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**EXAMINING ILLNESS NARRATIVES IN CHRONIC  
FATIGUE AND IMMUNE DEFICIENCY SYNDROME:  
A MINDBODY PERSPECTIVE**

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# CONTENTS

	Page
Acknowledgements	i.
Dedication	ii.
Contents	iii.
List of Figures	
Abstract	
<b>Chapter 1: Introduction</b>	<b>1.</b>
1.1 Chronic Fatigue and Immune Deficiency Syndrome	1.
1.2 Research Question	7.
1.3 Proposed Method of Addressing This Question	8.
1.4 General Layout of Thesis	9.
<b>Chapter 2: Literature Review</b>	<b>10.</b>
2.1 Introduction	10.
2.2 Medical Research	11.
2.3 Psychological Research	24.
2.4 Social Research	34.
2.5 Implications	39.
<b>Chapter 3: Method</b>	<b>42.</b>
3.1 Why Qualitative	42.
3.2 Sample	43.
3.3 Procedure	44.
3.4 Analysis	46.
<b>Chapter 4: Illness Narratives</b>	<b>48.</b>
4.1 Introduction	48.
4.2 Level One (Illness Events)	48.
4.3 Level Two (Inner Journey)	62.

<b>Chapter 5: Medical and Lifeworld Models</b>	<b>67.</b>
5.1 Overview of patients' illness experience and meaning	67.
5.2 Medical Model	69.
5.3 Lifeworld Model	75.
<b>Chapter 6: Mind-Body Medicine</b>	<b>95.</b>
6.1 PNI	95.
6.2 Implications	105.
6.3 Energy Medicine	107.
6.4 Implications	113.
<b>Chapter 7: Psychodynamic Theory</b>	<b>116.</b>
7.1 Proposed Affect Etiology	116.
7.2 Emotional Schemas	117.
7.3 Stimulus Entrapment	120.
7.4 Influence of Affect	122.
7.5 Accessing Affect	127.
7.6 Implications	128.
<b>Chapter 8: Conclusion</b>	<b>131.</b>
<b>Appendix A: The BATHE Technique</b>	<b>139.</b>
<b>Appendix B: Consent Form</b>	<b>140.</b>
<b>Appendix C: Semi-Structured Interview</b>	<b>141.</b>
<b>Appendix D: Maudesley Psychiatric Interview</b>	<b>143.</b>
<b>References</b>	<b>147.</b>

## LIST OF FIGURES

	Page
FIGURE 1. Comparison of Two Days' Normal Activity	4.
FIGURE 2. The 2-5A Synthetase/Ribonuclease (RNaseL) Pathway	18.
FIGURE 3. Explanatory Model for Disease Susceptibility Applied to <u>CFIDS</u>	31.
FIGURE 4. Cell- Mediated Immunity	97.
FIGURE 5. Antibody- Mediated Immunity	98.
FIGURE 6. Molecules of Water	99.
FIGURE 7. Binding Process	100.

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## ABSTRACT

A semi-structured interview was used to obtain illness narrative data from 10 Chronic Fatigue and Immune Deficiency Syndrome (CFIDS) patients. A qualitative narrative analysis was completed and the findings were discussed in relation to the patients' subjective understanding of their illness process. This was related to current CFIDS research findings, and more especially to the four theoretical paradigms that underpin this research – namely, Medical Illness Model, Lifeworld Illness Model, Mindbody Medicine, and Psychodynamic Theory. Each one of these illness theories highlighted an aspect of the healing influence on CFIDS patients' illness course and meaning. The analysis confirms the importance of all these healing influences. Thus it was concluded that the medical treatment, arising from the Cartesian dualistic understanding of mind and body, proved inadequate on its own as an effective intervention to bring release from CFIDS symptoms and enable the patients to engage a new meaningful life-process. The four paradigms together represent the mindbody reality and indicate the importance of patients receiving interventions at all levels of their lived experience. This intervention approach was shown to be most effective. It is therefore suggested that the Health System work towards such collaborative, integrated health care for chronically ill sufferers.

# CHAPTER 1

## INTRODUCTION

To fully appreciate the sick person's experience, the clinician must first piece together the illness narrative as it emerges from the patient's complaints and explanatory models; then he or she must interpret it in the light of the different modes of illness meanings - symptom symbols, culturally salient illnesses and social contexts (Kleinman, 1988, p. 49).

### 1.1 CHRONIC FATIGUE AND IMMUNE DEFICIENCY SYNDROME (CFIDS)<sup>1</sup>

#### KAREN'S STORY:

"I was an engineer with a job I loved: I was a wife with a husband I loved (and still do): I was a hotline volunteer, a league volleyball player, and I traveled extensively for work and pleasure. I was a happy, active 42-year-old. On March 12, 1993, I woke up with the "flu" and my life has been altered ever since. I have flu-like symptoms continually, mental confusion, memory loss, extreme fatigue, severe headaches, etc. I have been unable to work. This is not depression. Nor is this the portrait of a deadbeat" (Eble, 1999, p.A11).

The incidence of chronic disease<sup>2</sup> is of growing concern generally amongst healthcare professionals as the body of chronically ill seems to mushroom steadily. In 1994 statistics from the Centre for Disease Control and Prevention (CDC) that more than 90 million Americans live with chronic disease, and these diseases accounted for 70% of all deaths in the USA. The overall medical care costs of such patients took more than 60% of the nation's medical costs, (<http://www.cdc.gov/nccdphp/about.htm>). With the onset of illnesses such as Autoimmune Deficiency Syndrome (AIDS) and CFIDS that continue to baffle the

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<sup>1</sup> This syndrome is also referred to as Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS).

<sup>2</sup> The Centers for Disease Control and Prevention give a broad definition of chronic disease: illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely.

medical profession, it becomes increasingly important to find a way to pool all our resources so that we may more ably approach greater clarity as to epidemiological factors and appropriate interventions.

Karen's story above gives a typical scenario experienced by CFIDS sufferers, and in examining it more deeply, reasons for choosing to research in this particular chronic illness will be made clear.

Firstly, it was written in reply to an Editorial in the *Wall Street Journal* that had lashed out against chronic benefit payments for "the mystery ailment known as chronic fatigue syndrome" (Editor, 1998, p.A14). From its inception, CFIDS has been considered a mystery illness and clinicians continue to be baffled, as no definite etiology or effective treatment has been established. In many cases the credibility of the illness is questioned, despite its having been officially recognized in the United States by the CDC, in 1988. This attitude has resulted in stigmatization of those who suffer from the syndrome. It is felt that this sense of stigma in itself would be a complicating factor in the treatment and experience of CFIDS, as it would increase the frustration and stress levels of all involved. Fox (1996) draws attention to this phenomenon in sharing some of the questions that sufferers have asked. Evidence of the feeling of frustration and stigmatization can be seen as people grapple with their illness experience when they ask:

My GP refuses to believe ME exists, never mind that I have it. Should I try to convince him or look for another doctor? (p. 88)

I've tried all sorts of alternative therapies with little success. How long should I walk the treadmill of trying new things in the hope of recovery? (p. 100)

Although I have been diagnosed with ME, it has been implied that my illness is due to stress. I know this can't be the reason for all my symptoms but I have, in fact, felt very stressed since I became ill. How do I know that I'm not just suffering from stress? (p. 91)

Relational stressors are depicted in the following cry for understanding:

I used to get on okay with my family but since I've been ill my relationship with them has deteriorated. Not only are they unsupportive but some of them are actually cruel. Why have they become like this? (p.103)

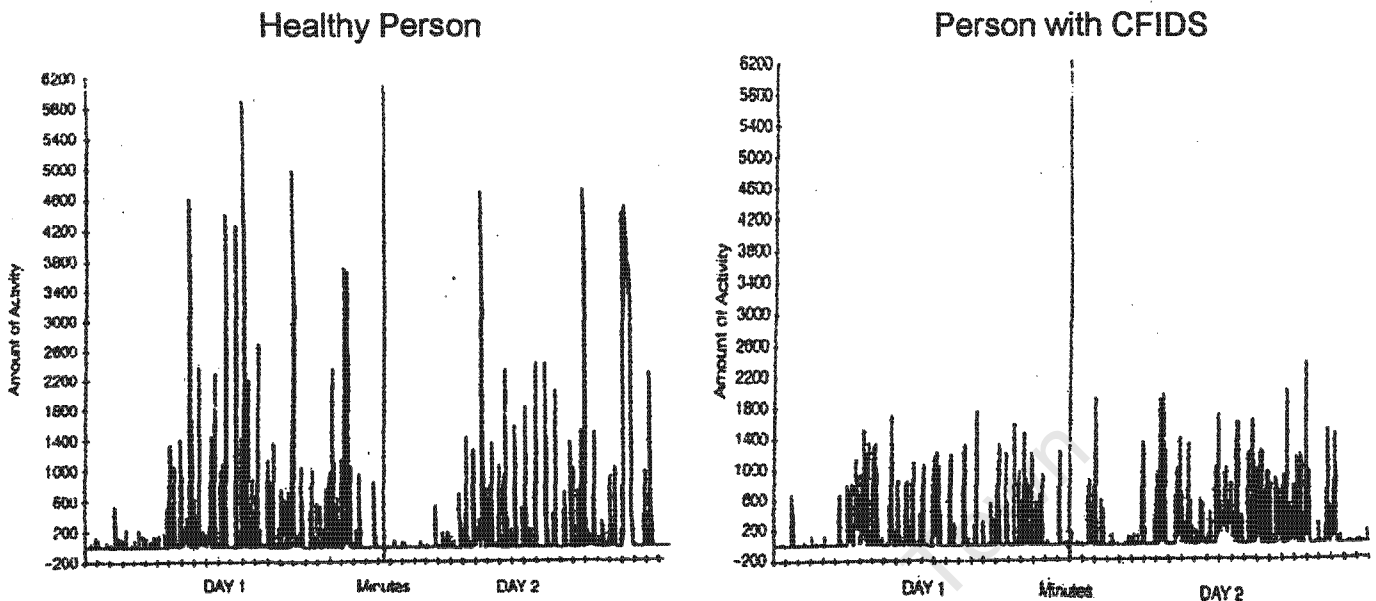
These excerpts certainly provide evidence of an added burden being placed on CFIDS sufferers due to the enigmatic nature of the illness and the scepticism with which sufferers are treated. This places inordinate stress on sufferers who have to work through feelings of guilt and embarrassment as a result of having this complex illness. Their physician or family and friends often negate the patients' illness experience because they question the validity of their symptoms. It therefore seems important to investigate CFIDS in order to try to arrive at a place of clearer understanding and less scepticism.

Secondly, Karen lists a string of symptoms indicating that this is an ongoing syndrome of symptoms with seemingly no end. Typically, Karen first noticed 'flu-like' symptoms that refused to disappear. Together with these, the mental confusion, memory loss, severe headaches and extreme fatigue, give us a characteristic cameo of a CFIDS sufferer. In themselves, these don't seem to be dangerous or worthy of special attention. They function as a syndrome - without any clear-cut causality that can be treated and resulting in life-changing consequences. Taken together they become confusing and frightening, and demand our attention. The situation currently is that CFIDS is being reported in increasing numbers. Countries throughout the world have established organizations to address the plight of CFIDS sufferers, constantly lobbying for more research to be done and medical benefits to be given.

One of the frustrating phenomena that CFIDS sufferers are subject to is that they do not benefit from exercising, in fact the reverse. The impact of the exhaustion experienced by a person with CFIDS is graphically depicted in the following figures. They indicate how the patient's normal daily activities are truncated when seen in comparison with the normal daily activities of a healthy person.

## FIGURE ONE

(Comparison of Two Days' Normal Activity)



(Jason, King, Richman, Taylor, Torres, & Song 1999b)<sup>3</sup>

In the 1994 CDC definition of chronic fatigue syndrome, a classification was set out:

Patient must display sufficiently severe fatigue persisting for at least 6 months. This must be of new or definite onset, not substantially alleviated by rest, and resulting in substantial reduction in previous levels of occupational, educational, social or personal activities.

In addition four or more of the following symptoms should be concurrently present for at least 6 months:

1. Impaired memory and/or concentration
2. Sore throat
3. Tender cervical or axillary lymph nodes
4. Multi-joint pain
5. Muscle pain
6. New headaches
7. Unrefreshing sleep

<sup>3</sup> This figure was retrieved from the internet and had no page reference.

## 8. Post-exertional malaise

(Fukuda, Strauss, Hickie, Sharpe, Dobbins, & Komaroff, 1994, p. 955).

Some of the latest demographical data from recent prevalence studies are as follows:

In metropolitan Chicago, rates of incidence of CFIDS are revealed to be 422 people per 100,000. However, when a whole community was studied, not only those being treated, the numbers increased significantly. New numbers indicate an overall adult CFIDS population of 800,000 in the USA. This is twice the number of cases of multiple sclerosis. The illness has been seen to be widespread in low-income and minority communities (cf South Africa's majority).

In these communities, the Latinos and African Americans evidenced higher rates than the Caucasians. The most disturbing finding of all, showed that only 10% of those with CFIDS had been previously diagnosed. This means that 90% of sufferers are struggling to maintain normal lives without any medical care. This is a hidden epidemic, and it seems to hit women most commonly (522 cases per 100,000 women).

It has been estimated that only 4% - 9+% of patients will fully recover, with an additional 39% showing some symptom improvement over 4 years. The risk factors for poor prognosis appear to be older age, co morbid disorders, and insisting on an entirely physical cause.

It is an illness that devastates lives and costs billions annually in healthcare. In USA it is acknowledged to be a major public health concern (Evengard, Schacterie, & Komaroff, 1999; Hill, Tiersky, Scavalia, Laviertes, & Natelson, 1999; Jason *et.al.*, 1999b; Joyce, Hotopf, & Wessely, 1997; Wall, 2000).

From these studies, and the proliferation of CFIDS studies taking place throughout the world, it can be seen that it is increasingly important to get to grips with an effective treatment programme and education of the public. This is especially the case here in South Africa where the illness seems to be underestimated<sup>4</sup>.

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<sup>4</sup> I have been unable to find any official estimates of the occurrence of CFIDS in South Africa.

Thirdly, Karen found herself completely removed from her normal lifestyle. This, too, is the inevitable lot (for a while at least) of all CFIDS sufferers, and so we have a growing number of unemployed/unemployable people. This impacts on both those who are ill and those with whom they live, in adverse ways. Our societies are not accustomed to having to cope with 'useless' members but are geared for those who can contribute a meaningful service, and 'laying about at home' certainly does not fulfill these expectations. The ensuing stress is indeed detrimental to all concerned. "Qualities of distress interact with culturally specific expectations for social life and personal conduct to trigger microsocial processes of marginalization: role constriction, delegitimation, impoverishment, and social isolation" (Ware, 1999, p. 303). This linking of chronic illness onset with sociocultural stressors is re-iterated by Ware and Kleinman:

Attributions of illness onset to social sources, the symbolic linking of symptoms to life context, and the alleviation of distress with improvement in circumstances point to the sociomatic mediation of sickness (1992, p. 546).

