENCES WITH FRIENDS AND FAMILY

Caregiving

Seven of the women described themselves as "caregivers of others." Five of these women found it difficult to have to ask others for help. Helga gave a typical response:

I have trouble asking people to do things. I've been sort of a traditional woman in society who did everything for everybody else. I've had to learn to ask for help.

For Janet, admitting that she needed help meant that she was "giving into the illness." She stated:

As long as I could cope with things myself, I could believe I wasn't really sick I could have had more help but I was too stubborn.

For the women who had children living with them, there was no question as to who comes first when mother and children were ill at the same time. One woman reported:

When we both get sick [her daughter also has ME] I look after her. She comes first.

However, the woman with two special needs children reported how difficult it was to mother alone:

I begged the children's father to quit work and look after them or even to look after them part time, but he wouldn't. I mean I love my kids but it is a constant strain of trying to maintain a life as a single parent that has kept me so ill.

Six of the women felt that family and friends found it difficult to accept that they could no longer be the caregivers they once were. Mary, who had always taken care of the social and economic needs of her family, found her husband having a difficult time taking over:

It was really hard for my husband because all of a sudden he had to take responsibility for things he never had to before. So our roles have been totally reversed.

The consequence was a 3 month separation. However, this woman reports that with the help of a support group for spouses and partners of people with ME, their relationship is better.

One woman had played the part of caregiver in many areas of her life - as a nurse, a volunteer, a wife, a mother, and an older sister. In her attempt to understand her position she had this to say:

Maybe it is better to give assistance, to be a nurse, to be a facilitator of a woman's group, to advocate for someone else, to organize and assist someone else, than to be part of the group who needs it. But that is wrong. There shouldn't be that division at all and maybe as an advocator I helped keep that division - the ones who help and the ones who need help. There is such a loss of self worth taken away in such a system I was creating that structure where it is dangerous to be vulnerable ... I was only aware of the power structure [before]. I used to be in the position of "do gooder." I thought I was saving the world, making the world a better place when in fact I was helping to perpetuate the division. But it is not all black and white. I could do with some advocacy right now.

Two women said they had no one to care for them when they became really sick. They were entirely on their own. Both women reported how frightening it was to have no one to rely on.

Receiving Care From Friends and Family

Five women reported receiving some tangible support from friends and family. All these women found that they

had friends who helped out occasionally. Helga stayed with friends, including her ex-husband, for months at a time when she was quite ill. Lily and Mary have friends who offer childcare occasionally. For one woman, the help from a friend had a price:

I had one friend who agreed to help me and I gave her so much an hour.

Three other women found their friends with ME to be supportive emotionally. One woman reported:

When I am really feeling down, I'll phone my friends who have ME because I know they have the kind of understanding of being ill.

Mary found her mother, who had post polio syndrome, to be very supportive emotionally and financially. Her mother offered to pay to have someone come into Mary's house and clean on a regular basis. Helga was touched when her son and his family asked her to move to the Yukon to live with them because they thought the fresh air would be helpful.

One woman found that her healthy "friends" were supportive in one situation but not in another:

When I worked on the lesbian feminist magazine, the women were very supportive. Sometimes I would fade in and out of conversations, sometimes I would be horizontal at meetings and they would be supportive. But if I would run into them at the bar or something, they wouldn't want to spend any time talking to me. It was as if they didn't want to witness the struggle.

Lack of Understanding and Support

All the women reported that when they first became ill, they did not receive much support or understanding from friends or family. In particular, family members were not very supportive either emotionally, physically, or financially. One woman had this to say about her husband:

He will let the dishes just keep piling up when I am really sick. And then he'll make comments that the dishes are not done.

Another woman had this to say about her in-laws:

My in-laws are not supportive at all. My mother-in-law has said 'just lose weight' or 'just ignore it'. My father-in-law is a doctor and at first he was one of those who didn't believe ME existed. But he has since changed his mind.

One woman tried to get respite care for her two children, but she reported that "it just did not work, it was too complicated." When she had a particularly bad relapse, she was told by welfare to put her children in foster care. One woman found that one of the most difficult things she had to deal with was having no support:

I don't have anybody coming over and cooking my meals or running errands when I am really sick. I don't have any one coming over and giving me money. Just being totally independent is hard but I don't know where to go to get help from I just wish I had a home to go to just to relax. But that is the way life is. I am an adult and I have to be responsible for myself.

Three women did not get support or acceptance from others (in two cases a brother, in the other, a friend) until the others had heard about other people who had ME. Sue reported:

One of my girlfriend's mothers has been diagnosed with ME and she called me up and said "oh it is a legitimate illness then!"

Many old friends vanished quickly for all of the women once they became ill. Thus they rarely received support from old friends. Mary had this to say:

I finally got someone to help me clean my house and my friend said 'are you cleaning with her, I always get so much more done when I clean with my cleaning person'. I just thought this was unreal. I have known this woman for years and saying that instead of saying 'I hope you are resting' or 'isn't that great' I find it interesting that old friends who knew me before aren't understanding and I would have thought they would have been because they know I am not the same person.

Sometimes it was shocking for the women to find that the people they thought would be supportive and understanding were not. One woman had a friend who was a psychologist who "lit into her" about how "irresponsible" she was. Janet found that her sister, who is a nurse would give her information about various drugs, but she really did not want to know about ME:

My sister just did not want to deal with me being sick. She is better now but she still gets annoyed with me. She thinks I should push myself more.

As well, Janet said that when she has a relapse her mother sometimes says "what were you doing" as if to say that Janet caused her relapse to happen.

One woman found out that as a mother it is not always so clear when it comes to believing in your children. When her daughter first became ill with ME she confessed that she "pushed and pushed her because she wasn't going to school and everybody was telling her she was faking it."

Three women's families were extremely critical of their illness and what the illness represented. One woman had this to say:

My family has always been in a rage that I am sick. My sisters have said things like 'I would rather die than go on welfare'. What I have done is cross the line that no one can accept and that is to need something They look at me like I have somehow morally collapsed because I am fat, I don't exercise, and I am sick.

Another woman whose family was unsupportive, found herself being referred to as "an embarrassment to the family" because she was not her "old self" anymore. A third woman's husband was critical of changes in her mental abilities. She had this to say:

He looks at me when I am trying to find a word and he has no patience with me It was my friend's birthday the other day and I was really sick and feeling lousy and it took me over a half an hour to write out this card. Then I lost the card. I was standing on it. My husband said 'my god you are moronic'. I thought right, I certainly was behaving that way but that was not the most supportive thing to say to me at the time.

Meg found her neighbor was very helpful for a time, until she started to try to take control over Meg's life:

She is a very good person but it got to the point where when I got my [motorized] scooter she would tell me she would like to see me use it more often.

Another woman's neighbor was the opposite of overly helpful:

I told my neighbor I had ME and the next day she went running to her doctor. It was like mass hysteria. Her doctor asked if she had been over kissing me and she said no. But now she thinks I have some dirty disease. I feel so much shame.

Many friends and families did not believe the women were truly ill. Helga reported that her only living relative from her family of birth, her brother, thought her illness was all in her mind:

He poopooed my letting my imagination getting away with me (sic) and saying things like if I just prayed properly and went to church, that I would be fine.

Another woman reported that:

My friends and family saw me so sick and they knew I was sick but because doctors couldn't come up with a name, they'd say 'maybe it is all in your head' or 'if the doctors can't find anything, it can't be too serious'.

One woman thinks that others have come to the conclusion that she gets some secondary gain from having ME:

They believe it is a relief, that somehow I would rather lie in this position than be functional and

taking responsibility for me and my daughter's life. That really bothers me.

One woman summed up her feelings about the lack of support and understanding she received:

You have to learn to depend on yourself. No one is going to understand [about ME] unless they have it themselves.

Abuse

One woman described an abusive experience she had when she was ill:

Once when I was really sick I asked my dad to come over. He is an alcoholic and it was a time when I was on antidepressants, and I had just moved into this apartment and I was really scared. I didn't want to be alone. So I was on this medication and I was also scared to be on it. I was all doped up, he's sober too, so that was fine. I thought he could cook something up while I laid down on the couch. But then I don't know, he just started coming onto me when I was doped up on this medication. I don't have my parents to lean on, you see. If I ask them over here it is just more stress to me.

Loss and Gain

Besides losing the support and understanding of friends, some of the women reported they have lost contact with many friends and lovers as a result of their illness. All eight women reported that they had lost friends since they had become ill. Janet said:

Some friends disappeared when I got sick. Some of the ones who disappeared surprised me because they were the people that I had supported and helped out in a lot of

ways. It surprised me that they were not willing to support me.

Francine has this to say about her friends:

The fact that I needed them scared the hell out of them I do not feel angry with these people. It is very hard to suddenly find someone you relied on to be poor, sick, and needy. It is just sad.

Four women felt they lost their friends because they couldn't keep up with them any more. Sue gave a typical response:

I just don't have the energy or time for friends or relationships. It is just too much work.

Four of the women felt the break up of their intimate relationships was a result of their illnesses. One woman described herself as "such a loser" because she was sick. She also had this to say:

If I could have been healthy, I think [the relationship] would have lasted but I was such a bore, a drag, no fun.

When Helga first started dating her male companion, they talked about marriage:

He didn't believe how sick I was at first. I think he was confused because he would usually see me when I was up and trying to appear well. When I became really ill, he distanced himself. Now he doesn't talk about marriage anymore.

Janet had a similar experience with her male companion, except that Janet said she "encouraged" him to leave because

as she put it, "he didn't know how to deal with my being sick."

Five of the women expressed that it was difficult maintaining intimate relationships. One woman finds it is difficult for potential partners to accept her illness:

I have had a few somewhat serious relationships but they all have had a hard time accepting my illness. One in particular was a doctor.

One woman had a relationship for two years with a woman who also had ME. She described it as "hellishly hard." Her partner was going through a lot (she was a survivor of abuse). She had this to say:

The thing is, that if I was healthy, I would have had the stamina to work through all that stuff but I was just worn out.

Despite all the losses of friendships and lovers, the women managed to gain some very close friends. As one woman said:

It seems I have eliminated the superficial friends and I've come very close to the rest. Now I have a wonderful circle of friends.