We are thus made aware of the need for an inclusive understanding of illness perceptions. Dean (1999) talks of the need for a holistic approach to chronic illness that affects the physical, psychological, spiritual, and economic aspects of the patient's life. Cooper (1998), in a review on patient perceptions, examines the manner in which illness perceptions mediate health outcome. The blending of the relationship between mind and body, which we learn from psychoneuroimmunology (PNI) and Somatic Medicine literature, also encourages us to consider the validity of illness being a matter of mindbody, necessitating that we take into account the totality of the sufferer's life experience and illness perceptions. Thus all these observations encourage us to acknowledge the importance of understanding how perceptions of illness are formed, as it is these perceptions which determine both the sufferer's and care-giver's responses to the chronic illness.

There is a need to examine the question of patients being honoured and given a place in their community in which to function, despite their apparent 'uselessness'. The concept of transformations being occasioned by chronic

illness endorses the understanding of bodily distress being a vehicle for negotiating change in interpersonal worlds (Ware and Kleinman, 1992)

This brings to mind a chronic illness described as serious and debilitating, and having severe physical and psychological symptoms. It is found amongst Xhosa and Zulu peoples, and is known as Intwaso. The traditional understanding of this illness is that it is a call to undergo initiation as a shamanic healer (cf. above-mentioned transformation process.) In fact it has been noted that where sufferers accept this understanding of their experience, and undergo the treatment given by the shamanic healer, they invariably come through the illness into a new role within the community. However, where this response doesn't occur, it has been noted that the illness is unlikely to be cured and could, in fact, end in death (Louw & Edwards, 1997). In this instance it is as if the acceptance and honouring of the illness state, by both sufferer and his/her society, enables a process of healing and transformation to occur. We could do well to note this in relation to our response to CFIDS. It is important to take a look at the syndrome from a comprehensive viewpoint, acknowledging its enigmatic nature. The totality of illness understandings must be considered in order to encourage an understanding of the need for life-transformation as indicated by the bodily diseased condition.

From all the above observations it has become clear that it is important to understand the full array of influences shaping our perceptions, and thus our subjective experiences of, and responses to chronic illness. This research intends to do so by studying the illness course/experience of a sample of CFIDS patients.

## 1.2 RESEARCH QUESTION

The supposition I make is that the illness has resulted because of a pattern of living that has been motivated by unconscious emotional content stored within the body, relating back to relationships within childhood. The current pressures that are experienced by the person within the sociocultural context eventually cause the information systems that control the body's well-being to become damaged, and the soma needs to be released from the added strain of the

unconscious somatized affect. The symptoms of bodily dis-ease act as messages of warning. This being so, I would expect to find a more or less homogenous pattern of symptoms and I would also expect to find that the patient has needed to go inward to address unwanted affect stored unconsciously. I anticipate that those who are able to become more conscious will also experience an easing of the bodily symptoms. In addition I anticipate that this inner journeying will facilitate the patients' process of giving meaning to their illness experiences. Therefore I ask what is the course of CFIDS in the lives of the participants, and are they able to find meaning and a new self-awareness through co-operating with the illness experience?

### 1.3 PROPOSED METHOD OF ADDRESSING THIS QUESTION

As has been underlined above, CFIDS is a complex illness pointing to physiological, environmental and psychological influences on its pathogenesis. Illnesses of the body tend to be seen as 'real', whereas an illness like CFIDS which has no diagnostic test that can be used definitively, and no clearly defined pathogenesis, tends to be viewed as psychosomatic/imaginative. With all this uncertainty, "The origin is bound to be complex, and it will come together with a more generally altered view about mind-body dualism, and the concept of illness and disease" ( Evengard *et.al.*, 1999, p. 464 ).

With all this in mind I propose a multi-layered qualitative analysis, which will examine the patients' illness course and the meaning they give to their illness experience. I will address the polarization between those who assess CFIDS to be a solely medical problem and those who carry the concept of interactive mindbody or psychodynamic explanations of the illness. The various illness beliefs will be discussed in relation to the impact they have on the illness process. The question of 'malingering' vs transformation will also be examined. All of these differences will be analyzed and discussed in relation to the effects they have on the sufferers who respond to their CFIDS and form their own particular perceptions of their experiences.

The analysis and discussion of the data obtained will be informed from CFIDS research and four theoretical models of illness, namely, Medical (the traditional medical practice motivated by the dualistic Cartesian understanding of mind and

body), Lifeworld (the sociocultural beliefs about illness plus the life-experience that shapes a person's responses to illness), Mind-body Medicine (flowing from the new discipline of PNI), and Psychodynamic (exploration of affect formation and its mentalization and somatization processes).

The majority of people in South Africa have minimal economic and medical resources. As the situation stands currently, treatments are available at a cost. The majority of our patients are not in a position to afford this. There is an urgent need to examine the feasibility of the amalgamation of our medical care facilities, making appropriate holistic treatment more available and affordable. The possibility of finding a way to ease the isolation of the chronically ill is yet another issue that needs to be addressed. I intend to examine these topics in the conclusion of this thesis.

#### 1.4 GENERAL LAYOUT OF THESIS

Chapter 2 will consist of a literature review of the most current research being done in the area of CFIDS, and chapter 3 will set down the methodology. In chapter 4 there will be an analysis of the illness narratives. Chapter 5 will discuss the implication of the analysis findings as they relate to the Medical and Lifeworld models of illness. Chapter 6 will consider the Mind-body model, and chapter 7 will examine the Psychodynamic model. Finally, chapter 8 will discuss some of the wider implications for South Africa's health care system and the training of health professionals, as well as an overall conclusion.

## CHAPTER 2

### LITERATURE REVIEW

A recent evaluation of patients with chronic fatigue in Hong Kong may provide an important insight for our "Western" medical practice. For these patients the notion of having "medical" versus "psychiatric", or "biomedical" versus "psychosocial", cause of their illness made little sense. Their perception was that, while they were clearly unwell, the potential causes of that suffering could lie across a broad domain of personal, social or medical factors (Lloyd, Hickie, & Loblay, 2000).

#### 2.1 INTRODUCTION

In a recent editorial in the *Medical Journal of Australia* (MJA), the question of the complexity of CFIDS was examined. After looking at the array of etiologies that had been investigated, and admitting that these studies had not been able to agree on a simple explanatory model, the editorial suggested that the heterogeneity within patients labeled as having CFIDS pointed to the likelihood of more than one process being operative. The authors decided that this resulted in the fact that, "CFIDS challenges the standard concept of discrete disease categories linked to specific etiologies. The practitioner is confronted with the challenge of explaining the patient's symptoms without reference to a coherent biomedical model" (Lloyd *et.al.*, 2000, p.472). They continue in an examination of traditional Cartesian dualism of mind and body and deem it to be "unnecessary polarisation (which) is intellectually shallow and harmful to patients" (p.472)

At the end of a brief review of the current status of CFIDS research and understanding, Manu suggests:

At the beginning of a new millennium, chronic fatigue syndrome remains a frustrating illness. Patients with the syndrome deserve our compassion, but also our insight, wisdom and discernment. More than any other issue in contemporary medicine, chronic fatigue syndrome reflects the unresolved conflict between the mechanistic and biopsychosocial constructs of illness (2000, p. 173).

The CFIDS treatment process remains a difficult area to agree upon, and this literature review aims to add support to the above observations as it reflects on the complexity of the CFIDS research and difficulties in finding explanations as to the fundamental nature of this illness. The most current research both scientifically and psychosocially will be addressed in order to provide the background against which my analysis of the illness experiences will take place.

## 2.2 MEDICAL RESEARCH:

### VIRAL/BACTERIAL INFECTIONS

Although no virus has been isolated as the pathogen of CFIDS, there is consistent evidence of significantly higher reactivation of viral infections in CFIDS patients than in healthy people. As yet the reason for this is not absolutely clear. Researchers tend to favour the consideration that the depressed immunofunctioning within these patients could be providing a more conducive situation for such reactivation, rather than the reactivation being the cause of CFIDS symptoms.

Epstein-Barr Virus (EBV) was the first to come under scrutiny in the 1980's.

The profiles were of a chronic reactivation of EBV resulting in infection (Jones, Ray, Minnich, Hicks, Kibler & Lucas, 1985; Strauss, Tosato, & Armstrong, 1985). Subsequent studies have confirmed these findings, and current opinion is that EBV reflects a state of immune dysregulation, rather than being a primary cause of symptoms (Evengard *et.al.*, 1999).

Human herpesvirus-6 (HHV-6) is more widely activated in CFIDS patients than in other disorders (Buchwald, Cheney, & Petersen, 1992; Patnaik, Komaroff, Conley, Ojo-Armaize, & Peter, 1995). Because it displays wide tissue tropism (movement into the tissues of the body) and is associated with several peripheral mononuclear white blood cells, respiratory and intestinal epithelial cells, central nervous system cells and fibroblasts, it is a strong contender for being a potential pathogenic agent in CFIDS (Evengard *et.al.*, 1999). The HHV-6 infection has three stages. The first is acute primary infection in infants, causing roseola

infantum. Secondly, it is seen to replicate in the salivary glands of healthy children and adults where it lies latent without inducing any pathology. The third stage is typically only found in immunocompromised persons and has been associated with pathological conditions such as multiple sclerosis (MS), tumors and CFIDS. Two distinct strains have been isolated- Variant A and Variant B. There is some question as to whether these should be seen as two different species, but as yet no decision has been made. Molecular analysis has isolated the HHV-6A as being significantly more highly prevalent in CFIDS patients when compared with healthy donors (HD). The consensus amongst researchers tends to be that it is not sufficiently clear as to whether this reflects an association with, or consequence of, an immune dysregulation (Campadelli-Fiume, Mirandola, & Menotti, 1999). It has been discovered that HHV-6 can produce clinical encephalitis and demyelating diseases in immunosuppressed individuals; in the immunocompetent it produces MS (Carrigan, Harrington, & Knox, 1996). Like EBV, the infection with HHV-6 is ubiquitous and not solely associated with CFIDS. It reflects immune dysregulation and no compelling evidence has been found that HHV-6 produces pathology leading to symptoms of CFIDS. (Evengard et.al., 1999; Johnson, De Luca, & Natelson, 1999). This makes it most likely that the reactivation of HHV-6 is a secondary event in CFIDS patients, confirming the opinion that it reflects immune dysregulation.

Mycoplasma is not a new discovery, but during the last 30 years, it has been found in altered genetic sequences. It is the smallest and simplest subclass of bacteria, and the original variety was not associated with severe illness. However, the new varieties have been found to be more lethal. Their gene sequences are unusual, and some researchers have suggested that they might have been specifically engineered in laboratories for use in chemical warfare (Briggs, 2000). However this is mere supposition. These new mycoplasma are more invasive and difficult to detect due to their slow-growing and stealth-like characteristics. Atypically, they have no cell walls and so are able to invade and penetrate body tissues and cells. They reside in leukocytes and can only be detected by a test performed on opened leukocytes. The Polymerase Chain Reaction of the DNA of the organism has so far revealed seven different species

of mycoplasma. Specifically in CFIDS only three species have been commonly associated with the illness, Mycoplasma Fermentans being the most common of all. Mycoplasma can activate the immune system and avoid detection by hiding in the immune cells. They are also systemic in nature and can invade any or all tissues and organs, resulting in an array of the complex symptoms we have come to associate with chronic illnesses, more particularly, CFIDS.

Research has established mycoplasma as a co-factor with CFIDS. In a study comparing CFIDS patients with healthy subjects, researchers found an overall presence of Mycoplasma genus to be 52% - 14% respectively, and Mycoplasma fermentans to be 34% - 8% (Vojdani, Choppa, Tagle, Samimi, & Lapp, 1998). These findings were confirmed in a later study finding the ratio between CFIDS patients and healthy subjects to be Mycoplasma genus 52% - 15% and Mycoplasma fermentans 32% - 8% (Choppa, Vojdani, Tagle, Andrin, & Magtoto, 1998). Another study on a sample of CFIDS/Fibromyalgia patients found that Mycoplasma genus measured 59.3% and Mycoplasma fermentans 52.7%. The test was for indication of multiple infection and actually five species of mycoplasma had been measured. The overall instance of multiple infection was 48.4% (Nasralla, Haier, & Nicolson, 1999). The consensus amongst researchers is that mycoplasma are co-factors in chronic illness generally, not only CFIDS, and most notably for us in South Africa, this includes AIDS (Baseman and Tully, 1997; Briggs, 2000; Lorden, 1999).

The question of contagion and treatment is being thoroughly investigated as well, although at this time there is no conclusive research available. Inferences regarding contagion have been made from observations of data about *situ* of mycoplasma in the body. The areas pinpointed are blood, body and spinal fluids, bone marrow, urine, lungs, nose and mouth. From this it has been deduced that contagion could be established through contact with infected sputum, saliva, blood, urine and sexual secretions.

The treatment process is to administer heavy doses of antibiotics over extended periods. The initial study [conducted by Garth Nicolson of the Institute Of

Molecular Medicine in California] was done over nine months (Nicolson and Nicolson, 1996). The antibiotics were given in six cycles of six weeks, and patients were tested for mycoplasma infection after each cycle. The results showed that after the first cycle there was a 100% relapse, second – 88%, third – 64%, fourth – 47%, fifth – 25%, sixth – 11%. As a result of these findings it has been ascertained that the treatment needs to be of lengthy duration. A group of CFIDS sufferers is currently undergoing such treatment, and after a year have found excellent improvement in their symptoms. There is obviously still need for extensive research in this area ( Briggs, 2000).

Stealth Virus (SV) research is one of the most interesting of current developments in CFIDS research. It has the possible explanation for the abnormalities of for instance, the new species of mycoplasma amongst others. The basic concept of this research is that “an active viral infection of the brain is the underlying cause of CFIDS and related disorders” (Martin, 1999a, p. 2). Research has been ongoing in the last several years on culturing atypical cytopathic viruses from the blood and cerebrospinal fluid of CFIDS patients. A matching SV sequence has been established with a virus derived from an African green monkey – the simian cytomegalovirus (Martin, 1999b). The significance of this finding is that since 1972 cell cultures from the kidneys of these African monkeys have been used for live poliovirus vaccine production in America. It is thus proposed that human infection with SV was made possible through these vaccines. The virus was named stealth as they were apparently unseen by the immune defences which trigger the anti-viral inflammatory response. The way this happens is that the SV is able to delete “critical viral genes that code the major antigens targeted by T lymphocytes” (Martin, 2000a:02).

Further investigation showed that a third of these cloned SV sequences did not match cytomegalovirus-related genes because some of the additional genes were shown to be of cellular origin. The researchers found that the SV had, “captured, amplified and mutated genes from infected cells” (Martin, 1999a, p. 3). Subsequently it has been observed that many of these new cellular genes are demonstrating repetitive and reiterated sequences. This process has implications

for explaining the complex array of symptoms associated with CFIDS and other related illnesses. In addition it has been observed that the prototype SV is able to assimilate an array of genes from bacteria. It can then function as a viteria – animal virus with incorporated bacterial genes. In this way researchers are observing a dynamic process of new life forms being created. This means that the SV gives unique metabolic functions to infected bacteria, and that it can pass freely between animal cells and bacteria. This virus is particularly menacing as it can take varying structural forms. “It has the basic capacity to imbed itself in the brain, persist in the brain causing brain dysfunction....stealth virus infections can progress to very severe illness, including death” (Center for Complex Infectious Diseases , 2000).

This virulent nature of SV was underlined in an experiment on cats. They were inoculated with the prototype SV and it induced severe multi-system disease in them (Martin, 2000c). Dr W. J. Martin of the Center for Complex Infectious Diseases in California was the first to isolate this virus, and his findings have generated research by other leading virologists who strongly support the concept of stealth-adaptation. What is now established is that SV produces multi-system stealth virus infections with encephalopathy and presents clinically in an array of neurological disorders typical to CFIDS. In addition, the virus has been isolated in cases of autism, attention deficit and behavioral problems in children, and in adults, cases of depression, chronic fatigue, fibromyalgia, and severe motor, sensory and cognitive diseases (Martin, 1999a). All this suggests that the adaptive, reconstructive nature of SV could well afford some explanation for the upsurge of the debilitating syndromes of recent decades. If this is indeed the underlying cause of CFIDS, it would suggest that the syndrome could well be contagious. All this augers ill for society, and Martin (2000c) urges that this research be given priority attention in order to perhaps allay more widespread epidemics of multi-system disorders occurring.

A very positive development in this research is that a potential treatment has been presented. A marked expansion of chemokine coding genes has been observed within the prototype SV, and this has led to the use of certain antibiotic

treatments being given to CFIDS patients. These antibiotics are effective in the suppression of chemokine production and, when administered together with other anti-chemokine and anti-viral drugs, have been found to bring significant relief of symptoms. However, the treatment needs to be given over a long period in order to be completely efficacious, and this has not as yet been possible to assess given the newness of the discovery (Martin, 2000b; Martin 2000d).

However there is already some encouraging research indicating that we could be onto something significant. Going with the theory that if the SV is a pathogen of CFIDS, and there would then be evidence of contagion, Martin (2000a) called on physicians who were consistently treating CFIDS patients to report any such experiences. He got many responses, and has written a paper outlining the case histories of the four most severe cases of infection with CFIDS that he has treated to date. All four physicians developed severe symptoms of the multi-complex nature that leads to the diagnosis of CFIDS. The progress of these symptoms, lead to the eventual disablement of each. They found themselves without the ability to keep on working, and so were catapulted into the social pressure of loss of income and heavy medical expenses. Two of the doctors exhibited signs of personality changes as part of their symptomatology, and this resulted in their being divorced as their spouses were unable to empathize with this condition. They have all reported significant benefit from the treatment (mentioned above), and this is most encouraging in regard to a possible pathogen plus therapy for CFIDS having been encountered.

## IMMUNOLOGY

There have been numerous immunological studies over the years, from different investigators and laboratories, on groups of CFIDS patients. From all of these a common theme is emerging – that there is generally a state of chronic immune activation in CFIDS patients. In this review the most currently robust areas of the immunological research in CFIDS will be highlighted.

Natural Killer Cells have been consistently found with depressed functioning in CFIDS subjects. Although this has no clear clinical implications as yet, the consistency of this phenomenon is important to note. Natural Killer cells are thought to play a central role in defence against viral infections.

An increasingly popular hypothesis in relation specifically to CFIDS symptoms, is that a chronic immune activation could lead to the production of Cytokines which disrupt the neurotransmitter function and thus result in the symptoms of CFIDS. The studies in this area have not been conclusive, but do offer a possible explanation for the link between an infectious agent and CFIDS symptoms (Evengard et.al., 1999; Komaroff, 2000a).

Evidence of the up-regulation (higher than normal activity) of the 2-5Asynthetase/RNaseL antiviral pathway in CFIDS subjects in comparison with a normal healthy control group was discovered by researchers (Suhadolnik et.al., 1994 in Evengard, et.al., 1999). Subsequent studies have confirmed this phenomenon, and in addition have found that patients with CFIDS showed a novel low molecular weight (37kDa) form of RNaseL<sup>5</sup> (Suhadolnik et.al., 1997 in Komaroff, 2000a). Again, in 1999, a study using a much larger cohort of subjects, from two different sites, confirmed both these findings (Suhadolnik, Peterson, Cheney, Horvath, Reichenbach, O'brien, Lombardi, Welsch, Furr, Charubala, & Pfeleiderer, 1999). Most interestingly, a study comparing CFIDS patients with two control groups – healthy subjects and fibromyalgia/depression patients - arrived at similar conclusions (De Meirleir, Bisbal, Campine, De Becker, Salehxada, Demettre, & Lebleu, 2000). The inclusion of the second control group helps to extend the significance of these findings. They found the CFIDS patients measured significantly elevated levels of 80kDa and 40kDa as against both control groups. In addition the presence of the novel 37kDa weight was also significantly higher in the CFIDS group as opposed to healthy controls (88% - 32%), as well as in comparison with the fibromyalgia/depression controls (88% - 38% in case of fibromyalgia patients; 88% - 14% in relation to the patients suffering major depression). The researchers suggest that the low molecular weight enzyme could "perhaps help to distinguish (CFIDS) from other disorders, including fibromyalgia and severe depression, in which it appears to be uncommon" (DeMeirleir et.al., 2000, p.104). Certainly the consistency of these and other studies have established "considerable evidence of an underlying

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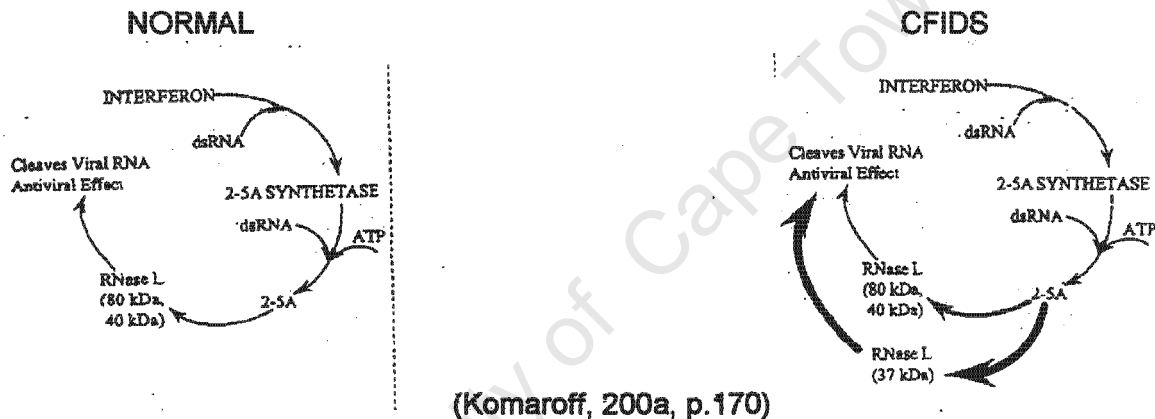
<sup>5</sup> See Figure 2.

biological process in most patients who meet the CDC case definition of chronic fatigue syndrome" (Komaroff, 2000a, p.170).

However, it must be noted that these findings have not been conclusively established as the definitive biological marker. The question as to why some and not others are succumbing to these symptoms begs the implication that the biological process is the only underlying cause - especially as this process varies so amongst the total CFIDS population.

## FIGURE TWO

### THE 2-5A SYNTHETASE/RIBONUCLEASE (RNaseL) PATHWAY



One extra biological process being examined in relation to immunomodulation worth noting here is Stress Inducement. In a review findings of the implications of stress on infectious diseases emphasizes that a significant amount of research literature has established the fact that stress is directly related to the down-regulation of the cellular immune response (Glaser, Ranin, Chesney, Cohen & Natelson, 1999). Communication between the Central Nervous System and the Immune System happens as a result of bi-directional signals linking them to each other. Psychological stressors however, disrupt the network and thus affect the immune functioning. In particular, several studies have shown a clear relationship between psychological stress and susceptibility to several cold viruses. Studies of patients with infectious diseases and other immune mediated diseases have also established the association of stress with greater severity and prolongation

of the disease. Against this background it is interesting to note that some CFIDS studies have focused specifically on this issue. For example it was found that patients perceive stress and viral interaction as causal agents in their illness (Chalder, Power, & Wessely, 1996). A particularly noteworthy study was conducted to observe the effects of Hurricane Andrew on clinical relapses amongst CFIDS patients. The researchers found there was a significant difference in clinical relapses between those who had been in the high impact as opposed to the low impact areas. The former displayed significant increases in physician-related clinical relapses as well as in self-reported physical symptoms. The experience of illness-burden was also significantly increased in this group. Overall, it was found that the distress response to the event was the single most usual predictor of probability and severity of relapse and functional impairment. It is interesting to note that social support and optimism were significantly associated with a lower illness burden after the hurricane. This study points clearly to an association between stress and illness experience (Lutgendorf, Antoni, Ironson, Fletcher, Penedo, Baum, Schneiderman, & Klimas, 1995). Later in this review we shall examine some psychological studies that confirm the presence of this association.

#### CENTRAL NERVOUS SYSTEM

Abnormality studies have added to the evidence of biological patterning within CFIDS. Here again the review will focus only on the most robust research areas. Magnetic Resonance Imaging has shown white matter abnormalities more often in CFIDS patients than in healthy controls, and it is suggested that these abnormalities might well be causing some of the CFIDS symptoms (Evengard, *et.al.*, 1999; Johnson *et.al.*, 1999; Komaroff, 2000a).

Single Photon Emission Computer Tomography studies reveal abnormalities found more often in CFIDS patients when compared with healthy controls or depressed patients. In studies by Ichise *et.al.*, (1992) in Evengard, *et.al.*, (1999) and Schwartz *et.al.*, (1994) in Johnson *et.al.*, (1999) it was found that 80% and 81% respectively of the CFIDS patients had decreases in regional cerebral blood

flow throughout the brain. These abnormalities have been likened to the encephalopathy of patients suffering from AIDS (Komaroff, 2000a).

Studies of hypothalamic-pituitary-adrenal axis show mounting evidence of reduced functioning and neurotransmission in CFIDS patients. This suggests an altered physiological response to stress. There is also evidence of abnormalities in the CFIDS patients' hormonal stress responses and serotonin neurotransmission. Most of the studies have also found that the direction of the CFIDS response abnormalities is in the opposite direction from the pattern observed in clinically depressed patients (Johnson *et al.*, 1999).

### PSYCHIATRIC STUDIES

The fact that no objective diagnostic test for CFIDS has been established, and that symptoms such as fatigue, sleep and cognitive disturbance are easily confounded with nonpsychotic psychiatric disturbances, has given rise to much debate as to whether CFIDS is in fact a psychiatric illness. However, consideration of this link to psychiatric illness is growing less common as research fails to uncover substantive evidence. In fact it has been shown that a significant percentage of CFIDS patients don't evidence any psychopathology criteria, and also that there is a greater prevalence of chronic medical conditions within affective and anxiety disorders. Thus CFIDS could well be of a similar association. (Evengard *et al.*, 1999; Johnson *et al.*, 1999)

There are three main areas to the CFIDS psychiatric studies.

Somatization Disorder (SD) has been investigated in relation to CFIDS. Johnson *et al.*, (1996a) examined the rates of Somatization Disorder in the CFIDS (N=42), Multiple Sclerosis (N=18), depression (N=21) illness groups in relation to healthy individuals (N= 32). The *Diagnostic Interview Schedule 111-R* was reanalyzed using different scales which coded rates of SD both from a psychiatric and physical set of attributions. CFIDS and Depression both endorsed a higher percentage of SD symptoms than Multiple Sclerosis and healthy groups. But when the attribution examined by the schedule was physical (linked specifically to a chemical imbalance), the CFIDS group dropped dramatically. Because

findings are so dependent on the researcher's attribution of symptoms, therefore, the diagnosis of SD is arbitrary and of limited value. In fact these researchers state that this is not a trivial situation, and findings should be treated with caution because treatment processes could also be affected. "Our present state of knowledge indicates that treatment for patients with controversial illness involving medically unexplained symptoms should be conservative because 'overinvestigation' consumes health care resources without benefiting the patient" (Johnson *et.al.*, 1996a, p.56).

Whether CFIDS is a form of Depression is the second area of much research.

It was discovered that core components of major depression - guilt, lack of self-esteem, self blame – were significantly lower in CFIDS patients. In fact they tended to show a lack of apathy and hopelessness and displayed anger and frustration and an eagerness to try anything to make them healthy (Powell, Dolan, & Wessely, 1990). Endicott (1999) was unable to establish any significance in the family history of mental disorders between psychiatric patients suffering from CFIDS and other non-CFIDS psychiatric patients. Thus there is no significant difference in psychiatric etiology between the patients who meet both the CFIDS and Depression diagnoses and those who are only diagnosed with Depression. Another research found that both psychiatric and physical status were significant predictors of long-term disability and subjective persistent fatigue in CFIDS patients. The researchers state that their results "emphasize the importance of taking a biopsychosocial approach in research and in the clinical evaluation of patients with Chronic Fatigue and CFS" (Russo, Katon, Clark, Kith, Sintay & Buchwald, 1998, p.25).

The *Medical Outcomes Survey 36-Item Short-Form Health Survey (SF-36)* was used in a study of CFIDS and major depression patients. The CFIDS patients had significantly greater impairment in physical and social functioning, and significantly higher scores for mental health and daily functioning (Komaroff, Fagioli, Doolittle, Gandek, Gleit, Guerriero, Kornish, Ware, Ware, & Bates, 1996). Finally, researchers mention studies which have confirmed the above findings in that they found that "dysphoric mood and particularly self-reproach symptoms are

low in CFS" (Johnson et.al., 1999, p.260). These are cited in comparison with the findings on those suffering from major depression (Powell et.al., 1990 in Johnson et.al., 1999). The New Jersey CFS Cooperative Research Center (NJCRC) has also refuted a study (David, Wessely, & Pelosi, 1991) that found a 50% incidence of depression and a 25% incidence of anxiety and somatization disorders within the CFIDS population (Johnson et.al., 1999).

Personality disorders have come under scrutiny, though to much less an extent. The fact that personality factors have been shown to influence symptom perception, makes this an area worth investigating. However, the earliest studies which showed that the CFIDS population tended towards histrionic and emotional type personalities, have not been confirmed. When methodological weaknesses were attended to in later studies, the findings were not so clear (Johnson et.al., 1999).

One study compared CDC-criteria CFIDS, Multiple Sclerosis (MS) and major depression (DEP) patients by examining Axis1and11 disorders. They found that CFIDS and MS had significantly less depression and fewer personality disorders than the DEP group. The rate of personality disorders did not differ between the CFIDS and MS groups, but CFIDS subjects showed a more frequent current depression than MS subjects (Pepper et.al., 1993 in Johnson et.al., 1999). These findings were confirmed in a study comparing CDC-criteria CFIDS, MS, and DEP patients, with healthy controls (HC). They also examined the Axis1and11 disorders, as well as trait neuroticism. The DEP subjects showed significantly more personality disorder and elevated neuroticism in relation to all comparison groups. CFIDS and MS showed intermediate personality scores, significantly higher than the HC sample. The CFIDS patients, in comparison with the MS patients displayed significantly higher scores in total personality disturbance and trait neuroticism. However, a small sub-group within the CFIDS sample, suffering concurrent depression, was found to make up the bulk of the CFIDS personality pathology. When these scores were deleted from the comparison, the remaining CFIDS patients were shown to closely resemble the MS patients in these areas (Johnson et.al., 1996b).