The new friends are "more supportive," "more understanding," and more "accepting." Francine believes her new friends seem to understand and accept that she "has less to give" and that "that is just the way it is when you have a friend with an illness." Lily has found that now she has a great

many friends who have ME themselves. Margaret, who stated that she does not have many friends with whom she socializes, does talk to many people on the phone. Margaret also has two dogs to keep her company whom she enjoys a great deal.

EXPERIENCES WITH OTHER PEOPLE (ACQUAINTANCES AND STRANGERS)

Discrimination

Five of the women reported they felt discriminated against because they had ME. The reports varied from general statements to specific instances of discrimination. Following are three general statements:

I feel ignored by doctors, society, and acquaintances because they don't want to talk about my illness, they don't want to know about it, they don't want to know that someone's life is hard.

I really have a sense that the world has no place for people with disabilities. I have a sense that people don't want to wait for the buses to get a [motorized] scooter on. People don't want to pay taxes for people who cannot support themselves. I think people really believe in survival of the fittest and I never felt that before. The idea I have in mind now is to get better, get more money, and get protection against what they are going to do to me.

People discriminate against you because you don't look sick. It is hard for people to accept what you have if they cannot see it.

Some specific examples are as follows:

I was discriminated against by a fellow who was disabled in a wheelchair when I was taking a job training course put on by manpower for disabled people. A man who had cerebral palsy told me I was not

disabled, that it was all in my head. I didn't have a diagnosis at the time.

A guy came up to me one day and said 'that [parking space] is for people in wheelchairs.' I turned and said to him, 'well some people don't have visible handicaps.' It didn't bother me. I felt he was just not informed.

One woman found the lesbian feminist community discriminatory:

I really think there is an amazon ideal, and if you don't match up to it, forget it. You are supposed to be so wonderful, a superwoman, have a career, be a political activist, take courses, parent, and have a wild sex life. There is no place for a woman who is disabled. We simply drop out of sight.

Another woman pointed out that "there is a potential for discrimination if it is proven that ME is contagious."

Difficulty Communicating With Others

Many of the women spoke about the frustration they had when dealing with the public. Francine talked about how her whole life involved helping others and that now when she needs someone to advocate on her behalf, she finds no one:

No one believes me or takes me seriously. It is really hard in this society to function as a person with an illness and get the respect you deserve.

Janet found that her healthy appearance to be one of the most difficult and frustrating things she has to deal with:

It makes it difficult to deal with strangers because they expect me to do something that if I do, I'm in trouble. The invisibility makes it awkward I mean I just don't acknowledge that I am sick to any one that I don't have to acknowledge it to.

Lily also had a problem with having an illness that was virtually invisible:

I think it is a pain to live with an illness that is invisible. Part of the pain is because people don't acknowledge your disability and if you talk about it, it is boring and depressing. But if you don't talk about it, people don't know you are disabled and don't understand it.

Support Groups

I had met three of the co-researchers at support group meetings. Support groups leaders gave me names and phone numbers of women who were not at the meetings I attended but whom they thought might be interested in participating in the study. Out of these lists, came the remainder of the co-researchers. All of the women belonged to an MEBC support group at some time. (MEBC is an umbrella organization in British Columbia for numerous support groups throughout the province.) Five of the women continued to go to support groups on a regular basis. Two women said they did not attend meetings any longer and one woman was in the process of finding a new ME support group to join. All the women felt that ME support groups were helpful. Sue gave a typical response:

I really feel lucky that there are others to talk to and we can just say 'me too' or 'I know exactly how you feel.' Before I was totally alienated.

Three of the women expressed how important the support groups were to them when they first became ill. For one woman it was her "saving grace." For another woman it was "what kept [her] going." One woman, who is a support group leader, stated that she felt the support group made her feel "useful and got her out of isolation" and that she had learned not to let it "drain" her.

However, not all the experiences with ME support groups were positive. Four of the women stressed how they occasionally came away from a support group feeling worse than when they went. Helga gave the following explanation for this phenomenon:

Sometimes I come away feeling terrible sometimes I am strong enough to hear their pain and not get into it. Other times I take it on and I come home and am really dragged down.

Mary put it another way:

Sometimes you don't feel supportive yourself. I find a lot of people in the group very lonely and in need of friends and help. But a lot of the time I can't do that cause it takes all my energy to get on with my own life. I just don't have the energy to spare.

One woman found her local support group emotionally draining and was in the process of looking for a more "upbeat" group.

The two women who no longer went to meetings were angry

about the stand, or lack of stand, MEBC took on certain issues:

I am mad at the moment because no one really deals with the terror and fear and the reality of this disease - that it may be contagious. They are helpful because they organize conferences for information and because they keep track of the number of people who have ME, but they ignore the reality of this disease.

I am angry at the lack of political work. The organization is very conservative The organization should look at all different aspects of ME and all different attitudes and all different theories. They should not align themselves to one doctor, or one theory

COPING STRATEGIES

In the Beginning

All of the women said that in the beginning of their illness they really don't know how they coped. They usually described the first six months to a year (for one woman, the first two years) of their illness as a blur. One woman described an endless cycle of work and exhaustion:

I just kept pushing and pushing for eight months. At the end of which I was an utter zombie. I didn't know how I was going to get out of bed and then it was how am I going to shower, not to mention how the hell am I going to get the kids to daycare. My life was to get the kids to daycare, fall into bed, go pick them up, feed them, throw them into bed, fall into bed. I don't know what we ate. I suppose we ate nutritiously but not with a lot of enthusiasm. I don't know how I coped. Force of will power I guess.

Another woman expressed feelings of dread:

When I first got sick I remember I would look outside and look at how far it was to the back yard. Or something would fall and I would think about how far it was to pick it up. I remember knowing I was very sick but I couldn't describe it to anyone. I didn't feel depressed or anything I wasn't feeling like I should go out and work or anything. I thought I might die the next day.

One woman who did not get a diagnosis for five years had this to say:

There was always an excuse for not feeling well - food allergies, tumor, cold. Without a diagnosis I learned to live one day at a time.

Francine felt her counsellor helped her to cope in the beginning of her illness. With the help of her counsellor, Francine went from wanting to be left alone to die, to actually constructing a very small world. Two other women found the ME support groups helped them to cope in the beginning of their illness.

Now

The most common strategies the women reported were "to take one day at a time," organize their day, follow a routine, and try to keep their days as full as possible. For one of these women, that meant she had to impose a structure on her life:

I basically imposed a structure on my life which was really hard to do. For example, I offered to drive this woman to work everyday at 11:00 o'clock because otherwise I would sleep all day. I follow my routine as

much as I can. Of course when I am really sick, I just stay in bed.

Three women reported that they had "learned to say no." They learned that they had to be clear to others about what they were able to do for others and for themselves. When they were asked to make plans in the future, the women learned to say "maybe." Helga reported that she often says "yes I would love to go, if I am able". That way she feels her friends and family know that the reason she cannot be with them is because she is ill and not because she does not want to be with them.

Three women find that it helps to do something nice for themselves. Sue, for instance, enjoys reading books and doing art work; Mary takes a pottery class. Lily has tried a few things:

I took a residential women's writing workshop for two weeks. I relapsed badly after that but it was worth it ... I try and meet with the group every so often even though I am too ill to write I go out maybe every two weeks or so. It is a big effort but I do it because it is important to keep in touch I try and get away every month or so for a weekend. Now being on welfare that is a mean feat but it is essential for my well-being.

Three women reported that they have learned to make the best out of their situation by changing their attitudes about their lives. Mary said it this way:

I don't dwell on my problems. I've learned to make the best out of it. I do this by looking at myself and recognizing the power I have within me.

Margaret spoke more specifically:

It is frustrating not being able to remember. I try and look at it as a rest. You don't need to remember all that shit in your life, so why worry about it. I mean if I can't remember what I wore yesterday it is no big deal. It's easier to move day to day that way. It causes less stress.

Three women reported that it helped to stop believing that their illness would go away. Helga elaborated on this:

I protect myself emotionally by not believing that I am getting better because it is so devastating psychologically to fall back.

Two women coped with feelings of depression and "self pity" by comparing themselves to others. As Margaret pointed out:

So many times when I have felt sorry for myself or felt resentful, God has managed to put somebody in a wheelchair in my next line of sight.

Two women said they simply "listen to their bodies and don't push themselves."

Lily and Mary said they use their good days for things they need or like to do. Lily explained it this way:

I get those odd good days. I usually don't think 'wow this is it anymore.' Instead I run around like a maniac and get caught up in everything or I'll grab those moments and go to the beach because I love walking on the beach.

Two women found their VCR's helped them to cope. Both women tape programs to watch at a later time. Meg prides

herself in having a collection of travel shows, tennis tournaments, and classical music shows. Lily likes to rent movies for entertainment.

The following are some of the unique ways individual women coped with their illnesses: Lily never rests in her bedroom because she spent two years in it and finds her bedroom depressing to be in during the day. She now lays on her couch to rest. One woman finds others to assist her with housework and childcare. Meg gets her groceries delivered. Helga keeps a journal everyday and rates herself on a scale from one to ten. She explains how this daily record helps her to cope:

I find it useful because I can look back and read where I was really in despair, feeling terrible and then read how the next day I was out and doing something. It reinforces the fact that it doesn't need to be the same tomorrow as it is today. It also helps other people. I tell them where I am and it seems to eliminate a lot of explanation and boring detail.

One woman found that when someone would ask how she was feeling it was difficult to answer, and so devised a casual response:

Sometimes I'll just say 'fine' and sometimes I'll just say 'I'm the shits, how are you.' It makes it easier to deal with that way.

To combat feelings of isolation, one woman encourages people to come over anytime and she always answers the phone. Similarly, Meg doesn't let her illness get in the

way of having friends over. When she wants to have someone to dinner she simply orders a pizza. Both these women reported that their friends know where everything is in their cupboards and they have learned to just "help themselves."

EXPERIENCES OF SELF

Are you Disabled?