The NJCRC studies have identified a 55% subgroup of the CFIDS population showing no evidence of psychiatric or personality pathology (Johnson et.al., 1999). A study was conducted to compare virally infected patients six months after diagnosis. The sample was broken into two groups, firstly those who were severely fatigued (CFS) and secondly those who were free from fatigue (Controls). In the overall statistics of each group, the CFS cases were significantly more likely than the controls to have past and/or present psychiatric diagnoses (especially depression). They were also assessed to have more medical problems and somatic symptoms, and they tended to use escape-avoidance styles of coping. However, a subgroup (21%) of CFS cases was deemed as "pure" chronic fatigue due to the fact that they displayed no psychiatric or physical disorder. It is felt that this group could correspond to the 55% subgroup identified above (Cope et.al., 1996 in Johnson et.al., 1999). This gives support to the theory that CFIDS patients should be separated into two distinct groupings (Johnson et.al., 1999).

In much the same vein, Wood and Wessely (1999) conducted a study that compared CFIDS patients with rheumatoid arthritis patients, looking for particular personality traits or social attitudes. In particular, they were examining the validity of the stereotype of CFIDS sufferers as perfectionists with negative attitudes toward psychiatry. They summarize their findings in this regard:

This study provides no evidence to support the anti-psychiatry tone that is so striking in the popular literature on CFS. On the other hand, the positive stereotype of the high-achieving, over dedicated sufferer with high personal standards receives no support either (p.396).

The study also failed to find overall differences in personality traits that may distinguish CFIDS patients from the rheumatoid arthritis group, a chronic illness with a firmly established physical causality. This finding underlines the need to move beyond the question of whether CFIDS is either a mind or body illness, and indicates the need for an inclusive approach towards the understanding and treatment of this illness.

Finally, a comparison between CFIDS, major depressive disorder and healthy control samples revealed that the CFIDS group was significantly higher in both neuroticism and introversion when compared with the healthy control group, and significantly lower in neuroticism when compared with the major depressive disorder group. However, the CFIDS patients had rated themselves as higher on neuroticism and introversion when ill as opposed to their well state. This leads to the suggestion that the high scores in these areas in the CFIDS sample could be a reaction to the chronic illness, and not an etiological factor (Buckley, MacHale, Cavanagh, Sharpe, Deary, & Lawrie, 1999).

The medical research has investigated the possibility of etiological factors for CFIDS in infectious agents, psychiatric disorders and personality characteristics. But none of these areas has been isolated as the definitive cause. The illness remains largely unexplained by this research and seems to call for a broader investigation. We will now move on to the wider sphere and look at what psychological research into CFIDS has come up with, in the hopes that this will add to our understanding of what is needed in terms of our strategy for improved therapeutic management of this complex and devastating illness.

### 2.3 PSYCHOLOGICAL RESEARCH

In the area of CFIDS, psychological research has stemmed from two basic paradigms of psychological understanding. The first says that as we learn to adjust our cognitions, we will experience new motivations for our behaviour. Putting this into the context of CFIDS research, it says that if the mindset towards the illness can be transformed into a positive perception patterning, the behaviour responses will also be changed and the patient will begin to be empowered physically as well. This approach is termed cognitive behavioural therapy (CBT). The second paradigm takes the viewpoint that the body is 'speaking' to the patient. There are emotions buried within the patient's unconscious which need to be addressed/'healed', and in order for them to be accessed the body is 'talking' symbolically or symptomatically. As the patient is

helped to understand the significance of the messages, the unconscious disease is made conscious and, with the support of a trusted 'other', can be attended to/healed. The discoveries of psychoneuroimmunology in recent years have given great substance to this psychodynamic paradigm. It is now an established observation that the emotional/psychological energy impacts directly on the physical bodily functioning and can in fact change the shape of the basic units of the immune and nervous systems – neuropeptides. This in turn prevents the neuropeptide from locking onto its specific receptor, it therefore becomes incapacitated, and so malfunctioning of the bodily system occurs (Pert, 1999). This review will give an overview of CFIDS research flowing from these two psychological paradigms.

CBT researches the efficacy of self-help as it aims to change unhelpful cognitions and behaviour. CBT has been used in research schemes – in a group or on an individual basis - and although the effect has not been curative, in looking at the studies it will be seen that there have been substantial positive outcomes in illness progress in patients (Johnson *et.al.*, 1999). The main focus has been on examining the role of illness perceptions on the course of CFIDS. In one research (Moss-Morris, Petrie, & Weiman, 1996) based their understanding of illness representations on previous studies (Leventhal and colleagues 1980, 1984, 1985, 1987, 1989, 1992 and 1993 in Moss-Morris *et.al.*, 1996). This can be summarized as illness perceptions being schema which give personal meaning to the symptoms of the illness as experienced by the individual patients. The illness representations lie along five cognitive dimensions – identity, perceived cause, time-line, life consequences of the disease and beliefs about curability/controlability. They also examined coping strategies in line with previous researches' findings. These included "strategies such as self-blame, emotional ventilation and cognitive and behavioural avoidance (which have been) related to poorer adjustment to disease, (and) positive reframing acceptance of the illness, planning and utilizing social support, and humour (all of which) have shown inverse relationships with distress" (Moss-Morris *et.al.*, 1996, p.17). The aim was to examine the relationship between CFIDS patients' illness perceptions and coping strategies, and the amount of disability experienced. They wanted to

determine if there was a clear relationship between self-reported daily functioning, vitality and psychological well - being, and the patients' illness beliefs and coping strategies.

The results showed that both illness representations and coping strategies had a significant relationship to the functioning and psychological well - being of the CFIDS sample. They confirmed the previous research findings cited above. The identity dimension of illness representation showed the most significant associations to physical functioning and vitality. The two coping strategies that demonstrated consistent positive effects on the sample's psychological well - being were seeking emotional support and positive reinterpretation. The former also showed significant relationship to the patients' ability to function positively in their situation.

This research confirms that the pattern of illness perceptions and coping strategies having a vital influence on the course of the functioning and psychological well - being of the patients. It points to the need for interventions which would encourage sense of control over the illness and facilitate the altering of negative illness perceptions (Moss-Morris et.al., 1996). These findings were again confirmed in a study conducted by Heijmans (1998) who examined the relations between illness representations, coping behaviour, and adaptive outcomes in a sample of CFIDS patients (N=98). One of the most significant findings was that illness representations appear to be a stronger predictor of vitality, physical functioning, and social functioning than were coping strategies. Once again the identity dimension was most significantly associated to physical functioning and vitality. This suggests the need to give greater attention to the operationalization of illness identity in CFIDS patients in future studies in order to gain full benefit of this phenomenon in understanding the nature of possible future treatment interventions. A strong correlation between the identity and time-line (duration of the illness) dimensions suggested that "patients take more severe or frequent symptoms to be an indicator of a worsening disease state" (Heijmans, 1998, p.48). It was also found that cognitive-avoidant coping (giving up and withdrawal of any effort to deal with the illness) was the greatest predictor

of negative adaptive outcome. This research also claims the importance of designing interventions that will encourage a sense of control and positive expectations and beliefs amongst CFIDS sufferers. In this way avoidant activity would also be discouraged and the functioning of CFIDS patients improved (Heijmans, 1998).

Another confirmation of the need for changing avoidant behaviour in CFIDS patients was a study by Deale, Chalder & Wessely (1998). They were investigating the effect of illness beliefs on illness outcome amongst CFIDS patients, and used a randomized controlled trial of the effects of CBT versus relaxation. They found that the physical illness attributions were less important in determining outcome than had previously been measured. There was no significant association between causal attributions at either pre or post treatment or at the 6-month follow-up. However, within-group analysis showed that between pre- and post treatment in the CBT patients, there was significant reduction in the number who agreed that exercise should stop when they were tired; that doing less would help their fatigue and that doing exercise was harmful. In the relaxation patients' significance was found in the number who agreed that exercise was harmful. Overall, the two significant differences between the groups at post treatment were that fewer CBT patients felt they should avoid exercise when tired ( $p < 0.001$ ), and that doing less helps fatigue ( $p < 0.05$ ). At 6-month follow-up the patients who maintained those beliefs were likely to be unimproved. Thus Deale *et.al.* suggest that:

Patients do not need to change their beliefs about a physical basis for CFIDS to get better. It may be more helpful, and lead to better outcome, if patients are encouraged to test out beliefs about avoidance of activity through a program of carefully graded activity (1998, p.82).

In similar vein, a study tested the hypothesis that behavioural, cognitive and affective factors play a role in perpetuating fatigue. Vercoulen, Swanink, Galama, Fennis, Jongen, Hommes, van der Meer, & Bleijenberg (1998), used CFIDS and MS patients as comparison groups. It was found that attributing a somatic cause

to the symptoms resulted in a lowering of physical activity. In CFIDS and MS groups a sense of control over symptoms had a positive effect on fatigue, whereas only in CFIDS focusing on bodily symptoms was shown to have an adverse causal relationship to fatigue. Again, it was demonstrated that there is strong evidence for the effect of psychological factors on the course of CFIDS. This would underlie the need for appropriate cognitive and behavioural treatments that would aid in changing patients' cognitions and attributions, and increasing physical activity. In fact the researchers go one step further in stating that, "The patient should be helped to accept that the original cause of the complaints is unknown and that continuing search for medical explanations is not helpful but rather has a detrimental effect on complaints. It would be more worthwhile to attempt a treatment program directed at coping better with complaints and that reduces symptoms and functional impairment" (Vercoulen *et. al.*, 1998, p.516). This point of view seems to be rather reductionist, but we can agree that it is worth acknowledging the need to encourage healthful cognitions and behavioural patterns amongst CFIDS sufferers.

Finally, and from a somewhat different stance, Russo, Katon, Clark, Kith, Sintay, & Buchwald (1998), conducted a longitudinal study, over a period of 2.5 years, on patients with chronic fatigue – some of whom met the CFIDS criteria and others who did not. The purpose of the study was to examine changes in CFIDS criteria, symptoms, physical signs, psychiatric disorders and general functioning over this period. The improvement in chronic fatigue and return to work would be related to these changes. The data suggested that improvements in physical status as well as psychological health were both important predictors of improved functioning and return to work. They are both associated with recovery from chronic fatigue and CFIDS. These findings lead to the understanding of, "the importance of taking a *biopsychosocial*<sup>6</sup> approach in research and in the clinical evaluation of patients with CF and CFS" (Russo *et.al.*, 1998:75). Overall the research in CBT has established, beyond doubt, that together with the biological

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<sup>6</sup> Emphasis is mine.

components of CFIDS, there is a psychological factor involved – once again we are confronted with the reality of “both and”, i.e. mindbody.

Psychodynamic therapy, as has been mentioned above, is concerned with bringing what is buried within the unconscious into consciousness. This is most relevant to our need to help CFIDS patients re-perceptualize their illness experience in order to gain recovery (as has been indicated in the CBT research). It seems relevant to set the scene for the review to follow, noting this explanation of perception:

Although consciousness is only a small part of perception, it serves a crucial function, since it enables the brain to pay more attention to environmental details, to gather more facts, so to speak, to enhance perceptual accuracy.

One way to conceptualise psychoanalysis is as a treatment method that encourages paying *conscious attention*<sup>7</sup> to the specific details of the interpersonal transference situation in order to develop greater perceptual accuracy and, when necessary, to be able to generate new categories of interpersonal experience (Pally, 1997. p.1029).

This truth is well illustrated in the research of the CFIDS dilemma conducted by Taerk and Gnam (1994). They examined the effects of psychodynamic therapy on two CFIDS patients. Their research proposal was “that both a psychological and physiological vulnerability exists in CFS patients as a result of problems in early object relations<sup>8</sup> which contribute to the clinical expression of the syndrome... (and) that this vulnerability results from a poorly developed capacity for regulating internal states in response to certain types of stressors, namely, disturbances in object relations” (p.320).

Their research was based on a combination of the theories of Self and Object Relations psychology. The aim of the study was to diminish the existing

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<sup>7</sup> The emphasis is mine.

<sup>8</sup> Ego identity is formed through the baby’s interaction with objects i.e. anything or anyone from whom the baby experiences satisfaction or frustration of his/her life needs. The good or bad object is internalized within the ego and according to the balance of good over bad or vice versa, the child will develop a strong or weak sense of ego-self.

vulnerability of the patients through establishing a tension-regulating component in the therapeutic relationship. Their premise was that this could then be internalised by the patient and have positive effect on the course of the illness.

Two CFIDS patients were treated over an  $\geq 18$ -month period and this provided the opportunity to view the intimate relationship of fatigue symptoms to disturbances in object relations over a period of time. They were able to note an improvement in symptoms when this relationship became seen and understood by the patient. They noted that the patient-therapist bond was a facilitating medium for clinical improvement. The findings flowing from these sessions of psychotherapy confirm the initial hypothesis, and point to a strong likelihood of disruption in early selfobject relationships having a profound influence on the whole CFIDS course within a patient. Both of the patients showed a significant improvement in their health and a renewed vigor and ability to cope with their life situation. As the patients trusted the stable relationship established with the therapist, they were enabled to reinstate their self-regulating capacities in their normal everyday life.

The experiences of retrogression and re-establishing of the CFIDS symptoms which occurred when there was a disruption to the transference relationship with the therapist, and the subsequent working through to a new place of equilibrium, served to create a strengthening of the self. The patients gradually were able to rely less on the selfobject<sup>9</sup> (therapist) and evidenced a greater capacity to withstand empathic failures both within the transference relationship and the outside world. It was found to be of especial importance to these CFIDS patients that they were enabled to recognize and name their affective experience. There had been a definite difficulty observed in their prior ability to identify and label inner states, and it was found to be of great importance that such affective experience actually be named.

The patients were very mistrustful of treatment to begin with, as they had experienced doctors minimizing their symptoms in the past. It was very

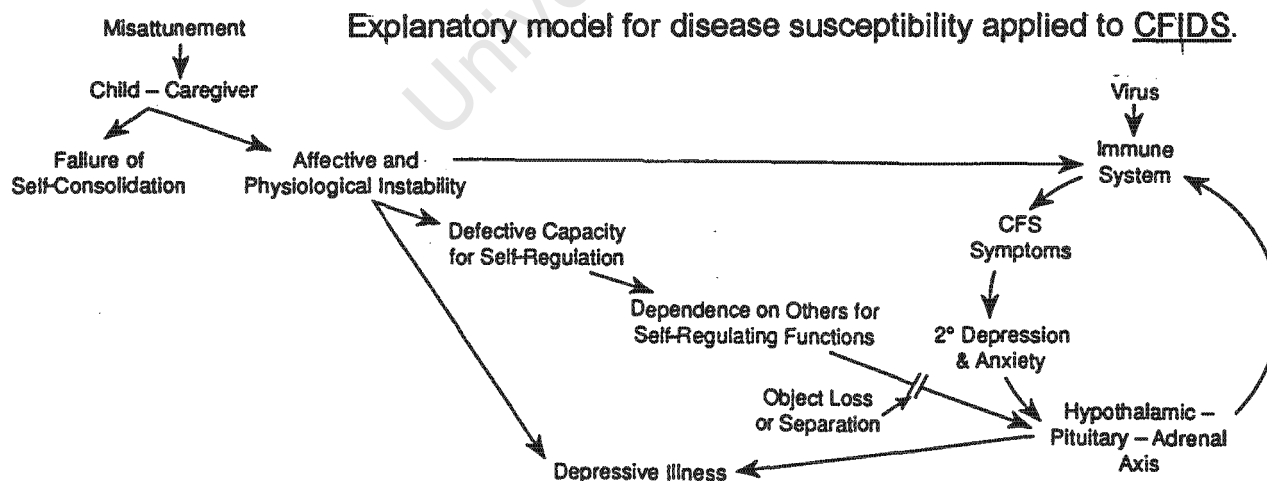
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<sup>9</sup> The selfobject is anything that gives rise to an intact sense of self as a result of having provided an empathic and trustworthy environment in which the person has been able to relate with this selfobject.

important, therefore, to establish trust. This was done by the therapist refraining from diagnosing their condition as a strictly psychological disease. A model<sup>10</sup> of disease susceptibility was used to explain the failure of self-regulating capacities that can potentially lead to psychological and physiological disruptions. The researchers however cautioned that this type of treatment would be too costly for most CFIDS sufferers, and in addition, the CFIDS patient undergoing such treatment would need to be of a certain sub-group – “patients who are verbal, introspective, and whose goals include self-knowledge and personality change in addition to symptom relief” (Taerk and Gnam, 1994, p.324). They felt therefore that the model of disease susceptibility could be a most valuable tool for use in treatment interventions. These could be set up at various points in the system and it would encourage practitioners to take seriously the psychological make-up of the patient, illness perceptions, and presenting complaint when deciding upon treatment approach. They emphasize the need to understand the interplay between psychological and biological factors in the pathogenesis of CFIDS. These observations lead to an understanding of the necessity for research that will attempt to correlate clinical improvement with factual evidence of biological measurement changes. Yet again, there is evidence of the complexity of this syndrome and the need for integrative treatments.

**FIGURE 3**

Explanatory model for disease susceptibility applied to CFIDS.



(Taerk and Gnam, p.320)

<sup>10</sup> See Figure 3.

A later research by Holland (1997) confirms the importance of the maternal "self-regulating function" and its internalization through the transference relationship within a safe environment, as stated by Taerk and Gnam (1994). She conducted a three-year psychotherapy intervention with a middle-aged woman CFIDS patient who was experiencing a "nightmare" of extreme fatigue, muscular pains, palpitations, insomnia and feelings of vulnerability, despair and failure... (she) felt that all the unresolved issues of her life came together in her (CFIDS), and that her physical symptoms had exposed underlying 'cracks' – psychological weaknesses" (Holland, 1997, p.217). The therapy was based on the understanding of the vital importance of attunement between mother and infant in the earliest kinetic and affectional modes. The inadequate maternal response fuels primal fears of abandonment or annihilation which impact on the needs within the infant and cause a swing to the defences of the self – detachment and dissociation, splitting and withdrawal – and this oscillation between the two extremes becomes a set pattern of behaviour. The patient in this study described her experience of this as a dreadful "pendulum of closeness and isolation".

Guntrip in Holland (1997) has described the effects of such oscillation as profound withdrawal and devitalization – bodily and psychic collapse. He could well have been describing the symptoms of CFIDS. Holland chose to recognize the need for her patient to express her dis-ease at her own pace and in her own way. This resulted in a long term of noting "the actuality, the awefulness, of the bodily experiences in their own right, rather than diminishing them by hasty associations, or dynamic interpretations" (Holland, 1997, p.222). This validation of the patient's experience of her disease – whether the physical or psychological component – afforded the patient to "draw the psyche from the mind back to the original intimate association with the soma" (Winnicott, 1949, in Holland, 1997, p.233). The complexity of the CFIDS condition was given space to 'be', and there was no attempt to "split the 'mindless body' from the 'disembodied psyche'" (Hubback, 1986 in Holland, 1997, p.232). Holland in fact emphasizes the urgent need for health care workers to rise above the Cartesian split between mind and body when dealing with this illness. She shows how stigmatization by medical/somatic proponents that "it is all in the mind", causes great harm, as well as how the psychologist/psyche proponent can cause equally harmful strain on

the patient when he/she experiences the CFIDS symptoms being belittled or even dismissed. Once again the patient is being thrown back to a core experience of "helplessness in the face of unrecognized and unmet needs" (Holland, 1997, p.233). Holland actually encouraged the patient's engagement with caring for her body through yoga as part of her healing process. Gradually there was a move into the affective transference, and new and containing experiences allowed a restructuring of the patient's basic responses to her life and her illness. After three years the patient claimed to be completely free of CFIDS, and had entered a new life completely through marriage to a widower with a young son. She has gone on to have her own child and is coping well with all the stresses that her life brings. Holland's final summation of her understanding of the importance of holistic intervention for CFIDS patients is worth noting.

I locate the potential for understanding (CFIDS) in the earliest development states, in distortions in the unfolding of the archetypal potential of the psychosomatic unity that is the self. To comprehend more fully the myth of (CFIDS), I argue that we ourselves need to be open to coniunctio, to transcend the Cartesian split between our myths of the body and the mind (Holland, 1997, p.234).

Finally, Simpson (1997) comes to a similar conclusion after a four-year therapy treatment of a young woman patient with CFIDS. During this time she had experienced a holding space where she felt understood and where she felt secure enough to regress to the primal state of having experienced an inadequate holding environment from a mother who was unable to celebrate the gift of her illegitimate child. The ensuing experiences of hostility she felt emanating from her mother and grandmother over the years resulted in her presentation of the debilitating and fragmenting symptoms of CFIDS. As these were allowed to lead her into a deeper understanding that these were acting as a confusional defense against her going back to her primal agony, she was able to allow the agony to surface into her consciousness. She learnt to be kinder to herself, and although greatly rehabilitated after her four years in therapy, continued to have to deal with the invasiveness of her CFIDS condition. She

found, however that, "because I am so much kinder to myself both mentally and physically, the remaining symptoms do not get such a grip on me" (Simpson, 1997, p.213). In large part, her coming to terms with her original agony had removed the need for symptoms as defenses. She was left to deal with the symptoms that continued as a result of infection, attitude, relationships and life-style. The fact that the therapist encouraged her to continue her medical treatment along with her therapy, validated both her physical and psychological suffering, and she learnt to be kinder to herself. This is the crux of the healing process, it seems, that CFIDS patients be nurtured into awareness of the interconnectedness of bodymind.

Overall, it has thus been established that there certainly is a place and a need for treatment to embrace the totality of the patient's life experience, and this takes the review on to the final area of research into CFIDS that will be examined in this thesis.

## 2,4 SOCIAL RESEARCH

Because the instance of fatigue illness continues to grow within our present day context, health professionals are beginning to consider the concept that this fatigue is actually a primary experience of disturbed relations of a person to his/her environment. They have coined the term "disorders of vitality" to describe this modern phenomenon, and the vitalism model is undergoing serious consideration (Henningsen and Priebe, 1999). They submit that the biomedical understanding has caused the belief of incapacity being a secondary result from a primary cause outside of itself.

Modern biomedicine is the only major medical system in the world that has banished vitalism; therefore, disorders of fatigue have to be secondary to something else. In every other major system (Chinese medicine, Ayurvedic medicine, most traditional folk healing systems), vitalism is central to the epistemology, and therefore fatigue in itself is not only a legitimate complaint, but a legitimate diagnosis, as a disorder of vitality (Kleinman, 1993, in Henningsen and Priebe, 1999).

It would seem that the vitalistic accounts, therefore, are more suitable explanations of the social phenomena within the new illnesses that center around incapacity – CFIDS being one such.

Firstly, they clarify the issue that patients find the thought of incapacity as being less 'kosher' than psychological illness. This arises from the context-ignorant biomedical implication that the patient experiencing the incapacity is malingering, because he/she is unable to accept the legitimacy of a context-dependent co-occurrence of disease and moral weakness as being an illness at all. Through this standpoint the patient feels abruptly denied the legitimization of her/his symptoms. This in turn encourages the patient to seek for causes outside of the fatigue rather than work with the fatigue itself.

This leads on to the second factor that vitalistic concepts explain and help us to understand why the struggle for legitimacy is so fierce amongst those who struggle with "disorders of vitality".

Thirdly, the vitalistic account suggests that within our modern day society with its sociopolitical transitions, many people have become faced with an imbalance between goals and perceived ability to achieve these. The individual's professional success has become the most important measure of her/his worth. And it is proposed that either failure to achieve goals or anticipation of failure, could explain the current pervasiveness of "disorders of vitality". Finally, the role of medicine in bearing the responsibility for the fierceness of the need to be legitimatised is explained by the fact that the biomedical model propounds legitimate versus illegitimate illness, and "unwillingness" to work is seen as definitely illegitimate. The fact of the struggle for legitimacy is also threatening to the medical profession's role as gatekeeper regarding such legitimacy. The importance of being able to accept the vitalistic accounts of incapacity as valid, is seen as resulting in, "not only a better understanding of the behaviour of patients, but also (a reminder to) us of the responsibility we have to use adequate concepts for the clinical and scientific interactions with this important group of people" (Henningesen and Priebe, 1999, p.214).

Medical anthropology has established the connection between disease pathology/illness experience and collective experiences, cultural categories and social institutions. The social construction of disease categories, social course of illness experience and the social organization of health services and practices have been well studied and clearly documented. These accounts clearly demonstrate that health and illness experiences are both collective and cultural. And from this the sociomatic processes connecting the body-self with the social world, are being explored. This "sociomatics" is able to bridge the divide between the social and biological worlds. It calls for interdisciplinary co-operation and research, challenging:

the models and methods that separate mind from body, but also (casting) the relation of mind and body in new and different ways. It may well require a new language for research. In this language, moral categories transform into emotions; political and economic experience transduces into mortality and morbidity; and power in interpersonal relations intensifies or depletes vitality in the person. And, mutatis mutandis, additional, dissociative, linguistic, and sensorimotor processes project psychophysiology into interpersonal relations. Sociomatics is one term in that new lexicon (Kleinman, 1998, p.392).

It is these understandings that have been used to motivate and explain the findings of the following research studies in CFIDS.

Extensive interviews in China with neurasthenia patients were compared with similar interviews with American CFIDS sufferers. The analysis of these interviews showed that both illnesses seemed to serve similar symbolic functions; they used the bodily distress "as a vehicle for the negotiation of change in interpersonal worlds" (Ware and Kleinman, 1992 in Johnson *et.al.*, 1999, p.261). Sixty-six persons meeting the CDC criteria for CFIDS, participated in a three year longitudinal study (Ware, 1998). The study examined social processes that construct the course of this chronic illness, most specifically, the role constriction in employment of these individuals. The desire to avoid the

social marginalization of chronicity resulted in resistance strategies aimed at maintaining their roles as employed persons. Four strategies were examined.

Firstly, *work prioritizing* meant that all other activities were sacrificed to work. This resulted in such scenarios as "...working full-time, every minute I wasn't working, I was sick in bed. I went for a long time without doing any social activities at all. All I would do is go to work and go to bed. Go to work, go to bed. Go to work, go to bed. I had no life" (Ware, 1998, p.397). The ability to stay employed was maintained by this management of fatigue, but at the cost of attendant restrictions. Those who felt that their career was their life, were content with this strategy, others grieved the loss of other important parts of their lives.

Secondly, the process of *compensating for deficits* was another strategy used. This meant reducing exertion requirements, usually by taking on a different "easier" job. They compensated for cognitive deficits by writing things down in order to be able to refresh their memories when necessary.

The third strategy is known as *passing*. Here they try to hide the fact of their disability by extra careful grooming in order to present the picture of good health. They also withdrew from any social engagements with colleagues that could highlight impairments, such as tennis for instance. They cultivated the habit of "playing dumb" to cover for their cognitive impairments. "I make myself look stupid so people will help me" (Ware, 1998, p.398).

The fourth strategy is *finding flexibility*. They achieved this either by working a shorter work-week, or by arranging a variable schedule of time spent at work.

The overall finding was that the opposing forces of marginalization and resistance define the social course of chronic illness, CFIDS as an example. It is "when marginalizing forces overwhelm efforts at resistance, (that) ill individuals may move so far from the social world of healthy persons that their experience is saturated with illness-related interactions and events. This 'social location' is chronicity; a marginalized position in social space" (Ware, 1998, p.400). From a

further analysis of retrospective narrative accounts of illness experience in CFIDS, a preliminary conceptual model of the social course of chronic illness has been promulgated (Ware,1999). The qualities of the CFIDS symptoms are seen to clash with the culturally specific expectations for social life and personal conduct, resulting in processes of marginalization being set up towards the CFIDS sufferer. Four such processes are outlined. Role constriction refers to the sufferer's increasing inability to meet the demands of his/her various social functions. The person becomes viewed as "different" through this inability to the extent that eventually questions of incompetence are raised. This usually leads to the marginalizing experience of unemployment. Delegitimation denotes "systematic disconfirmation of the experience of being ill" (Ware,1999, p.312). This experience tends to cause patients to keep their condition secret and so disrupts their sense of connectedness as well as depletes the energy resources through these acts of dissembling. In this way the gap between the CFIDS world and the well world widens. The effect of this tends to be a sense of non-existence for the sufferer. Impoverishment due to loss of income and heavy medical costs results in the necessity to make life-style changes. The new straitened circumstances emphasize marginalizing effects as people become disengaged from their former, familiar way of life. Social isolation occurs as the energy impairments make it difficult to stick to schedules/engagements, and so both the friends and the patients themselves withdraw contact. There is also a certain stigma attached to the unknown etiology of the illness, causing some to fear contagion. The culture of lauding health means that the patients tend to be silent about their situation in order to preserve as much contact socially as possible.

Cognitive impairments tend to cause withdrawal from social interactions. An example of this, "When I am amongst people I get very embarrassed because I can't concentrate, can't think. So I like to just not get myself into those sort of situations" (Ware,1999, p.317). For as long as is possible the chronically ill will resist such marginalization with strategies that they hope will preserve their world of wellness, or re-make the lifeworld in such a way that they can still feel that they are able to make a meaningful contribution even though a somewhat different one. This preliminary model emphasizes the social meaning of CFIDS

symptoms to be incompetence in the workplace, triggering role constriction, and causing a sense of delegitimation due to scepticism regarding their validity. It:

locates illness course in social space: specifically in the relations

of chronically ill people to their immediate interpersonal environments.

For chronic fatigue syndrome, social course consists of successive, bi-directional movements along a 'continuum of marginality' by persons living lives with chronic illness (Ware, 1999, p.323).

The theory of sociomatics that lies behind this area of CFIDS research has been adequately covered in this chapter, and so when dealing with the theoretical underpinnings of the lifeworld model of illness in chapter 5, I shall be examining theory that gives explanation as to why some CFIDS sufferers are able to deal co-operatively with their illness experience within the social context, whilst others seem unable to do so. The particular theory I shall be examining is the Salutogenic Model (Antonovsky, 1990; Strümpfer, 1990) to explain the participants' discrepancy in co-operative responses to their illness situation.

## 2.5 IMPLICATIONS

The complexity of the CFIDS dilemma has been established demonstrating how this illness encompasses both the individual and social aspects of a person's life. The variety of the CFIDS research that has been reviewed in this chapter reflects this complexity, as it struggles to come to terms with effective methods of treatment. All this highlights the need for integration of all resources, together with the understanding of the particular subjective state of suffering of the patient, when we deal with the CFIDS challenge. The research into the etiology of CFIDS that has been (and continues to be) undertaken, is in fact vast, covering many different areas of medical, psychological and social investigation.