When asked "Do you feel you are a member of the disabled community why or why not?" seven women said that they were disabled. However, at the same time, six of these women reported having difficulties with naming themselves "disabled." Here are some of the responses to the question:

Fuck no! If I did, I would become disabled Disabled to me is in a wheelchair, laying on your back, something you have to be helped with. Disabled to me is a real horror. [Three months later, this woman phoned me up and said she had been thinking about her response. She told me she changed her mind. She said:] Yes, I am disabled.

[This woman had been ill for ten years]
I know I belong to the disabled community but it has just been recently that I realized it. It has been a long process, I was always pushing myself in some way by saying 'I just don't look disabled' or 'I know that everybody else can walk to the store only if I pushed myself harder.' When you enter into the world of disability, it is very frightening, scary, and shameful, it is like somehow I shouldn't be there.

No, because I can still be on the bus and give my seat to somebody. But then there are days when I can't obviously. I guess I am disabled ... but compared to others in wheelchairs or with AIDS, I am not disabled.

I know I am disabled but I don't feel disabled. I can still do so much for other people.

I am slowly accepting myself as a member of the disabled community. But as long as I can do volunteer work, I find it difficult to describe myself as disabled.

Concern about a "disabled" image affected some of the women's willingness to use aids. Two of the women used motorized scooters to get them places they would not normally be able to go. One woman described it as giving her "freedom." The other woman said it made her feel "elegant." After a lengthy discussion about using wheelchairs and motorized scooters, one woman concluded this:

I am not sick enough to be in a wheelchair or [motorized] scooter. I don't feel qualified to take that step. Maybe it is that step between visible and invisible. I worry it may invalidate those people who have to be in a wheelchair all the time. I don't want to be seen as someone well enough to walk down the street one day and not the next I feel I would be treated like a hypochondriac.

Janet knew she was eligible to receive a B.C. transit concession bus pass but was hesitant to apply:

I have to concede how sick I am and that is hard on me psychologically. I prefer to stay as much as possible in the positive.

Denial and Acceptance of the Illness

Six of the women reported that accepting that they had ME, and understanding what it meant to live with a chronic

illness, proved to be a long and difficult process. These women described a period in their lives (sometimes months, sometimes years) where they denied they had any chronic illness. Here are two typical responses:

I pushed myself to the absolute limit. I always had a lot of excuses for why I was ill. For awhile I tried to tell myself it was normal to lie down after a hard day's work even though once I lay down I literally couldn't move.

I lived my life with the expectation that if I just did the right thing I would get better.

Two women still seemed to be denying their chronic illness at the time of the interviews. One of these women had this to say:

If I have a good day, I forget and say 'it is gone' and then I relapse and realize it hasn't.

Acceptance for Lily came after a severe relapse. She said:

I think the relapse after two years was the turning point because before that I really did believe I was getting better.

It was not easy for Meg to accept that she had a chronic illness and that her life was not going to be the same as it once was. She had this to say:

I finally realized that I could never go back to my old life and if I tried, I would just relapse. That was very difficult.

For two women, "learning how not to push" their bodies was the most difficult part of accepting their illness. In addition, they both spoke about "choosing to push." Lily put it this way:

At times I choose to push myself if it is something I really want to do. I know I will be in bed for all the next day and maybe the next day after that. It is really a balancing act.

Although Janet has accepted her illness and what it means to have ME, she stated clearly that accepting did not mean giving into the disease. She had this to say:

I have never accepted that I can never get well because I believe in mind over matter.

Sexuality

Five women reported that having ME has affected their sexuality. Two of these women said they were too exhausted to keep up with an ongoing sexual relationship. One woman described it simply:

By the time I got the kids to bed, I was just too exhausted. We did have a good sex life when we were both able. [Her partner at the time also had ME.]

One woman was afraid to be intimate with anyone in any way, because she was afraid she would pass ME on to someone else. Another woman did not want to have sex because every time she had sex she seemed to get a bladder infection and "phenomenal" thrush. One woman stated that her sexuality

had not been affected by ME at all. One woman described her ideal situation:

My ideal fantasy is to have a relationship where we see each other once a month for a weekend. Then she goes home and I go home.

Two women did not believe ME had affected their sexuality "too much." They described their experiences in almost identical terms. Here is one response:

I don't know if it has affected my sex life too much. I don't have a partner every night. I see my partner every two weeks or so and I am always able to be sexual. But I am sure if it was on a continual basis I would not feel the same.

Death and Dying

Three of the women had contemplated suicide one or more times during their illnesses. One woman had gone so far as to write farewell notes to loved ones. This was her experience:

I nearly killed myself a year ago. I had written farewell notes to everyone. I do feel very hopeless at times. I feel that the quality of life is not worth sticking around for at times. But that doesn't usually last. The depression is very short-term.

The mother of the teenage daughter with ME reported that she was afraid her daughter may commit suicide:

My daughter really internalized many of the things the doctors were saying about her. She was really feeling bad about herself. I really think she could have committed suicide at that point.

Three women spoke about feeling close to death at times because they were so ill. Meg gave a typical scenario:

What I remember thinking each morning, when I was really bad, is "I'm still here!" I wasn't afraid of death, there is no fear when you are that sick. I couldn't care less if I was coming or going.

As a consequence of frequently being extremely ill, Francine is literally prepared to die all the time. She reported that she has made her will and keeps it beside her bed where someone can easily find it. Another woman who is frequently extremely ill, deals with death differently:

I don't feel I have long to live. I think a lot of times that [my illness] is going to kill me but I keep telling myself I'm not going to let it I don't think I'll go much longer. A year maybe. I don't know. I don't think I'm going to live a long life I try to live just for today.

Self Image

When asked if the women thought they were good partners, five women stated that they were and the remaining women stated that they were not. Two of the latter women reported that the reason they were not good partners was because they could not keep up with "their half" of the relationship. The third woman had this to say:

I have always been told that I am a good partner but I know deep down I am not. In a sense that I am no fun, I am sick. I can't do what other girls do I feel like a big time loser. I feel so inadequate. I feel my boyfriend doesn't deserve me and that he should have somebody better.

When the mothers were asked if they thought they were good mothers, all five women said yes in terms of trying their best. In terms of doing what a "good" mother "should do", four of the women said they felt they could not be a good mother. Here are some of their responses:

When I first got ill, I was a mechanical mother. I was barely there ... I think it is frustrating having a disabled mom because I don't take them out on outings like other moms do.

In terms of what a kid deserves, I think she lost out on a lot.

I am unable to do and be for my children what I would like because of my limitations.

All the women answered "yes" to the questions "Do you feel you are a good friend?" and "Do you feel you are a good sister?"

At other times throughout the interviews, women would make comments about how they felt about themselves. The following are some of those comments:

As far as the kind of women's community, there is a lot of emphasis on what you do especially where I live, it is more the political end of the city. I feel like a nobody because I am not really doing anything political in the lesbian feminist community. I feel disconnected.

I have a lot of anger inside and I don't express it. I try and do positive affirmations although I don't think

ME is psychological unless there is something I have no control over. Like I want to do meditation for the stupid mind in case it is something I am doing while I am sleeping, unconscious, or something.

There are times when I have outbursts of anger. I never used to be that kind of person. [Sometimes] I get so angry I'll smash something. But the anger doesn't last long. I get angry at doctors and I get angry at my body.

"What is the Matter With You?"

When the women were asked, "what do you say when somebody asks you what is the matter with you," four of the women stated in various ways that they had ME or CFS. Lily reported that she liked to explain it in very precise terms:

I have ME, it is a chronic viral disorder and I am not able to do much.

Meg reported that she usually answered in more general terms.

I have ME and FM [Fibromyalgia] and I hurt from top to bottom.

The other four women stated that they did not even mention ME or CFS when someone asked them what was the matter with them. These women chose to stress their most debilitating symptom in an effort to have somebody understand what was the matter with them. Following are some examples of how they responded to my question:

I say I am seeing a specialist right now and I talk about the respiratory problems. I don't even say I

have ME or EBV. Sometimes I cover up the fact that I am sick.

I say I have a muscle disease. If I say I have ME or CFS or FM these are big words and they want to know about them. I get sick of having to go through it.

"What Do You Do?"

When the women were asked how they responded when someone asked them, 'what do you do,' three women reported it was a big problem for them to find appropriate responses. One woman explained why:

That is a very difficult [question]. I feel intimidated and still get that feeling in my chest when someone asks me that question. It never comes out easy. I say 'I am bringing up my children', or 'I have a disability and I am bringing up my children' I can't say I am anything, like a "nurse". It is a double burden because not only are we devalued for being sick because somehow we are morally inferior to the healthy person, but as parents who stay at home, we are devalued.

Two women confessed they lied about their situation because saying 'I am retired' or 'on disability' made it sound better than the truth. One woman explained that by doing so "it made [her] out to be a survivor rather than a victim."

The remaining five women had no difficulty responding to the question. Their responses were straightforward:

I have ME and I am off work with it.

I am a flight attendant and I am on long term disability.

I say I am a design draftsman, self employed working under contract and that I am not working right now. If I feel there is a need for some reason they should

know, I'll say I am off work for health reasons for a while.

SUMMARIZING THEIR EXPERIENCES

"How Has Your View of Yourself and of the World Changed?"

When the women were asked, 'how has your view of yourself and of the world changed since you have become ill,' four of the women stressed they are now more aware of people in pain, or people with disabilities, and the lack of support there is for such people. One woman said she "used to believe that Canada had a health care system that was supportive of disabled people" and now she realizes that that is not true. Margaret stated simply that she now sees "all the pain in the world," whereas she never noticed it as much before.

One woman said she has "become more interested in nature and the world as a whole rather than [her] own community." Two of the women stressed how they have come to realize how much strength they have within themselves. One woman said she now realizes how vulnerable she is. Another woman reported:

I am more humble. I am much more content to have a conversation with someone who is not my academic equal because I have more time.

Janet had this to say:

I used to think that I could do anything, be anything if I worked at it. Now I don't think that anymore.

"What Have You Learned?"

Three of the women who responded to the question, 'have you learned anything that is important to you through your experience of ME,' stressed that they had learned that they are much stronger than they realized. Francine put it this way:

I have learned I am a lot stronger than I thought. I have a will to survive emotionally and physically that I never knew I had before.

Two women stressed that they discovered their spiritual selves. Janet said:

I have learned to get more in touch with my spiritual self. I have come to accept that there are reasons things happen in life. God never gives you more than you can handle.