Komaroff (2000b) states that there is now irrefutable evidence that CFIDS is, in fact, a real and serious illness that involves both the brain and the immune system. Research over the past 15 years has identified numerous biological abnormalities underlying the reality and seriousness of CFIDS, which, although

they have not isolated a specific cause for CFIDS, have provided many clues as to the pathogenesis of this illness. "Taken together, these findings provide important evidence that CFIDS is not 'all in the mind' or an imagined illness. While there is not a test, scientists are moving closer to developing tools to assist clinicians in the diagnosis of CFIDS" (p.367). Together with the medical diagnosis, however, it seems of paramount importance that doctors are trained to work from a broader base of collaboration with the total life-situation that the patients face. All interventions need to be integrated.

In support of the idea of integration, Weil (2000) makes a strong case for the espousal of integrative medicine as the way ahead in the new millennium for both medical training and practice. Already the *Department of Medicine of the University of Arizona*, has an established programme of training in place. It began as a 2-year postgraduate fellowship in integrative medicine, and has now been extended to include an internet-based associate fellowship programme as well as providing a component of the residency and medical student rotations at this university. Together with the training, they operate an Integrative Medical Clinic, and a robust research programme. The primary purpose of this venture in integrative medicine is to develop new models of education that will be incorporated into medical schools states-wide. In fact the USA Congress has mandated the teaching of integrative medicine for both postgraduate fellowship and medical school levels. In July, 1999, a consortium of deans and representatives from eight of the leading medical schools, met to discuss curriculum reformation. They arrived at a consensus that integrative medicine was the future direction of medicine, and that it needed to transform medical practice by restoring the centrality of physician-patient relationship, realigning medicine with healing and nature, and establishing an expanded scientific paradigm. They agreed that both economic necessity and consumer demand would ensure that this new integrative development does take place.

In a review of the status of CFIDS at the dawn of the new millennium, Manu (2000) states that CFIDS remains a frustrating illness that calls for treatment to be given to patients with compassion, wisdom and insight. He claims that CFIDS,

"more than any other issue in contemporary medicine, reflects the unresolved conflict between the mechanistic and the biopsychosocial constructs of illness" (p.173). Most certainly an integrative treatment approach to the CFIDS conundrum would seem the most suitable to put into practice.

In acknowledging the importance of the doctor-patient relationship, Servan-Schreiber et.al., (2000b) recommend a very helpful interviewing technique that ensures a comprehensive exploration of the patient's situation and disposition. It is called the BATHE Technique (Appendix A). It is also important that a relationship of trust be established by scheduling regular visits so that the patient is given opportunity to share her/his full agenda with the doctor. As the limitedness of the Cartesian dualistic understanding of mind-body is being more widely acknowledged, communication, listening to the illness story is seen to be of paramount importance (Charles et.al. 2000; Dibben et.al., 2000; Servan-Schreiber, et.al., 2000a; Servan-Schreiber et.al., 2000b).

All the above show clearly that there has been no overall resolution to the question of CFIDS etiology and treatment. Therefore it seems most pertinent that I join in the search for greater insight into this damaging illness by undertaking this research thesis. The following chapter will deal with the methodology used.

## CHAPTER 3

### METHOD

Many researchers have made use of narratives as data in a meaning-centred approach, analyzing personal illness accounts as a kind of coping strategy by which human beings ascribe meaning to suffering. Often such narratives are being presented as clinical case stories or as patients' accounts told in interviews to a researcher. But apart from having been methodologically created data personal stories also have their own life. They are a way of expressing experience, and as reality manifests itself as experience in us, stories are fundamental to human understanding (Steffen, 1997, p. 99).

#### 3.1 WHY QUALITATIVE:

The choice of a qualitative research was made on the basis that it was the best manner in which the research question could be addressed. "Certain questions cannot be answered by quantitative methods, while others cannot be answered by qualitative ones" (Walker, 1985 in Bryman, 1988, p.106). This thesis seeks to comprehend and illuminate the attitudes, beliefs and experiences of CFIDS patients, and as such, needs to deal in-depth with the subjective realities of the patients, and this necessitates the qualitative method of investigation. More specifically, the method of obtaining data is from the illness narratives of a sample of CFIDS patients This is in accordance with the understanding and procedure of illness narrative as expressed by Kleinman (1988):

The clinician listens to the sick individual's personal myth, a story that gives shape to an illness so as to distance an otherwise fearsome reality. The clinician attends to the patient's summation of life's trials. The illness is a story the patient tells, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative, are drawn from cultural and personal models for arranging experience in meaningful ways and for effectively communicating those meanings. To fully appreciate

the sick person's experience, the clinician must first piece together the illness narrative as it emerges from the patient's complaints and explanatory models; then he or she must interpret it in the light of the different modes of illness meanings -symptom symbols, culturally salient illnesses, personal and social contexts ( p 49).

This suggests that as the patient is taken seriously and allowed to express her/his experience of the illness in its fullest context, s/he is being enabled to go beyond the easily identified somatic symptom, into the suppressed affect that could well be impacting on the course of the illness as well. In this research the process of narrative analysis is chosen to examine how and if the patients were enabled to access such affect, integrate it into the conscious mental processes, and begin the process of transformation out of the 'imprisonment' of their illness symptoms. It seeks to understand the perceptions and experiences of this particular sample, individually, and where applicable as a group, as they confront their illness story.

### 3.2 SAMPLE

The participants interviewed had all been medically diagnosed with CFIDS, and were recommended to me by a number of sources; doctor, physiotherapist, clinical psychologist, and the network arising out of contact with these patients. Ten patients undertook to be interviewed for this research. The sample size settled at this number because when ten interviews had been completed, there was sufficient data from which to investigate the theoretical issue of the mindbody nature of CFIDS. This sampling principle is known as "theoretical sampling' (where) the researcher observes only as many activities, or interviews as many people, as are needed in order to 'saturate' the categories being developed" (Bryman, 1988, p.117).

It is thus the degree to which a sample allows the researcher to develop her/his theoretical framework that determines its adequacy. In this research there was no need to meet statistical sampling criteria for generalizability, as the aim of this research is to see and understand in the way these participants see and

understand. Their subjective illness experiential reality is being sought, and in that sense the sample has to be unique (Bryman, 1988).

The following table illustrates certain demographic information about each interviewee:

INTERVIEWEE	AGE	GENDER	ILLNESS ONSET	CURRENT <sup>11</sup> ILLNESS DURATION	RELATIONSHIP STATUS	OCCUPATION
P1	45	Female	Acute	9 years	Single mother	Unemployed
P2	55	Female	Chronic	4 years	Married mother	Unemployed
P3	21	Female	Chronic	8 years	Single	Student
P4	28	Female	Chronic	3 years	Married	Unemployed
P5	58	Female	Chronic	5 years	Divorced mother	Unemployed
P6	55	Female	Chronic	3 years	Single	Receptionist/ Photography
P7	34	Female	Chronic	3 years	Divorced mother	Part-time Lecturer
P8	29	Male	Chronic	9 years	Single	Kinaesiologist Self Employed
P9	38	Female	Acute	10 years*	Married mother	Unemployed
P10	31	Female	Chronic	4 years	Married mother	Nutritionist Self Employed

\*This patient was clear of her CFIDS symptoms after the 10 year period, i.e. her experience was not current.

### 3.3 PROCEDURE

Before embarking on the process of interviewing, each participant signed a consent form (Appendix B) in which the purpose of the research was clearly

<sup>11</sup> The course of this illness seems to settle into a pattern of remission and relapse in most cases, and so the intensity of the symptoms varies – however, most of these patients still need to live within the limitations of reoccurring symptoms, to a lesser or greater degree, when engaging with their lifeworld activities.

explained, confidentiality promised and agreement given to the participant's withdrawal from the process at any stage s/he would so desire. This is in line with ethical principles of research on humans (Sieber, 1992). Once the interviewee had given signed consent, the interview process began.

A semi-structured questionnaire was used (Appendix C). It had three distinct sections, i.e. Illness Narrative, Biographical History, and Meaning of Illness. These were used in two separate interviews per participant lasting between one to two hours each. The biographical history questions were based on the Maudsley psychiatric history and examination interview. (Appendix D).

It was important to have a structured format for the interviews so that a clear focus would be maintained throughout, and each participant would have covered all the same topics – any overall trends of behavioural response to the illness could then be gathered and assessed in the light of the theory informing current CFIDS research. The questions were pre-established in accordance with the theoretical enquiry being made (Fontana & Frey, 1994).

Each question was open-ended, and in this way the benefits of unstructured interviewing were amalgamated. It allowed for in-depth interaction where, "the interviewer and interviewee jointly create this knowledge; the former is fully implicated in the process of gaining knowledge about the interviewee's subjective experience" (Bryman, 1988, p.116). As the interviewees' subjective experience was shared in the context of the whole interview process, any seeming discrepancies were able to be questioned and thus a clearer understanding of what was being shared was made possible. The meaning attained was therefore embedded in the context of the interview situation, in this in-depth open-ended form of the interview (Bryman, 1988).

As has been mentioned above, the aim of the interview was to gain understanding and insight of the participants' subjective experiences, and so it was important to establish a rapport between respondent and interviewer. This demanded an ability from the interviewer to be "in the role of the respondent and to attempt to see the situation from their perspective, rather than imposing the

world of academia and preconceptions on them" (Fontana & Frey, 1994, p.367). It meant concentrated listening and attending to each participant, in fact allowing the "other" to "blossom to full living colour and come into focus as a real person" (p. 373). This is a privileged experience of interaction and disclosure of lives, and is invaluable to health professionals' ability to make informed decisions regarding effective interventions for healing through the deepened understanding of how to work co-operatively with the patient so that a reciprocal co-operation can take place.

### 3.4 ANALYSIS

Each interview was tape recorded and then transcribed onto computer discs. These were then programmed into a qualitative analysis computer programme ATLAS.ti. The principle guiding this programme is known as VISE i.e.:

*VISUALIZATION* – direct support of the way human beings think, plan, and approach solutions in creative, yet systematic ways.

Tools are offered to visualize complex properties and relations between the objects which accumulate during the process of eliciting meaning and structure from the analyzed data.

*INTEGRATION* – not to lose the feeling for the whole when working on details. The main "container" object integrating all the other entities studies are made of is the "Hermeneutic Unit".

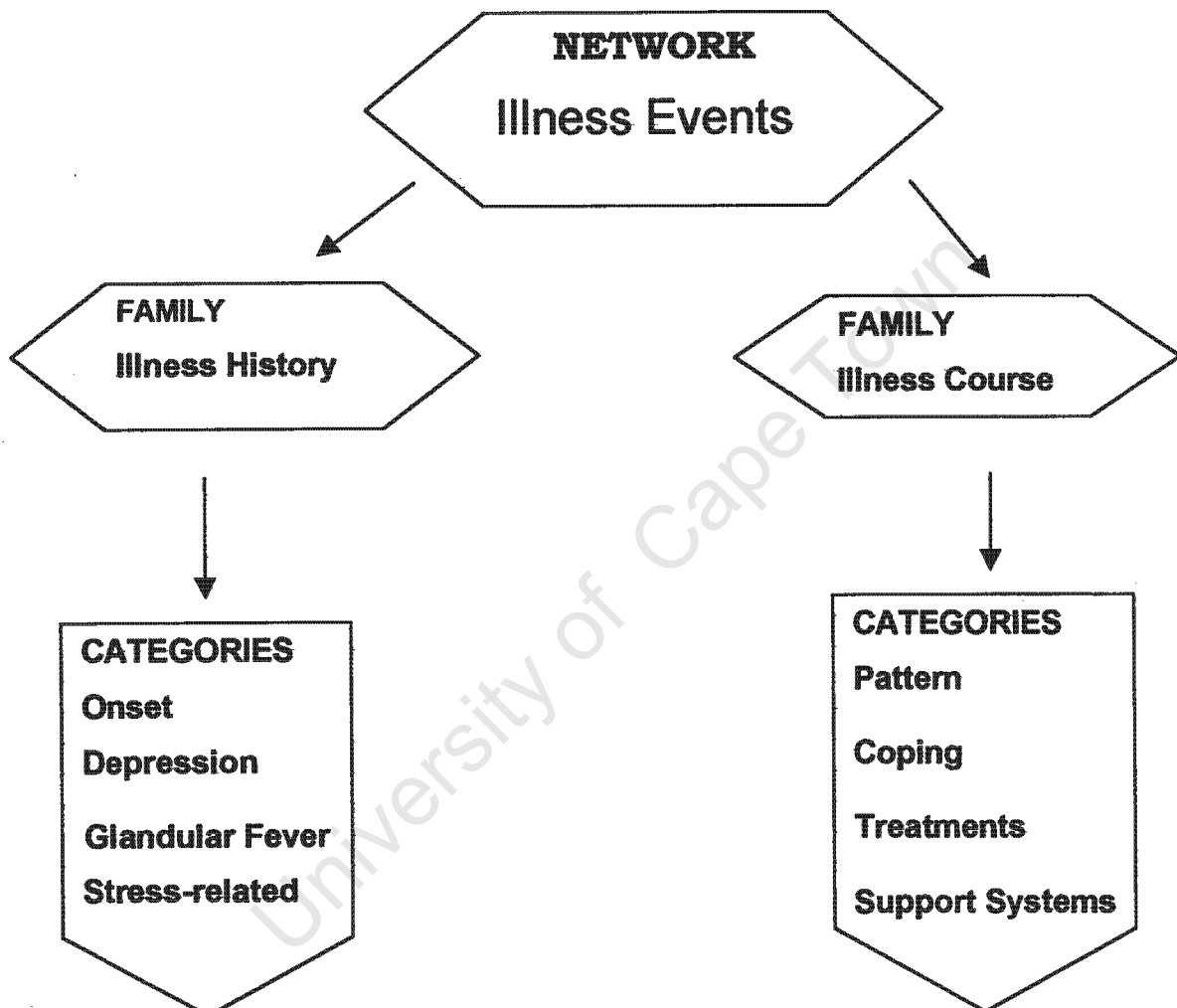
*SERENDIPITY* – enables browsing, an intuitive approach to data- "making fortunate discoveries accidentally".

*EXPLORATION* – an exploratory yet systematic approach to data greatly benefiting theory building. The whole conception of the programme is aimed towards an exploratory, discovery oriented approach (Muir, 1997, p.2).

This programme enables the placing of all the transcripts (Primary Documents) into a Hermeneutic Unit. This can then be broken down into categories of quotations that can be coded, and these built into families of themes that can also be placed into networks (levels) enabling differing levels of analysis of the material. In this research, there were two basic levels that emerged for analysis, Illness Course and Inner Journeying, and the themes were examined accordingly

within each level. The chosen quotations were coded, classified into categories and then grouped into families. These were then placed into two networks as was pertinent. Once all the data had been printed out an analysis of the networks was performed as set out in chapter 4.

The following diagram demonstrates the process I followed in compiling level 1 of the analysis:



1. The relevant categories of coded quotes were selected from the general pool and placed into smaller family groupings. In this case, Illness History and Illness Course were the families.
2. The families were then combined in a network view named Illness Events. This enabled a quick overview of where I was heading and helped to keep me on target.

## CHAPTER 4

### ILLNESS NARRATIVES

Categories of difference determine the construction of the idea of the patient in a direct and powerful manner, drawing the boundaries between the "healthy" observer, physician or layperson, and the "patient".

The construction of the image of the patient is always thus a playing out of this desire for a demarcation between ourselves and the chaos represented in culture by disease.

But we are all at risk - we will all be ill, will fail, will die.

What happens, however, when our sense of ourselves as "the patient", of ourselves as existing on the wrong side of the margin between the healthy and the diseased, becomes salient to our definition of self? (Gilman, 1988, pp.8-9)

#### 4.1 INTRODUCTION

In reading through the illness narratives a clear mindbody experience was manifest. This can be depicted as two levels – Illness Events and Inner Journeying. By examining narratives from this perspective some common themes have emerged and will be discussed in the light of the meaning that they had for the patients. An analysis of the Illness Events (level 1) will be followed by that of the Inner Journey (level 2). Each of these levels will in turn be looked at from a number of perspectives, and related to the theoretical underpinnings of CFIDS research as covered in chapter 2.

#### 4.2 LEVEL ONE (ILLNESS EVENTS)

This level consists of two sections – Illness History, (covering the background of illness experiences which led up to the onset of CFIDS, as well as the onset pattern itself) and Illness Course, (explaining the symptoms of the illness and examining the doctors'/community's responses and the availability of support systems for the patients).

#### 4.2.1 ILLNESS HISTORY

4.2.1a It is interesting to note that only 2 of the 10 patients experienced an acute-only onset of CFIDS (no previous history of chronic ill health). The history of each of these was that they had no recollection of illnesses, other than the normal childhood ailments, before coming down with CFIDS. Both these patients are female and have children – P1 and P9.

P1 expresses her onset as completely out of the blue. She had a job which gave her scope to express herself fully and provided a lot of social interaction which she loved.

Prior to me getting ill I... I... I had a very good job, it wasn't overly stressed. I used to run 3 times a week and I belonged to a gym....

There was no warning. It was a completely instant thing...

I didn't have weeks or years or months of just not feeling well, it was completely over night, and I can even remember the day that it happened. It was on November 30th 1989. I woke up and my whole body just felt like lead...it felt like it was encased in concrete, that's the only way I can explain it.

This is very different from most other accounts. There seems to be no apparent current stressor which triggered this event. She had, however, experienced some severe life stressors in the preceding years. She fell pregnant out of marriage, and this resulted in her parents' rejection of her. Her lover and the father of her child turned out to be a "bounder" and left her to cope alone. She subsequently lost of the one true love of her life. These events failed to express themselves in her body in the form of stress related illnesses at the time they occurred. The "concrete body" only arrived a few years later when she was living a full and happy life as alluded to above.

P9, also cannot recall any chronic illness history, and at the time of the

onset she was very happily engaged as a parish priest's wife in Stellenbosch and had a 2-month old baby. However, just prior to the onset, her husband accepted a call to a parish in Cape Town known as the flagship parish of their denomination where there was a very large congregation and a team of staff. This was a daunting prospect for her and undoubtedly placed extreme stress on her as she anticipated the move. It was just six months before the move that she:

had these terrible flu-like symptoms, like flu but with no snotty nose, and I actually had a temperature, I must say that as well. I had a temperature and night sweats, lots of night sweats. And a very, very sore throat... the local GP prescribed antibiotics for this red sore throat. And um I continued like this for six months, until I just couldn't anymore... Um and it was discovered that I had Epstein Barr Virus. And um I just had to rest. I did my very best through it all, I mean there were times when I just couldn't move. But still maintained a home, you know as best I could.

It seems as if the stressors of having a small baby and having to face the move to a new demanding parish, could well have been the catalyst that re-activated the Epstein Barr Virus known to be associated with CFIDS symptoms.

In both these cases the appearance of the CFIDS symptoms came as a completely new experience, and without any warning.

4.2.1b The remaining eight patients all had a history of chronic ill health experiences finally culminating in full blown acute CFIDS symptoms. These preceding patterns of bodily reaction to stressors can be seen as warning signals that some lifestyle changes needed to be made in order to strengthen the body, and enable a more healthy life experience. The "warnings" were seen to come in two main streams:

*Depression* was common to 6 of the 8 patients, and in all cases was experienced, in varying intensities, some time prior to the CFIDS onset. They were all diagnosed as reactive depression at the time of occurrence.

For instance, P4 was recounting her life-pattern of response to stressors, and how this had encouraged incidences of depression over the years:

I get very upset when I'm under a stressful situation - um ja I didn't cope- although I did cope academically ... Um but just struggled, just felt always that I wasn't coping...when (rebound relationship) broke up I just hit rock bottom. I was very depressed to the point that I didn't want to get out of bed in the morning and kind of gave in to that. Um, I had been depressed before, or depressive but hadn't given in to, "I don't want to get out of bed", I always did.

P5 reflected over the course of depression in her life, and stated that she had been under treatment for this illness for many years prior to her CFIDS onset saying, " I started with depression twenty years ago ... I was in a terrible state. I think it was caused by my marriage. And um – they call it reactive depression."

When P7 finally got to university fulfilling her childhood dreams, about 10 years before her CFIDS episode, she was confronted by the stark reality of initiation practices, which she describes as, "no this, this initiation thing just seemed to me like, not silly only, but extremely humiliating, extremely silly. Extremely misguided,...um...extremely invasive." Three months later she was taken home after having experienced a most appalling depressive breakdown in response to these initiation activities:

I one day I woke up and just knew I...something strange had happened...I suddenly had a complete breakdown. I couldn't work out – like if I had to fill in a form or something you know I couldn't read it, and make sense of it. Newspapers, books, anything, strange kind of...ja it felt as if my head was here. I had no access to it...I couldn't follow conversations properly...I sort of somehow, didn't, wasn't able to function...it felt like being under water. You know trying to move fast but you, you kind of everything's just like slow motion you know.

The final example of depression history I want to look at is where P6 said that the depression she was experiencing with her CFIDS was not a new

event, as over the years she had become familiar with this inability to manage life's stressors:

I did go through very intense depression before this. In fact I tried to, I jumped off a garage. I didn't want to die as such, I didn't really want to die but I did want to, I just had to do something desperate. I went to Valkenburg for six weeks. They didn't give me any medication They talked about it being reactive depression.

In the above there is a pattern of emotional distress as a reaction to life's stressors – a reaction that evidenced itself in clinical depression. This ties in with the findings in research where there appear to be two groups of patients – those who suffered depressive episodes prior to CFIDS onset (the 6 mentioned above), and then the group with no previous history of such episodes (the remaining 2). The 2 acute-only onset patients would also fit into the second group.

The second stream of "warnings" came in the form of a constant battle against *chronic infectious illnesses*, now acknowledged by the medical profession to be stress-related (as was emphasized in chapter 2 by the research covering compromised immune functioning in CFIDS patients). *Glandular fever* was one of the common indicators that there was a weakened ability to fight off viruses, and episodes of this illness were a recurring factor in the build up to CFIDS.

For example, following a traumatic experience of sexual molestation from his older brother, P8 began his history of glandular fever episodes:

and 3 weeks following this abuse by my brother, I came down with this mysterious illness. And I didn't make a connection, the nurse didn't make the connection because she probably didn't know. But it was glandular fever- undiagnosed – but it was glandular fever, and it went on probably for about 8 weeks... While I was having this relationship with her (a black woman attending a training course he was at) my first sexual relationship, um I had a recurrence of something... Then I came to UCT when I was 20... and in the middle of that year I came down with glandular fever that

this time was diagnosed. The first time it'd been diagnosed, and it wouldn't go away.

Research has established that it is when the immune functioning is compromised that the glandular fever is likely to be triggered, and severe stress has also been associated with the inefficient performance of the immune system. The severe stress of P8 having been sexually molested by his brother, and his having experienced a first sexual relationship with the added stress of secrecy which he felt he had to keep (presumably because he was still under age), and the stress in his first year at varsity of living a hippie lifestyle that he wasn't proud of and didn't want his parents to know about, had culminated in the practice of 'hiding away' would have placed inordinate demands on his immune functioning. He says, "I was, I was always in an underlying anxiety about being caught, being exposed, my parents finding out."

P5 had a similar pattern of glandular fever episodes starting with her having suffered an embolism in the right lung and resulting in "seven months I just wasn't right. I was in and out of bed with pleurisy and bronchitis and glandular fever... Glandular fever – when I say I kept getting it, you don't get it, apparently it's always there and it can trigger, but I must have had it about 9 times".

In both these patients, and the other six patients as well, the experience of feeling out of control physically and emotionally had become established. P5 explains this state as "tiredness sort of developed and it never left me."

In addition to glandular fever there was an array of other stress-related illnesses. For example P2 reached the age of 40 and from then on a pattern of general unwell ness took over starting with, "I seemed to have lots of things, I had brucellosis, pneumonia and uh shingles all in one year."

The pre CFIDS history of P7 covers the type of episodes that were experienced by all these patients:

OK um I've always been um, I've always suffered from headaches – well not always – but since my adolescence. It's been you know, quite a debilitating problem... They were strange complaints such as I'm thirsty all the time, um you know my headaches were increased, more and more and more headaches and they were more and more severe... What was strange about it was that you know that nothing, I, I just was sick with different things you know... I got bronchial infections which turned into bronchitis and I took antibiotics.

This pattern is much the same as those reported by patients examined in various research studies alluded to in chapter 2.

4.2.1c The actual acute phase in these eight patients grew out of the previous debilitating illnesses that they had been living through – the two patients mentioned above were diagnosed with CFIDS out of a final severe glandular fever episode; two others experienced a flu attack which never cleared; and the remaining four patients could not shake syndromes of pain and exhaustion. We will look at an example from each of these last two groups by way of illustration

P10 had an attack of flu from which she couldn't recover:

Towards August, July/August I got sick with a bad dose of flu. And I got very sore, and, and it, it never got better. And I would go back to my doctor and I would say, 'I'm still sore'. Sore throats, sore muscles, terrible headache and felt like a virus I just couldn't get over, and it got so bad uh the pain, that I was admitted to hospital under a physician. Uh I couldn't walk, that's how bad it got.

Thinking, concentration that, that at this stage I was in a blur, in that I had no idea what was exactly going on, it was just pain... He did an antibody scan and he found that I had incredibly high antibody count at the sight of my glands... He closed my practice down and sent me home for 6 weeks of rest and sleep.

P3 was one whose general state of unwell ness escalated to the point where she became completely incapacitated leading to her diagnosis of CFIDS. “Um, I had a headache all the time, felt nauseous all the time, dizzy, I couldn’t concentrate. I couldn’t – my muscles were very sore. I had a sore throat most of the time. Ja no, it definitely wasn’t just exhaustion at all.”

P5 recounts how her episodes of glandular fever resulted in her weakening physically to the extent of her becoming unable to keep going with her working life. She was also diagnosed with CFIDS at this stage. “And every time I got it obviously it knocked me right back. And uh so I was actually diagnosed in like May ’93. Um – still continued working because I had to be self-supporting. And um in October of that same year I applied for disability through Liberty Life. I did get the disability payment and I actually ceased working.”

#### 4.2.2 ILLNESS COURSE

I will be looking at the illness course under four main sections – *pattern* of the illness as it unfolds; *treatments* which were undergone; *coping* mechanisms which the patients used and *support* systems that were experienced.

4.2.2a The pattern of the illness usually went from chronic symptoms to an acute phase of inactivity, followed by a time of major relapse and remission incidents, and finally settling into a new lifestyle which was punctuated by experiencing mini relapses when too much stress or reversion to old lifestyle habits occurred.

P9 had an acute phase lasting for four years, and she describes how she lived during this period:

There were terribly painful and dark days - terribly ill. And um that’s how it continued, although um, there were a few days now and again where I would feel a bit better. And then I’d just get up and go for it. There were also days where I remember I would just lie on the floor and my daughter

would be playing, crawling all over me. We'd put music on, listen to music. And I just could hardly keep my eyes open. I'd just want to sleep... In retrospect looking back now it was probably one of the most terrible times in my life. Um and, and it was like a black hole.

P3, who also had a four-year long acute phase, explains how, "all I would do basically for those four years was lie on my bed and lie on my couch. Um – I mean it was a huge thing trying to walk around the house."

P7 says the acute phase found her basically "staying in bed for eight months, which was hard." Each day she would set herself one task, for instance, 'like maybe I'm going to wash the dishes. Then I'll say, 'OK, um, I'm going to do it in an hour', and maybe I'll spend a quarter of an hour doing it and then I will lie down."

This acute phase seems to gradually improve over time, but three of the patients believe that there was a significant turning point that enabled the process of recovery.

P3 found that once her parents had joined her with her psychologist in order to address the situation of their bad relationship (which was stressful for her) that "I did start getting better after that."

P8 felt that a major factor for him was kinesiology. "Something clicked in me when I started doing kinesiology... and my health you know improved."

For P10 the turning point came when she and her husband worked through their alienation to a new place of restoration. "And it was miraculous really – that he was able to, and I was able to go through our differences, and forgive, and work on it... And I went home and my husband was changed completely. He loved me, I mean he made supper..."

All eight patients experienced a time where they had major remission – relapse episodes.

For instance, P1 had two such episodes a year apart from each other. In the first year, nine months into her illness and in the midst of her initial acute “concrete body” phase, she woke up one morning feeling totally well again. For the next three months she was back at work part-time, exercising, socializing and she also dropped off the 25kg she had accrued. As suddenly as the remission arrived a relapse to the acute phase occurred. Nine months later she had her second major remission:

I was completely better again. I didn't have any hangovers from the illness. I didn't have the sore throats that I'd always had permanently – the headaches that I'd always had.....I was better for three months....I had a wonderful time, that during that second remission....I'd put on 20-25 kilos again and I'd lost them all again. Then I met a really nice guy and was having this fabulous time. It was really like being released from jail.

Once again the major relapse occurred and she says, “It was the middle of October and my body started feeling like lead, and I thought ‘Oh no!’. This was just a nightmare...I was so ill and it all just came back...I've never had a remission since then.”

These major remission/relapse experiences are extremely cruel and there seems to be no explanation for their occurrence. It is only once the acute phase has eased off gradually that the patient seems to settle once again into a chronic phase that can either slowly improve or keep on interminably. Of these ten patients, only P1 and P5 seem to have settled into an ongoing chronicity that totally debars them from functioning within the community at all. The remaining eight patients continue to find improvement in their situations to different degrees, and all of them are back in touch with society, albeit in a much changed manner than before their CFIDS episode. During the post acute phase they all experience mini relapses from time to time.

P10 expresses this phenomenon as it affects her present day situation:

I think during a two-week phase you can have a mini relapse. The whole of Sunday I spent in bed, 'cause I just realized I'd got completely tired and weak. And with children's parties, you know that's emotionally exhausting and I was so tired that I had to go to bed. So you get these mini relapses, but it's not like a big thing.

This observation leads on to the second aspect that needs to be covered.

4.2.2b Coping with this illness demands some radical changes in the patients' attitudes towards their situation and in the way they organize their lifestyle. They find themselves prey to many new emotions as they respond to their circumstances. The array of emotions was the same in all of the patients with only P1 and P5 seeming unable to move past the negative feelings of victimization. Firstly, they had to deal with intense anger and frustration in experiencing the overwhelming control that CFIDS had over their lives.