Other women said:

I have learned that no matter how bad I am, life is tough and not to sit and dwell on it.

I have learned to be aware of other people's feelings.

I have learned to have patience and if you live on this earth, you should enjoy it.

I think being shut in here I have learned to appreciate all forms of life, especially on my patio. I have birds come to my birdfeeder all the time, my whole patio is filled with flowers in the summer.

The Future

When the women were asked how they saw themselves in the future, the answers varied a great deal. One woman was too frightened to talk about the future because she did not believe she was well enough to consider a future. She said:

My life is totally focused on my illness ... I don't even like to think about tomorrow because I don't know what I am dealing with. I could be dead tomorrow.

Two women said they took life one day at a time and that to look to the future was too stressful. One woman was optimistic. She saw herself cured within three years and living a similar life to the one she had before becoming ill. The other four women saw themselves as still ill but improved and either working part-time, volunteering, studying, or travelling.

CHAPTER IV

DISCUSSION AND CONCLUSION

At the beginning of my investigation, I documented my own assumptions and expectations about the study. Then I examined the main interviews and concluded that almost all of my expectations had been directly met. However, many of the experiences were much worse than I had expected. In addition, because my expectations were quite general, there were many unique experiences I never anticipated. In this final chapter I will discuss patterns that emerged from the women's stories, as well as some of the unique experiences, and discuss the practical and theoretical implications of both these patterns and unique experiences. Although I have tried to reflect my co-researchers' voices as closely as I can, this section of the thesis is clearly my own interpretation of the results.

SHORTCOMINGS OF THE RESEARCH

The experiences of my eight co-researchers were negative overall. I had expected this because women with ME do not fit neatly into any category (e.g., they are disabled but don't fit the image of disabled people; they are ill but there is no known etiology (cause); they are affected on a

physical level but also on a cognitive level; and they are ill but they do not look ill). However, the experiences the women reported were perhaps more negative than positive because I failed to ask questions about the positive experiences of having ME. For instance, I did not ask questions like: "what is the best thing that has come out of having ME," or "what was the funniest thing that happened to you," or "what do you find humorous about ME".

Another shortcoming was that I failed to ask the women specifically about symptoms in the interviews. I purposely chose not to ask questions about their symptoms because I did not want to have long descriptions of symptoms. However, the symptoms seemed to be such an important part of the experience of ME that the women could not help but discuss symptoms and the impact they had on their lives. As a result, the symptoms I have outlined in the results section are by no means an exhaustive description.

In spite of these shortcomings, the study raises many important issues, not only for women with ME but for a range of people such as the medical community, the disabled community, the disabled women's community, the feminist community, the lesbian feminist community, the ME support group community, therapists, non-medical helping professionals, the government, families and friends of people with ME, and other women with hidden or similar disabilities.

SYMPTOMS

Although I did not ask the women what symptoms they experienced, we invariably did discuss them. It is worth mentioning that some of the symptoms that were quite debilitating are not considered primary symptoms by leading medical researchers. For instance, for one woman the most debilitating symptom was her respiratory problems. For another woman, cognitive impairment was by far the worst symptom. This suggests either that I am ignorant of the disease process in individuals (for example, perhaps people experience the same illness differently and are affected more differently than I thought), or that the symptom list needs to be more accurate. Even when women experienced similar symptoms, the degree of impairment varied greatly among them. For example, all the women had experienced fatigue. But the fatigue varied in degree, and in whether it was constant or cyclical or sporadic. Seven women experienced memory and / or concentration problems, but again, the degree of impairment it caused them and the regularity of impairment varied widely. For the first time I sympathized with researchers and physicians. According to the symptom variation I discovered, and the fact that there is no known etiology, or test for ME, I would have to agree that ME can be a difficult disease to diagnose.

I found it interesting that the women attributed other conditions and disorders to their ME, especially the two

cases of sinusitis and cysts, and the individual cases of recurring yeast, recurring abdominal pain, tumors, and staphylococci infections. Since these conditions and disorders are rarely stressed or even mentioned in the literature on ME, I felt it worthwhile to mention them here. Since ME is still new and diagnostic criteria are not agreed upon, it would seem that all symptoms, conditions, diseases and disorders need to be taken into account and none should be dismissed.

EXPERIENCES WITH HEALTH PROFESSIONALS

As I had anticipated, all the women had negative experiences with the medical establishment. These negative experiences usually began when the women first became ill. Their doctors either did not believe they were physically ill, or they did not take their symptoms seriously. As a consequence, all but one woman had other diagnoses given to them. These diagnoses were often psychological in nature, for example, depression, stress, and psychosomatic disorder. This I did not find surprising, given the research done by Anderson (1981) and Howell (1974), that indicates women often receive psychiatrically-based diagnoses for physical complaints. Other diagnoses were also not surprising, given that the co-researchers were female: the "catch-all" diagnosis, menopause; and what may be "fad" diagnoses, anorexia and pelvic inflammatory disease (PID). One woman's

doctor simply described the illness as the "flu" every time she came to see him. All these diagnoses suggest that many doctors did not take these women or their symptoms seriously.

Invalidating the women's experiences had devastating effects on them. Some of the women believed their doctors and followed treatments for other diseases. For example, one woman had a hysterectomy as a way to cure her supposed PID, while another woman took antidepressants for her supposed depression and had violent reactions to them. Some women did not believe their doctors' diagnoses, and as a consequence, simply gave up on getting a diagnosis. Thus, these women went for years without knowing what was the matter with them. Some women began to doubt their own sanity because of a combination of incorrect diagnoses and the sporadic nature of the disease (one day they felt fine, and the next they felt deathly ill). They started to believe that they were going crazy and imagining their symptoms.

Having a correct diagnosis was very important psychologically, because it validated what these women were experiencing. Having a diagnosis that did not correspond with what they were feeling created psychological havoc and made it difficult for friends, family, and society to take them seriously. It was also important financially to have a diagnosis that reflected what the women were experiencing, because with a diagnosis they qualified for benefits such as

disability benefits, GAIN for the handicapped, homemaker service, bus passes, handicapped parking decals, and federal tax exemptions. (If a diagnosis is "the flu," such financial benefits are not available.) Since there is such trust and belief in the medical establishment in our society, it was not surprising that people were suspicious of the women who had illnesses without names. A diagnosis, any diagnosis, was important to these women because family, friends, and co-workers seemed to accept their illnesses more easily once the illnesses had names. If anything, these findings suggest that doctors need to be made aware of the power that labeling has on people, psychologically, socially, and financially.

A different aspect of getting a diagnosis that surfaced from the women's stories, and one that was not anticipated, was that in five cases the doctors did not initially discover the disease. The women did. These five women heard about ME through the media, recognized their own experiences and told their doctors that they wanted to be checked for ME. The doctors then agreed that it was ME / EBV. This was frequently true for the women who were ill for five or more years. The two women who became ill within the last three years were diagnosed with EBV, which suggests that doctors are increasingly becoming aware of ME / CFS / EBV and are beginning to accept it as a legitimate illness. These results also suggest that, given the opportunity, people can differentiate between illnesses they have and

those they do not have. For example, the woman diagnosed as suffering from menopause knew her symptoms were not congruent with menopause.

I see the problem of diagnosis as stemming partly from the fragmenting approach of current western medical practice. The patient knows her / himself as a whole person, whereas the doctors are concentrating on lists of symptoms and cause and effect relationships. Thus, the patient potentially has a better understanding of what is health for her / him, and therefore her / his opinions of the diagnosis and descriptions of the experience should always be taken into consideration. The current lack of consultation with patients, in particular female patients, and the tendency to disbelieve them is, in part, a consequence of medicine's being a hierarchical organization.

The negative experiences with the medical establishment spanned the length of time the women were ill. Although the women often spoke of specific incidents, there were also many general statements of ongoing negative experiences, such as "I don't get taken seriously by doctors," or "doctors treat me as if I am lying about my symptoms." Some women experienced verbal abuse, being refused as patients, being ridiculed and ignored, and being refused letters of support. Some negative experiences I would categorize as outright abuse were: the unnecessary hysterectomy; the poorly done myelogram that left the woman disorientated for three months; and the bowel biopsy performed with no

anesthetic and where the woman was left a half an hour with a hose down her throat. These negative experiences reflect the patriarchal and capitalistic nature of the medical community. These women were treated as inferior human beings and as commodities. Considerations such as the desire to make money by performing surgery or, in the Canadian universal medical care system, occasionally to save government money, enter into such medical decisions.

One interesting discovery was that several women reported instances when their doctors lied to them or kept their opinions about them secret. Up until June 1992, in all provinces except Quebec, patient's files were confidential even to the patients themselves. They were the property of doctors and could only be read by medical personnel. There was no way to police what doctors wrote about patients. The ways the women found out about their doctors' opinions of them were very revealing: they illegally read their own files, or were told what other doctors had written about them in their files, or found out by the consequences of their doctors' actions (e.g, losing insurance money) and then confronted the doctors; one woman found out by having her files read out loud in court. What these women stressed to me was that they were not aware that their doctors did not believe them, or that their doctors did not believe ME was a legitimate disease. These women (one of them a nurse) were astonished at what was written about them in their files. Some of the examples: "I don't

believe her", "she is lying about not throwing up," or "she is identifying with the rape victims she counsels," demonstrated to the women the power these doctors had over their lives. One woman, who was diagnosed as psychosomatic, realized the power doctors had after she could not get any doctor to take her seriously. Three doctors in a row said they "agreed with the psychosomatic diagnosis." As one woman pointed out, "once there is something written about you, there is no way of erasing it." Another woman experienced the consequences of having damaging medical files. Medical files which indicated that she was a liar and mentally disturbed were used against her in a court of law five years later. Hopefully, with the new law which declares that patients' files are not the property of doctors, physicians will be more cautious about what they write about people in the files, and women will demand to have access to their files and to extract harmful and inappropriate comments and diagnoses.

Other helping professionals were also problematic for some of the women. Naturopaths, homeopaths, massage therapists, herbalists, psychic healers, yoga instructors, and chiropractors were too costly for most of the women to be able to try, or to maintain treatments. Another problem with some of the "healing" professionals is that underlying many of their philosophies is the assumption that if you just take this remedy or do this exercise, you will be healed, and if you choose not to take the remedy or do the

exercise, then it is your own fault that you are sick. As a result of this assumption, there is often a psychological pressure to try any new treatment that comes along. Evidence of this underlying assumption surfaced when one woman's naturopath commented: "how much are you willing to dedicate to your good health?" Lily pointed out that her problem with Louise Hay (an author "guru" who stresses that changing negative thoughts into positive thoughts using positive affirmations, can cure disease) is her underlying assumption that if you change your attitude, you will be healed, which blames the victim. These examples suggest that the total responsibility for the illness is on the ill person, which ignores other possible contributing factors in ME, such as a virus, genetic weakness, societal and environmental influences.

A problem with other helping professionals such as nutritionists, nurses, and receptionists is their subordinate position in relation to medical doctors. They are often dependent on medical diagnosis. For example, one nutritionist refused to accept that Janet was sensitive to wheat products because she had not been diagnosed as celiac. In addition, other professionals often have to adhere to doctors' orders. When the receptionist told Lily to lie about having ME to avoid a confrontation with the doctor (and probably to avoid getting into trouble for not following doctor's orders), it demonstrated the absurdity of the doctor's power.

As a result of the numerous negative experiences with medical and other helping professionals, the women changed their views about the medical establishment drastically. Where once they believed and trusted the medical "experts," now they have many doubts about medical authorities' claims to heal and to be experts on the body. The co-researcher who was a psychiatric nurse questions her own field of work. She worries about the number of people in psychiatric wards who are really chronically ill and who should not be on psychotropic drugs. I think this is an important concern, as it relates to the studies that suggest women are often given psychiatrically-based diagnoses when they show physical symptoms that are not easily explained. (Anderson, 1981; Howell, 1974; see also Penfold, 1986)

Now most of the women do not view doctors as omniscient gods but as human beings who have limited knowledge about the body. This is important because these women had unrealistic images of doctors before they became ill. This is not surprising since doctors are portrayed unrealistically in our society. The media, for example, do not tell people about the failures of medicine. Rather, they report on the successes and portray doctors as superhuman. Doctors sometimes seem to view themselves as superhuman. In my opinion, we have to begin to "humanize" medical doctors, not only for the good of patients, but for the good of doctors as well.

The medical system failed these women in so many ways that it is not surprising that the women became distrusting of it. One woman's comment that she has become so cynical about doctors that she "expects" the information she gives them not to be respected, exemplifies this distrust. Many of these women now go to doctors only for maintenance checks and for prescribing medications. They do not rely on medical technology to find answers or to get support. However, some women, those who have not fully accepted their illness or those who are extremely ill with what may be complications of ME, are still relying on medical advice and medical treatments, even though they distrust and question medical authority. Instead of giving up on the medical establishment, these women try different ways to be heard and taken seriously by doctors. One woman explained how she plays little games with doctors so she can get the medical attention she needs. She pretends that she is ignorant of what she knows about her body and about ME because she is afraid of being labeled a hypochondriac. This example demonstrated to me the extreme, and perhaps dangerous, measures to which women may resort to be heard. Instead of "playing the doctor's game", another woman decided to take control of her situation and be more assertive. She interviews doctors to see if they are suitable for her, because she refuses to commit herself to any doctor until that doctor has proven her/himself. This approach seems to be a better way of dealing with doctors than pretending.

However, this woman was not as ill as the woman who "played the games." Perhaps the woman who is extremely sick does not have the energy or will power to do what it takes to be assertive (e.g., interview), and finds pretending to be an easier way to deal with doctors.

The women's health movement that began in the 1970's has focused on the importance of being in control of one's health and of making informed choices about one's health. The idea is that we should not have to learn to distrust the medical establishment through our mistakes, but that we can be aware of the patriarchal and capitalistic goals of medical and other healing professionals before we enter into these relationships. However, as seen by the women's negative experiences, the movement has not been terribly successful at either changing the practice or reaching the women I interviewed. As with all feminist endeavors, progress is slow and many times information is only accessible to a small group of women who seek it out.

The women I interviewed clearly had fewer positive experiences with the medical profession than negative experiences. As well, most of the positive experiences were single occurrences, such as the occasion when the doctor filled out an insurance form promptly, or when the doctor read the information on ME that a woman brought him, or when the doctor discovered giardia and prescribed medication that worked to alleviate the diarrhea. The women did not always stick with those doctors who were supportive or

understanding, because the doctors moved, retired, changed their attitudes about ME, became unsupportive, or refused to try new treatments or refer them to specialists. One of the surprising discoveries was that three women had positive long-lasting experiences with psychiatrists / therapists. I expected psychiatrists and therapists would attribute ME to psychological causes. However, the opposite occurred. The women were believed, and the psychiatrists and therapist helped the women learn how to cope with their illnesses. It is interesting to note that the two psychiatrists and one therapist were all female.

I was not surprised that the massage therapists and chiropractor were helpful and supportive, because they are quite far removed from traditional medicine and thus are not under pressure to conform to the rules set down by physicians. They are not dependent on diagnostic labels to do their work. In addition, it is in the financial interests of these helping professionals to take their clients' word. It seemed that the massage therapists and chiropractor took their clients' word on what the women were feeling and experiencing and were receptive to reading literature about ME that the women brought them. As a result, they were helpful and supportive.

TREATMENTS

I expected the women to have tried a wide variety of medical and non-medical treatments, and to have changed their behavior in several ways in an attempt to alleviate symptoms or cure their illnesses. My expectations proved to be true. All the women did try a large number of treatments and did try to change their behaviors. However, it was clear that among these eight women, there was no cure for ME. Some treatments helped to alleviate some symptoms in some women, and in other women the same treatments made the symptoms worse. None of the women ever got rid of all their symptoms. The women tried to eliminate stressors in their lives, and doing this often meant learning how to be more assertive, and learning how to ask for help. All of the women also tried to avoid activities that could contribute to relapses, such as dancing, being with people who smoked, consuming alcohol, walking, and doing housework. In essence, most women felt they had tried everything they could think of to get well.

Treatments and behavior that seemed to be most beneficial for the majority of the women were resting, eliminating wheat and dairy products from their diets, relaxation, visualization, meditation, staying away from cigarette smoke, perfumes, and anything toxic, doing nice things for themselves, taking one day at a time, keeping in contact with the world, and building a life that

incorporated their illness. The treatments and behavior that seemed to be most harmful for the majority of the women were prescription drugs and pushing the body past its limits. At the time of the interviews, the women were all trying different treatments and behavior changes. One woman was using an alarming number of harmful and addicting prescription drugs, in addition to herbs and vitamins. Another woman was on bed rest and Tylenol alone. Another woman was on an elaborate regime of treatments - herbs, diet restrictions, chiropractor, massage therapist, TENS machine, vitamins, positive affirmations and visualization, among others. In most cases, the women reported that at sometime during their illnesses they had tried numerous treatments. However, due to little or no success, or because of cost and time, most of the women stopped trying new treatments or behavior changes, or, at the very least, became cautious about trying them.

WORK AND FINANCES

It was evident that most of the women tried to maintain their ability to work for wages as long as possible. Eventually, however, they were forced to quit. The determination to continue working seemed to be tremendous, given how ill they were. For these women, working seemed to give them a sense of pride and self worth. Giving up a job was not an easy decision for any of them. Psychologically,

not being able to work was difficult to accept, and many of the women still seem to feel bad about not earning a wage. In addition, financially, not earning a wage was difficult to accept. All but one woman went from living comfortable-to-affluent lifestyles, to living well below that standard. The financial strain for all of the women was an added stressor on top of the stress of being ill. Most of the women had to move to less expensive housing, some had to rely on family to help pay the bills, and one woman lost her car and her pride when she declared personal bankruptcy. Some women underwent horrendous experiences with insurance companies, social service agencies and federal government agencies in their quest for money to live. Many times they had to resort to drastic measures, such as threatening to do something illegal or threatening to take people to court. There is no doubt that these added stressors contributed negatively to their illnesses.

Most of the women are now in the process of discovering what additional financial aid and other benefits are available to them. Some are applying for Canada Pension Plan, GAIN for the handicapped, tax exemptions, and co-op housing. Those women living on social assistance pointed out several times that social assistance is inadequate and does not meet their financial needs. One woman discussed how she has accumulated debt because she has no way of ever catching up. She was "in the hole" before she was able to get social assistance and is further "in the hole" now.

Even if the women were able to take on part-time or temporary jobs, the money would be deducted from their assistance cheques. So in other words, there is no incentive to work even if they are able. The most blatant example of how desperate these women are is the woman who prostitutes herself once a month for the same man for 100.00. Although it is totally against all her principles, religious and moral beliefs, she finds it to be a temporary solution to her problem. An interesting aspect of her story is that she found out about this form of prostitution from a woman with MS who also uses it to supplement the inadequate amount she receives from social assistance. This I found shocking since I had not come across anything in the literature that suggests that such a phenomenon might exist.

EXPERIENCES WITH FRIENDS AND FAMILY

As in the case with the women's experiences with the medical profession, there were many more negative than positive experiences reported with friends, family and society. They ranged from personal experiences, such as an incident of abuse, to more general experiences, such as the problems disabled people have living in a society that devalues disabled people.

Transportation was problematic for many of the women because they had to depend on others for it such as family, friends, or public transport. It was difficult to arrange,

but it was also difficult psychologically always to depend on others to take their places. The women felt they were imposing on people when they asked for rides. I was not surprised that it was difficult for the women to become dependent on others for transportation, because all the women were able to drive previous to their illness and were used to the independence of driving. As well, since in this country driving and walking are valued and accepted norms, being unable to drive or walk is not welcomed. Two women combatted part of the problem by getting motorized scooters. The motorized scooters seemed to give them back some independence. The high cost of taxi cabs meant that only rarely could the women use them. Utilizing buses was also problematic because they only went to certain destinations and often the buses were late and the women had to stand to wait for the buses, which was too tiring. Utilizing the buses designed for the disabled was not an option for the women, since in our society "disabled" does not include people whose disabilities are invisible. The women did not feel entitled to use social services specifically designed for people with disabilities. Seeing how problematic transportation was for these women made me realize that for women who live in remote areas, the problem of transportation must be an even greater problem, and one that contributes to the general problem of isolation.

Since the nature of ME is that symptoms come and go, and the severity of symptoms can vary daily, weekly, monthly

and yearly, some of the women felt they could look after themselves without any help. They seemed to cope by living each day as it came. After a while, they began to realize that no matter how ill they might become, they always seemed to recover (although not totally). This is simply a characteristic of this chronic illness. The women had difficulty asking others for help in part because one day they might need someone to help, and the next day they might not. Some of the women stressed that they did not want to bother anybody by asking for rides and that that was why they did not ask for help. The women seemed to be more comfortable with their roles as caregivers than with their roles as receivers of care. This was especially true in the beginning of the illness. Incorporating a receiver role into their personae seemed to be a difficult adjustment. One woman had a unique reason why she had difficulty asking others for help. Janet believes strongly in "mind over matter." In other words, she believes that her mind has the capability of healing her body. She felt that asking for help meant that she was "giving into the illness." It was important for her to feel that she was in control of her body and of her illness at all times even when she was extremely ill. Now she realizes that at times she could have benefitted from some help in the beginning of her illness.

Not surprisingly, many of the women found it difficult to ask others for help. It was a long process for most of

the women to learn how to ask for help, not only from friends and family, but from society as well. In the beginning, many women expressed that they felt friends and family should "just know" when they required help, because if it had been their friends or family who had been ill, they would know when they needed help and would have helped them. As a consequence of their expectations, many of the women were shocked and angry at the lack of support and understanding they got from friends and family. It took time for many women to be able to get up the courage to come out and state their wants and needs. The majority of the women's experiences with friends, family, and society indicated that others were not willing to be called upon for help and support, especially on a long term basis. I had anticipated that the women would find asking for and receiving help to be difficult given that women are socialized to be caregivers of others, not receivers of care.

The caregiving role became difficult to play for most of the women once they became ill. Mothers, of children all ages, discussed how hard it was to keep up with the demands of their children. The single mother with two special needs children stayed quite ill most of the time as a result of the relentless demands put on her as a single parent. The mother with a three year old and a husband struggled with her husband to change his role and accept more responsibility for the child, house and finances. In

addition, having a vibrant three year old often meant she did not have the time she needed for herself. The woman who was a grandmother discussed how upsetting it was for her that she could not be depended on to help out with her grandchildren or her grown children as much as she wanted. She had always looked forward to her role as a grandmother, but now finds that because of her illness, she is not able to handle the stress of having small children around for long periods of time. It is a very emotional issue for her. These issues of dependency clearly demonstrate the stereotypical expectations society has of women to be caregivers and of mothers to be solely responsible for the rearing of children.

Some of the women were not able to be dependent on others because there was no one in their lives they could depend on. One woman would have welcomed someone to lean on emotionally, physically and financially, but had no one. Another woman felt okay about not having anyone to depend on, on a day to day basis, but was afraid of being alone in the house when she became really sick. She was concerned that when there was an emergency she might have no one to help her.

Most of the women reported that isolation was a big problem for them. Isolation seemed to be one of the repercussions of being ill. It seemed almost "natural" for the women to fall into their own little worlds when the illness got bad. In the beginning, it seemed a way to cope.

However, as time wore on, the women reported that they became more and more isolated from friends, family and their community. They stressed how it was easier to crawl inside themselves and try to cope with their own life problems than to incorporate others. Some of the women got to the point where they were truly alone. As friends and family gave up on them or ignored them, these women seemed to forget there was a world beyond. One woman who worked for a while during an "up" period in her illness, found that she could work, but that work was basically all she could do. She had no life outside her job because she was too ill. When she came home from work she was barely able to feed herself. Socializing, or even thinking about socializing, was out of the question.

All of the women seemed to have escaped extreme isolation at the time of the interviews. Some women, mostly those who have been ill the longest, have worked out elaborate ways to avoid isolation. Since the women were not able physically to get out of the house much, some women socialized on the phone. Others have adopted an open door policy so that friends feel more welcome. Other women literally force themselves to go out once a day, or once a week or once a month. In other words, they impose a structure which incorporates realistic social activities into their lives. It seemed that getting out of extreme isolation was difficult to do and did not come early in the illness. As time wore on, the illness became less severe

and at the same time the women learned to cope more effectively with the illness.

I did not anticipate that women might have a need for solitude or that isolation had positive implications. The one woman who reported that she needed more solitude was the single mother with two special needs children. Her days were filled with trying to survive in the midst of chaos. She longed for solitude and quiet. This woman did not see how she could improve her health until she could get away from the pressures put on her by her children, her community, and her society. The literature discusses isolation as a major problem for disabled women (see Ridington, 1989; Saxton and Howe, 1987), and there is no doubt that it is a major problem. However, there is no discussion of the need for some women to be alone, especially women who are poor and single mothers. There is respite care or foster care, as this single mother pointed out, but both options are complicated to get, and in addition, foster care has a stigma associated with it (i.e., bad mothers have their children in foster care).

Another aspect of isolation I never anticipated was developmental advantages. Two women reported that being isolated forced them to look within themselves, to develop those parts of themselves they might never have developed. For example, one woman began writing poetry, and the other woman began to discover her love of nature.

To combat the negative effects of isolation and the lack of understanding and support from others, the women became involved in ME support groups. Most women felt the groups helped them to cope with their illness, especially in the beginning stages. All of the women felt it was important to keep connected with other people and felt the support groups offered a safe environment for that connection. However, most of the women felt the support groups were draining and often depressing, and as a result, they would sometimes leave meetings feeling worse than when they came. As a consequence, one woman was searching for an "upbeat" group that did not focus so much on the negative aspects of ME. I thought it was interesting that support groups could be detrimental to one's health, as that goes against the basic premise of what support groups should do. These findings demonstrate how our mind and body interact in illness.

Upon further research, I discovered that experts on pain management discuss how concentrating on pain makes pain worse. Thus, the goals in chronic pain management are to "eliminate pain-talk and pain-behavior" (Guck, 1984, p. 5). This idea would account for the negative effects of support groups, because often in support groups the focus is on how everyone is feeling, symptoms, failed treatments, etc. The result is that people begin to concentrate on their pain and bring it into consciousness. My own experience doing this research has been similar. Immediately after I had done the

main interviews, and during the writing of the results chapter and this chapter, I felt worse than I have in over a year. It is as if I am acutely aware of every ache and sore spot in my body. Support group participants and, in particular, support group leaders, need to be aware of this phenomenon.

EXPERIENCES WITH OTHER PEOPLE (ACQUAINTANCES AND STRANGERS)

A major problem many women brought to my attention was that because ME is largely invisible, people often have difficulty accepting its existence and thus accepting the women as legitimately ill or disabled. Whereas, theoretically, the term *disabled* encompasses chronic illness and other invisible disabilities such as epilepsy, it seems in practice that *disabled* has a much narrower definition. Usually, as the women pointed out, a disabled person is pictured as someone who requires a wheelchair or other aid, is deaf or blind, is bedridden, or totally dependent on others for day-to-day survival. Because of this narrow view of disabled people, it was not surprising that the women had difficulty being taken seriously. Some women reported that when they were describing their disease it was not unusual to have someone reply, "is that that yuppie flu", or "I'm tired all the time too, I probably have it", "or my memory is bad too."

I found it interesting that two women talked about how society ignores sick and disabled people. One of the women felt that sick and disabled people were ignored because people do not want to know how hard someone's life is. It could be that people are afraid of discussing illness, death, and poverty because somehow by acknowledging these hardships they feel they may have to take responsibility for sick and disabled people. The other woman who talked about how society ignores sick and disabled people felt that such people are ignored because basically people are selfish. People do not want to share their wealth or their time with needy people. This is evident by the inadequate services available for chronically ill and other disabled people.

Examples of outright discrimination were experienced by all the women. All the women were discriminated against by friends and family. Friends and family drifted away from the women, or ignored the reality of the illness and the impact it was having on the women's lives, or told the women off, or called the women names. One woman discussed how the lesbian feminist community in general discriminated against her. She stressed how there seemed to be no place for disabled lesbians because they do not fit the "amazon" ideal. It seems that there is no room for women who are needy or weak in any way in the lesbian feminist community. Her experience also seemed to be congruent with the literature on women and disability, that states that the feminist community has no time or place for disabled women

and that there seems to be a fear among feminists about becoming responsible for disabled women if they are included. Although there was only one incident of discrimination by a member of the disabled community, it was a revealing example of how people with ME are not accepted as disabled, even by the disabled community. One woman's concern that there is a potential for discrimination if it is found that ME is contagious is an interesting and important point.

COPING STRATEGIES

What seemed to be one of the most effective ways of coping with ME on a daily basis was to be well organized. It seemed that the women who were ill the longest, and who had accepted that they had a chronic illness, were the most organized. These women made sure they planned their days according to their abilities, which meant that they set realistic goals each day. They ensured they got the rest, the food, and the social interactions they required to stay as healthy as they could. They also took advantage of various aids (e.g., motorized scooters) or services (e.g., homemakers) to help them with their day to day existence. Some of these women were involved in some kind of volunteer work. At the same time, these women were fairly flexible psychologically. They learned to say "no" or "maybe" to invitations or requests from others, and they learned to

live with not being reliable all the time. The order in their lives seemed to bring a sense of accomplishment and purpose. However, being organized did not mean that all these women had a positive outlook on their future or saw any future at all. Some of these women still only lived day to day. It did, however, seem that their existence was more meaningful than for those who seemed to be living in a haze and struggling with every day.

EXPERIENCES OF SELF

Most of the women seemed to have healthy attitudes about themselves at the time of the interviews. However, as the women pointed out, they did not always have these healthy attitudes. There seems to have been a definite pattern in the way the women viewed themselves. Before they got sick the women had a high level of self confidence and self esteem. (I did not ask the women about their self esteem, but seven of the women discussed it.) Six months after they got sick, their self confidence and self esteem plummeted. At the time of the interviews, their self confidence and self esteem were higher. However, it seems that their self confidence and self esteem did not reach the same levels as before they had become ill. Some of the women said the reason their self confidence and self esteem were not up to where they had been, was that they could no longer work outside the home. For them, self esteem and

self confidence were highly correlated with working outside the home. For example, one woman referred to her self as a "nobody" because she could no longer do volunteer work and be involved in the lesbian feminist community. Not every woman had her self image tied to work, however. One woman, who consistently referred to herself as a "loser," seemed to have her self image tied to her ability or inability to be a partner. She felt she was a "loser" because she was not like other women (i.e., healthy) and therefore no man would want her as a companion. She stressed several times that men (in particular, the men she dated) deserved someone better (i.e., healthier). Other single women also commented on how difficult it was or would be to find a partner who would understand and accept their limitations. However, for these women, it seemed that the problem was not with themselves, but with the fact that there were not enough sensitive men.

The women who were mothers felt they were doing the best they could but compared to other, "normal" mothers, they did not do as much as they "should." I detected in the women's comments about mothering that there was some guilt at not being able to give their children what they would have liked, even though they knew they were doing their best. This demonstrated to me the enormous pressures on mothers to be superhuman. Most of the women described themselves as basically good people. (i.e., when I asked them if they were good partners, five women said they were

when they had a partner; all the women said they were good friends and sisters.)

Interestingly, the one woman who has a negative self image is still quite sick, and that may account for her negative attitude. This woman referred several times to her body and mind as "stupid" and referred to herself as a "loser," and said she didn't deserve any help because she was an adult and should be responsible for herself. Instead of blaming others for not being there for her, she tended to blame herself. It could be that she is at the stage where the other women were six months into the illness, where self confidence and self esteem are at an all-time low. It could be that she reverted back to that stage, because at the time of the interview she was quite ill (This woman had been ill for eight years).

The stages of grief that Kubler-Ross discovered for people who are dying seemed applicable, to a degree, to the stages of grief that the women in the study experienced. I identified three stages: first denial, then bargaining, and finally, acceptance. However, as I discovered, and as Register points out, the stages are not as linear as Kubler-Ross's stages, because with a chronic illness there is no "certain resolution" (1987, p. 235). Often when the women had a bad relapse they started over again at the denial stage. As well, in the case of some of the women who did not get a diagnosis for several years, it seemed that the stage of denial was extremely long. This makes sense, given

the fact that they had no illness to accept. How could they accept something they were told they did not have, or how could they accept something they knew they did not have?

While the changes in their physical and mental abilities came about quickly with the illness (overnight, in most cases), the changes in their lives and their behaviors were a more gradual process. In the denial stage, the women all reported resistance to change. They struggled to maintain their styles of life, ignored what their bodies and minds were telling them, and often pushed themselves to utter exhaustion, denying they had a chronic illness. This stage was also coupled with other people denying their illness. Eventually, the women began bargaining. They tried enormous numbers of treatments and behavior changes in an attempt to cure their illness. The idea was that if they did just the right thing or took the right medicine or herb, they would be alright. This stage was coupled with others' suggesting various treatments and behavior changes. (One woman had a friend suggest she get a tee-shirt saying "yes I have tried everything!") Eventually some of the women began to accept that they had a chronic illness, that they were disabled and that they had to learn to live with it. At this point they cut down the number of treatments they tried, or at least seemed to be more cautious about trying new treatments. Of those women who were at the stage of acceptance, their attitudes about life and about themselves seemed to change. Usually when the women were at this stage

they made sure that people in their lives were people who accepted them for who they were - illness and all. Not all of the women reached the stage of acceptance. At the time of the main interviews, there were still some women who were in the denial or the bargaining stage.

It seemed evident that the women felt uneasy about having ME rather than an illness that was well known and accepted and had visible characteristics. It was not as if they wished for a worse disease; it was just that there was some reluctance to admit they had ME. This was evident when I asked the women how they responded when someone asked them 'what is the matter with you'. Some women felt they had to lie about having ME, or not mention ME at all in their responses. For example, having a "muscle disease" sounded better and was less complicated than explaining what ME is and their having to contend with the comments 'I know how you feel, I am losing my memory too' or "I'm tired all the time too." Many women tried to avoid all discussion about their illnesses. In that regard, passing as normal had its good points, as the women could usually pass. Other women reported that they did not try to hide the fact that they had ME. They usually took the time to explain it in understandable terms, if they thought a person needed to know.

When I asked the women how they responded when someone asked them "what do they do", three of the women expressed that it was difficult to answer. They tried to avoid the

subject of work as much as possible. The difficulty seemed to be that in our society work is so linked with self esteem. In some instances, if a woman does not work outside the home she is devalued. Many of the women lied about what they did, or at least stretched the truth as far as possible to avoid looking "bad." I found it extremely interesting that the women whose answers were more straightforward were those who were accepted as being disabled by their insurance companies and thus were receiving disability benefits. In other words, they had their experiences validated by institutions, which made their illnesses legitimate. This perhaps helped them to be more forthright in their answers.

One of the most interesting discoveries in the study came when I asked the women if they felt they were members of the disabled community. All but one of the women stated that while they did feel they were disabled, they had difficulty calling themselves disabled. One of the main reasons seemed to be that they did not fit the societal image of a disabled person, yet they knew they were disabled. I had expected the co-researchers would have difficulty in responding to that question because they usually looked well. It seems that the problem with not looking ill or disabled is that others have difficulty accepting them as disabled. As one co-researcher could attest, people have difficulty accepting what they cannot see. She admits that when her teenage daughter began to display symptoms of ME, she had problems believing her

daughter was truly ill because the doctors were saying there was nothing the matter with her. This woman had already experienced a great deal of difficulty getting others to believe her when she became ill.

Perhaps as a result of such invalidating experiences, the women themselves had difficulty seeing themselves as disabled and chronically ill. One woman who said in the main interview that she was definitely not disabled, phoned me three months later to tell me she had been thinking a lot about the question and that she would like to change her answer. After much consideration, she decided she was indeed disabled but just different than the stereotyped view of a disabled person. In other areas of the interviews, the women demonstrated ambivalence about viewing themselves as disabled. Although the women were qualified to apply for and receive aids and benefits, many of them did not feel comfortable using visible aids (e.g., motorized scooters, wheelchairs, bus passes, homemakers service, or handicapped parking spaces), because they did not look disabled. They were afraid of what others would say to them (which was a valid fear given their experiences of discrimination), and afraid of how they would be perceived by others. Since the majority of the women did not see themselves clearly as disabled, this may be one reason why many of them never applied for assistance (e.g., bus passes, disability tax credits, homemaker service, GAIN), or if they did apply for assistance, why it took so long to ask for it. Clearly, in

the first part of the illness the women never saw themselves as disabled. Janet, for example, used up her savings, sold her car, and went bankrupt before asking for social assistance. In addition to having problems viewing herself as disabled, one woman had another reason for not wanting to use a motorized scooter or wheelchair. She was afraid that by using a motorized scooter or a wheelchair, she would be invalidating those people who have to be in a wheelchair. In other words, she believed she had a choice, whereas some people do not. The stigma that surrounds the term "disabled" may be holding people back from utilizing aids that might help them live more comfortable lives. One problem for people with ME seems to be that they are often living on the line, sometimes needing and sometimes not needing help.

The emotions that permeated all of the women's lives were fear and anger. They expressed fear about the unknown nature of ME. For example, for a few women there was fear that ME might be contagious and that they might be passing ME on to loved ones and family. For one of these women, the fear of ME being contagious consumed her thoughts. There was also sometimes a fear that they would die because they were so sick. One woman was afraid that she would die as a result of a respiratory illness that she believed was related to ME. Some women expressed fear about not being believed every time they tried to explain what they were feeling. This fear came from their experiences of not being

believed by doctors, friends and family. As a result of the fear of not being believed, some women sometimes thought they were going crazy, or that somehow their illness was not real and they were imagining it. In other words, at times they doubted their sanity.

The women were angry at the medical establishment for various reasons: for not taking them or their symptoms seriously; for abusing them both verbally and medically (e.g., prescribing harmful addicting drugs, and in one case performing an unnecessary hysterectomy); and for portraying themselves as all-knowing about the body when in fact they know little about the body or chronic illness. There was also a lot of anger and disappointment about the lack of understanding and support from family, friends, communities, and society as a whole. The women were angry because they were discriminated against for being disabled, unable to work, poor, overweight, and for having an invisible illness. The women were also angry because they had to use up scarce energy to fight for their rights to financial and other aid. There was one woman who was angry at her body because it was not responding to medication or the tremendous care she was taking to heal it. (This woman lived on a very strict vegetarian diet and did yoga, meditations, visualization, hypnotherapy, and took vitamins, herbs and various medical and non-medical remedies and drugs.)

SUMMARIZING THEIR EXPERIENCES

As I had anticipated, the women did change their views of the world and of themselves in profound ways. In a sense it was as if they began to see life through a different lens. They learned to see pain, suffering, social injustices, and to appreciate birds, flowers, music, poetry, and the value of friendship. One woman realized the American dream was a hoax, a person cannot be anything or do anything just by working hard. One woman discovered a new world of interesting people (working class and poor) she never associated with before. One woman who used to live in the "fast lane," now states that if she ever regained her health she would never return to that kind of "rat race" because it is destructive psychologically and physically. Many realized they were strong women, but at the same time vulnerable. Lastly, some of the women discovered their spiritual selves as a result of becoming ill.

The majority of the women seemed to have fairly positive feelings about the future. They seemed to accept the research that states that ME gets better over time. However, a few of the women were still quite fearful about having a future because they were still fairly ill, and for one woman, because she was afraid of dying by her own hand.

FURTHER RESEARCH

There are many issues that arise out of this exploratory research, but I will focus only those areas that I think need the most immediate attention. They are not listed in order of importance.

First, since the women had so many negative experiences with the medical establishment, I feel it is imperative that further research be done on the relationships between doctors and their female patients, and in particular females who are disabled or chronically ill. In addition, it would be worthwhile to examine what doctors are taught in medical school today about women, about chronicity, about disability, and about the enormous impact that diagnosing and not diagnosing has on people.

Second, since the women who went to psychiatrists and therapists had positive, long lasting experiences, I think it would be worthwhile to study successful relationships between therapists / psychiatrists and women with chronic illnesses and disabilities. In addition, it would be beneficial to discover what psychiatrists, psychologists, and social workers are taught about women who have disabilities.

Third, it would be worthwhile to see if other people with ME have seemingly related conditions and disorders such as cysts or sinusitis, as it may shed some light on the disease process. As well, researchers must continue

studying known symptoms of ME, such as fatigue, to discover why there is such variation among people in how they experience symptoms.

Fourth, it is evident that research needs to be done on poor, disabled single mothers and their need for solitude, and on ways society can make respite care and temporary foster care more appealing and accessible to them.

Fifth, since I think it is important to bring humor into the lives of women with ME and because humor was not addressed in this study, I feel it would be worthwhile to collect ME humor and make it available to people with ME.

Sixth, since I did not interview women with ME who are currently employed, or women who were full-time homemakers before becoming ill, or women who have never been involved with ME support groups, I feel it would worthwhile to see whether their experiences are similar to or different from those of the women in this study.

Seventh, it would be interesting to compare women with ME to women who have other invisible disabilities such as heart conditions, or similar diseases like MS or Lupus, to discover whether they have similar experiences. In particular, it would interesting to compare how the women see themselves and how others view them.

And last, there needs to be research into what financial difficulties women with chronic illnesses and women with disabilities are having. In addition, I feel it is imperative that we discover how many women who are

disabled resort to prostitution, and the reasons why they might choose prostitution.

RECOMMENDATIONS FOR SOCIAL POLICY

The results of my study suggest several practical steps that could be taken by governments, employers, and feminist organizations to improve the lives of women with ME.

Since there is little understanding by physicians, media, and the general public about the nature of ME and how it affects people, there is a need for massive education as to what ME is and is not, the symptoms, how it affects the lives of those who live with it, how it affects those people who live with people with ME, and the different issues women with ME face. In addition, the media need to be better educated about ME so that they can give ME the same attention and respect as other disabling chronic illnesses such as MS.

The welfare system also needs to be educated about ME and about chronic illness and how it affects people. For instance, welfare policy-makers, officials, and case workers need to be aware of the added monetary costs of being chronically ill, such as expensive treatments, dietary requirements, and transportation expenses, and to incorporate these basic requirements into their financial support of chronically ill people.

There is also a real need for women to be educated about their health, about what their options are for health care, about their rights as receivers of health care, and about the systemic faults of the health care system. To do this, I would recommend regional health centres, similar to the Vancouver Women's Health Information Centre, where women can use resources to make informed choices about their health and communicate with each other about their experiences. Perhaps, the centres could be connected to existing women's centres and be linked together by computer.

Women's groups should begin to focus on women's health issues at a national level. My immediate suggestion is to get organizations like National Action Committee on the Status of Women (NAC) to make policy resolutions and to lobby the government for services, research, and education about women's health and especially about the health and wellbeing of women with disabilities.

Women working in the feminist women's health movement also should begin to direct their energies towards educating the medical community. In particular they should target teaching hospitals and educate students about women's health issues, and more specifically about how inadequate and destructive some aspects of the bio medical model are for women, and how their patriarchal and capitalistic system is destructive and costly (monetary and otherwise) for all people, but especially for women.

Governments and employers need to redefine what accessibility in the work place means for disabled people. Some people with ME could work part time if there were, for example, financial incentives instead of financial disincentives, flexible hours, transportation to and from work, and if it were possible to work from their homes. Furthermore, governments could retrain people with chronic illnesses into jobs that are suitable to their abilities.

Lastly, governments need to make transportation for chronically ill people more accessible and inviting, perhaps enlarging the bus system for people with disabilities and then advertising that people who are disabled come in many shapes and sizes and have both visible and invisible disabilities.

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APPENDIX A

I am doing a study to try to understand women's experiences of having M.E. In particular, I am interested in understanding your experiences relating to the medical establishment, and the ways you cope day to day, your relationships, and your self concept. To begin with, I would like you to tell me your story of your experience since the time you became ill up until the present. After you have told me your story I will ask you specific questions and many open ended questions. Once we have finished the questions, you may add anything you think may have been missed in the questions. I want you to feel that you have told me all there is to know about your experience with M.E. As you are talking, try to recall what you were thinking, feeling and doing at the time of your experience. If you begin to feel you cannot continue the interview because of your ill health, please do not hesitate to let me know. Do you have any questions?

LIST OF QUESTIONS

1. Before I begin with a few background questions, I would like to ask you if there is a fictitious name you would like me to use when I write up this report? If yes, what is it?
2. (I will define myself to the co-researcher as white, 31 year old mother of one, who has ME, and then ask them to identify themselves). How would you define yourself in terms of age, race, ethnicity, etc?
3. What education level have you completed?
4. Briefly describe your relationship with religion.

5. With whom did you live with when you first became ill?

6. With whom do you live now?

EXPERIENCES WITH MEDICAL ESTABLISHMENT

7. How long you have been experiencing the symptoms associated with M.E.?

8. Were you ever given any other diagnoses besides M.E. or Chronic Fatigue Syndrome that were supposed to explain all your symptoms?

9. Starting from the onset of your illness, how long did it take to be given your present diagnosis of M.E.?

10. How did you feel when you were told that you had M.E. \ Chronic Fatigue Syndrome?

11. Starting from the time you first started to show symptoms of M.E., approximately how many doctors did you see before you received a diagnosis of M.E.?

12. What were the qualifications of the person(s) who diagnosed you as suffering from M.E. (i.e., general practitioner, specialist, psychiatrist)?

13. Have you ever been prescribed medication to alleviate your symptoms?

If "yes":

- (a) what type of drug(s) were you prescribed ?
- (b) how frequently were you expected to take them ?
- (c) did you take the drug(s) as prescribed?
- (d) did they help?

14. BETWEEN the time you STARTED showing symptoms of M.E. and the time you were diagnosed with M.E., was it ever said or implied that you were malingering, that you were depressed, that it was all in your head, or that it was any other type of disease or disorder? If so, describe your experience(s).

15. Were you ever referred to a psychiatrist, psychotherapist, or counsellor?

If "yes":

- (a) How would you evaluate that experience?
- (b) Did it help you cope with the illness?

16. Has your view about doctors \ medical establishment changed since you have become ill? In what way? Why?

(16a. Describe any experiences you have had with the medical establishment where you felt you were not given the best care.)

(16b. Describe any experience of receiving very good help from medical practitioners)

17. Describe all avenues of treatment you have tried regarding your chronic illness. Which, if any, helped you?

18. Have you had any accidents, diseases, disorders, or surgeries that you think were related to ME.

COPING STRATEGIES

19. Have you ever tried to change your habits or behavior to try and make your symptoms go away?

20. Describe a typical day.

21. What do you find the most difficult thing to deal with since you have become ill? How do you deal with it?

22. What are some everyday problems that you have had or still have trouble coping with? Describe how you deal with them.

23. Describe any good or bad advice you have received from other people about coping with M.E.?

24. Describe any "tricks" \ or little things you do that seem to help you cope with your illness?

25. If you are involved in a lay support group how has it affected you?

WORK

26. If you worked outside the home, how has your employment status changed since you have become ill?

27. How has your income level changed since you have become ill?

28. What special problems, if any, have you had in obtaining some form of financial assistance or special benefits from the government of insurance companies?

29. In relation to your job outside the home, how do you feel about losing your job \ not being able to work \ not being able to work full time \ not being able to work as you used to?

30. What has changed in regard to your household work since you have become ill?

31. If you have children, how has M.E. changed how you look after your children? \ grandchildren?

32. If you were a caregiver to others, how has ME changed how you look after them now?

33. Are the people you live with helpful \ understanding with the change in your abilities to do physical and \ or mental work?

34. Are friends, family and co-workers you do not live with helpful \ understanding with the change in your abilities to do physical and \ or mental work?

35. How has M.E. affected other areas of your life? (e.g. hobbies, sports, recreation, volunteer work, studies)

RELATIONSHIPS

36. Do you feel M.E. has put a strain on any of your relationships (family, friends, partner, business)? If so, in what way?

(36a. Describe any changes in your friendships since you have become ill.)

37. Describe how having M.E. has affected your social life.

38. If you live with other people, describe what happens when another member of the household becomes ill?

39. * [OPTIONAL] How has ME affected your sexuality?

SELF CONCEPT

40. How do you describe yourself when someone asks you "what is the matter with you"? \ "what do you do"?

41. Do you see yourself as a member of the disabled community? Why? \ Why not?

(41a. If yes, have you felt you have been discriminated against because you have ME?)

42. I want to know how your feelings about yourself have changed since you have gotten ill. In regard to the following words describe your feelings about yourself BEFORE

you became ill, three to six months AFTER, and how you feel about yourself NOW.

	Before	After	Now
(1) HEALTH	_____	_____	_____
(2) SELF-CONFIDENCE	_____	_____	_____
(3) BODY IMAGE	_____	_____	_____
(4) SPIRITUALITY	_____	_____	_____

43. Do you feel you are, or have been, a good mother \ wife \ partner \ friend \ daughter \ sister? Why? \ Why not?

44. How does the future look to you and how do you picture yourself in the future?

45. Has your view of yourself and of the world changed since you have become ill? Why? \ Why not?

46. How do you think your family \ friends \ doctors picture you ? How do you think they see you to be in the future?

47. Have you learned anything that is important to you through your experience of M.E.?

48. Is there is anything you would like to add that you think is important to know about your experience with M.E.?

CONSENT TO PARTICIPATE IN STUDY

I, _____, agree that I will participate in the research study being conducted by Ingrid Deringer as part of her Master's thesis in Women's Studies at the Simon Fraser University, supervised by Professor Susan Wendell, Phd.

I understand that my involvement will extend to the completion of three interviews regarding my illness. I further understand that my participation in this study is voluntary and that I may discontinue the interviews at any time. In either case all responses will be kept entirely confidential.

I give my consent to publish any version of this study provided my identity is not disclosed.

Signature: _____

Date: _____

Should you have any questions or concerns regarding your involvement in this study please feel free to contact Ingrid Deringer at 944-4802 or Dr. Susan Wendell at 733-6647.