P8 expresses this aspect of his response very powerfully:

I can't accept it, it's just too cruel – um –very specifically it feels like I've been kicked in the face, and that's a real image there...with a big heavy boot. You know it's violent, it's cruel, it's nonsensical. Um so I've still got so much anger and bitterness and rage about having ME.

P2 robustly answered the question of how she felt during this process with the immediate "I felt very, very angry".

Isolation and loss were also common experiences needing to be faced. "I've lost 9 years of my life... I've had no job, I've lost a lot of my social skills", was P1's reflection of her situation.

P5 feels the loss of her familiar lifestyle very deeply as she describes her response to the illness;

And it is a punishment, because um, it takes away your dignity, it takes away everything. You know, there you are, one minute you're a person and the next you're a nothing. You know people look up to you and then they uh look down.

The participants also expressed a sense of hopelessness, purposelessness and emptiness. P1 expresses something of this when she explains, 'I mean with virtually any other illness you're either going to die or you're going to recover. But this just drags on and on and on with no – there's no light at the end of the tunnel really'.

P5's expression of hopelessness was "You know I hate myself for what I am".

And P7 touches a key issue when she shares how, "I identified myself so much with the work I do and being a mother, and without those things I, I you know I just didn't see any purpose in my being around".

Depression was a common experience to all – even those who had no previous history of this. P7 talks about:

So through this, that whole process I just became more and more depressed and I found it was just like my worst nightmare come true you know. Being completely debilitated in bed, being powerless and helpless to get up, and also I was very fearful of being on my own. I was incredibly fearful.

P8, who had no previous depressive episodes, describes how "I kind of become depressed, and because I'm depressed I can't help myself as much. So yea I'm aware of a depressed aspect there".

And P9 reflects that, "Now in retrospect when I think back to those periods of sadness, and frustration of not being able to do what I wanted to do... Where I was really, I was depressed".

In order to come through these painful emotions, it was necessary for the patients to achieve acceptance of their limitations, and then find ways to adjust their lifestyles accordingly. Eight of the ten were able to do this and they have gradually re-entered society in a new way. From being a highly active professional P10 has been able to pare her activities and build a less pressured lifestyle and shares:

Let's first look at home...cleaning and cooking and washing...caring for the children...so mostly 4 days of the week I'm doing that. And then I work 3 days of the week now. I really like it. I really like having some work, because I really enjoy consulting and getting into my career. But I have time for children, and time to take them to the beach or to the park, because I really like being with them. Um but time also for me.

Overall, the various adjustments made by these patients echo the findings of the social course research examined in chapter 2.

#### 4.2.2c The treatments used followed a similar pattern amongst all ten patients.

They combined conventional medicine with alternative interventions. The conventional treatments were in the form of blood tests, antibiotics, anti-depressants, vitamin injections and bed rest. The alternative interventions covered homeopathy, kinesiology, body alignment, reflexology, aromatherapy, hypnotherapy, acupuncture, and various health diets. When it came to addressing the emotional aspects, eight of the ten had psychotherapy or spiritual counseling, and the remaining two went for the chemical treatment without psychotherapy. It is interesting to note that all those who had psychotherapy/counseling were able to come to a place of self-discovery and acceptance, and were restored into something new as they went on an inner journey with their therapist/counselor. The two (P1

and P5) who had psychiatric intervention relying on medication only, remained in a place of isolation from society.

4.2.2d Support systems varied. Of the eight patients who came through to a place of re-integration in the community, six had support from parents/partner with whom they lived, one had limited support from her husband before the marriage finally dissolved, and the last patient managed through sheer tenacity and determination together with psychotherapy. They all had a problem with finding doctors who would take them seriously. This is expressed by P5, 'You know you'd go to a doctor you'd say well you know 'Please help me I've been told I've got ME', and they'd throw their hands up and say, 'ME, ME what's ME – it's all in your head you know, you've got nothing'. And um to find the right support and the right um medical help and what have you, is virtually impossible".

However, impossible it is not, as they all eventually were able to find medical support which was very important for their progress. P2, after suffering a lot of scepticism at the hands of the medical profession, was delighted when she was introduced to a doctor whom she describes as "a healer, - he wasn't just a, just a mechanic".

Only a few people were able to sustain a friendship with the patients, and basically a new group of friends was established with those who were either fellow sufferers or in the healing professions. Family also found it hard to cope with the changed person, and all this increased the sense of isolation. Only a couple tried to attend a support group but found it unworthwhile because of the unreliability of the illness making it virtually impossible to commit to any regular activity. P9 was an exception as she found her church community a constant support.

Overall, it was clear that being in a state of chronic illness is an isolating and frightening experience. Society does not cope well with such difference, as we saw from the social course findings in chapter 2.

### 4.3 LEVEL TWO (INNER JOURNEY)

Once again we find that two of the patients (P1 and P5) were unable to engage in any meaningful inner exploration, and the other eight patients all followed a similar pattern of inner engagement. This section will have four parts – overview of P1 and P5, family background, inner journeying and new understanding, explanation of onset and illness meaning.

#### 4.3.1 OVERVIEW (P1 & P5)

In accordance with the other eight patients, P1 and P5 came from family backgrounds where certain expectations were placed on them and no scope given for communicating feelings.

For example P5 remembers her childhood as being very controlled and harsh in that, "There was no love there was no communication. We were all looked after and we had everything we wanted materially, but it never went deeper".

Unlike the other eight participants, they did not associate their childhood experiences with their own behavioural or attitudinal patterns and so did not consider the effects these might have had on their bodily health. P1 evidenced a tendency rather, to choose a pattern of denial in her life experiences and this was very clear in the way she described her response to CFIDS:

I go into that trance stage where I don't really think – about my life and where I'm going, because I'm not really going anywhere. So it's depressing to think about, and what I am as a person. I don't really know. It's difficult to say.

When P5 was asked to explain the onset of the illness and any meaning it had for her, she showed no awareness of her part in the whole process, "I don't know, maybe it's a punishment. I don't know what it means. I don't know why I was chosen. I can't do and be what I want to be... No, there's nothing positive. I don't believe in all that crap that God sent it to me to teach me something."

And P1 stated that she thought, "It's exceedingly bad luck....I just feel that my life is on hold. I don't regard this as any sort of life. For me I'm just, I'm waiting".

It seems significant that only these two of the whole sample, continue in a place of feeling isolated and useless. They have been unable to work co-operatively with their illness experience.

#### 4.3.2 FAMILY BACKGROUND:

As has been mentioned, all of the remaining eight patients were in therapy or had counseling, during which they were confronted by their family background and the patterns of behaviour that they had established as a result of their experiences there. They all worked through to places of new insight of the impact these patterns had on their quality of living.

For example P10 says:

I just know I had to be the good girl. My brother at 18 months was colicky demanding, and I knew that it was very important for my mom's happiness that I tow the line, and was good, and the best opportunity was outside play...I remember my mom saying, 'oh she's such an angel, such a good girl, she just plays for hours on end.' So suddenly this registered, oh this makes mom happy. So that's what I carried on doing....I was just the good one, I didn't do anything wrong. And I don't think I had an adolescence....he (therapist) said my adolescence finishes at 30, I've got 2 years, and I became very much more relaxed....he(husband) let me get to grips with a bit of me and a little bit of rebellion...and I threw out a lot of clothes and oh it was good....Suppressed – just have realized I do that so often. I've done that for most of my life, this major suppression of uh any angry, bad, different thoughts.

#### 4.3.3 NEW UNDERSTANDING/INNER JOURNEYING:

In all eight of these patients the new understanding arising from inner journeying centred around the growth of a new sense of self and an ability to make changes in their lifestyle with equanimity because of this.

P4 understands that, "it's all been involved with me and the way I feel about myself...that it's actually that internal fight that one has with not being at peace with who you are, but because you don't know who you are".

P7 reflects on what she encountered through this inner journeying saying, "I think my entire sense of self was invested in other people, and, and how I could support their lives...I just did not have any sense of me to be me... I just really didn't see that this person was worth looking after...fighting Really at the very you know sort of deepest level, for my own sense of identity And I think it was a very bitter fight, it really was a life or death issue. Because I think my, my sense of self was, was um threatened to the point where um yeh you know, I suppose you either just had to keep fighting and hoped something survived um or you give in".

The ability to make the necessary changes of attitude and pacing of one's life seemed to flow out of this new sense of self.

P2 was helped into this new way with help from her doctor. " I think there's a way of healing myself. I really do. Doctor H says stop listening to other people. Listen to yourself. I've actually started to look at things completely differently...it's awareness that we can actually feel ourselves...you know really basically, we could, can heal ourselves – obviously through diet and lifestyle, and a – look meditation and spirituality."

#### 4.3.3 EXPLAINING ONSET/ILLNESS MEANING;

There was a consistent sense that the illness was brought on as a reaction to stressful living that got out of control – being caught up in the milieu of having to achieve and perform.

P3 looks back at the onset of her illness when she was a young child and determines that:

Um but I think um what I was going through when I was younger was too much to handle and in a way um getting sick – I was either physically – you know it was too much, or emotionally I don't know. Um – and I think that's how I got sick.

P6 comes to the conclusion that, "Part of my thinking is that I was trying to do too much, and wasn't getting enough feedback in um to, to kind of support me".

There was an overall positive meaning given to their illness experience by these eight patients. For instance P3 says that:

I think I've had to rely on myself, and be confident in myself because there was no-one else really. Um and I have learnt what's more important in life – I mean I know as much as, as hard as I work I know it's not the most important thing at all. I think I have learnt a lot from it, um which I wouldn't have learnt if I didn't have it. But honestly I really would have preferred not to have had it.

P9 came to understand that she had, "more empathy, more understanding when people are ill. And life as well. Life is very precious, and I think we take it for granted."

And finally, P10 has made great strides in learning a new way of listening to herself and her bodily responses:

In a way it has created a great deal of health in me, because I work with, with me – I don't work against me. I um – I listen to my needs, and I listen to me. And I, I'm very true, true to me. Um I listen to my dreams – I suddenly have dreams of total chaos, and everything's going wrong ....and I realize shew ok, that's a warning that you're very vulnerable – relax. So I've got to be careful not to do too much. But I'm very happy doing that, and I like to do it.

#### 4.3.5 IMPLICATIONS

The analysis has confirmed the complexity of CFIDS, and the research that has shown that there is a need for the illness to be addressed holistically and according to what each situation uniquely demands. The suppression of emotions is seen to give rise to system stress and thus the immune functioning becomes impaired. There is also indication of viral infection setting the process in motion. Whatever the initial cause, it seems from this sample, that there needs to be a component of inner journeying which leads to new perspectives and a new way of living within society; of acknowledging and accepting the constraints of the illness. Those who were unable to do this continued to experience a hopelessness, isolation and sense of victimization. Chapter 5 will be a discussion of these findings in the light of the theoretical illness models of Medicine and the Lifeworld.

## CHAPTER 5

### MEDICAL AND LIFEWORLD MODELS

Until the academic discourse of medicine is expanded beyond the languages of molecules and drugs to include the language of experience and meanings, however, medical science will reinforce the profession's resistance to the problems of illness rather than contribute to the broadening of its vision (Kleinman, 1988, p. 266).

This chapter will start with an overview of the analysis of patients' illness experiences and the meaning they attached to these. The implications of the findings will then be discussed in the light of two models that underpin the theory behind some of the current research of CFIDS. These are the medical model of disease, and the lifeworld model of the influence of the sociocultural and experience factors on the course of illness.

#### 5.1 OVERVIEW OF PATIENTS' ILLNESS EXPERIENCE AND MEANING

5.1.1a Although each patient had her/his own set of symptoms, the overall pattern of symptomatology included excessive pain (muscular/head), series of recurring viral infections (glandular fever, candida and flu), longstanding and incapacitating exhaustion.

The overall outcome of this was impairment of functioning:

*Physiological* impairment that meant patients were unable to continue their normal lifestyles and work engagements.

*Cognitive* impairment resulting in their inability to hold concentration for any length of time, and a loss of short-term memory.

*Emotional* impairment where patients found themselves unable to contain their feelings of anger, hopelessness, isolation and loss. This resulted in experiencing bouts of severe depression.

5.1.1b. All patients experienced periods of acute symptoms rendering them bed-ridden for various lengths of time. This placed a very heavy burden on those with whom they lived.

5.1.1c The pattern of the illness was one of remission – relapse and as such was completely unpredictable. This severely affected the patients' reliability in the lifeworld and caused them to have to withdraw from social, work and family engagements. It also meant that they were unable to join any support group and this increased their sense of isolation.

5.1.1d All the patients tried a variety of treatments. They were treated by doctors with antibiotics to address the various viral infections. Different alternative interventions were seen as being most helpful in both the way patients felt physically and in helping them to face up to inner realities (P1 & P5 failing to make this connection). This led to engagement with psychotherapeutic intervention and/or spiritual engagement that played an important role in enabling the patient to let go into the new process of lifestyle that would enable them to move towards a more stable health experience and a new involvement in their lifeworld. It is important to note that all these treatments were costly and poverty-stricken patients would not have been able to utilize these interventions under our present national health care system.

5.1.2 The participants fell into two distinct categories in relation to making meaning of their illness experience.

5.1.2a The two patients, alluded to above, who were unable to make the journey out of mind-body dualism, became locked into the need to find a medical solution to their situation. They clung to their previous identity as healthy participants in the lifeworld and so were unable to accept that any form of mind/emotion causation could be affecting their progress. They were left feeling isolated and irrelevant and they saw the meaning of what was happening to them in these words, P1 "a sick joke" and P5 "punishment". They were living as those condemned.

5.1.2b The remaining ten patients all came to the position where they found that inner reflection enabled them to understand the need to engage their lifeworld less intensely, and to take time to listen to their own wishes and build a strong sense of self – an identity deeper than any role identity they might need to engage at different times. They learnt to take care of themselves and become responsible for their own well-being from a mindbody understanding of wholeness.

5.1.2c Although the second group agreed that their lives were more harmonious and fulfilled as a result of their experience, they were at one with the first group in finding the illness harsh and cruel. All would have chosen not to have had the illness at all. This underlines the complex ramifications of this illness which affects the total life-experience of those who suffer it in a way that is extremely painful and difficult to cope with.

## 5.2 MEDICAL MODEL

The history of medicine's concept of disease is traced back to the seventeenth century when Descartes established, in conjunction with the reigning Pope, that the care of people would be divided under two authorities:

Religion and Philosophy would determine truths about the soul and mind, (currently, there is the addition of Psychiatry and Behavioural Science). Science would be the ultimate authority in matters of the body. Since that time, the mind-body dualism has become increasingly entrenched as a basic given by the medical sciences, and so this concept of disease being solely a body malfunctioning has become established (Helman,1994; Kleinman,1988; Pert,1997). In the following section I shall examine the implications of the traditional medical disease concept in the treatment of illness. More specifically, I will focus on its impact on the sample of patients interviewed in this thesis.

### 5.2.1 SCIENTIFIC RATIONALITY AND MEASUREMENT

This is the premise that the disease, in order to be authenticated, needs to be able to be objectively observed and measured. The clinician is seen as the

impartial observer whose interest is theoretical. He/she would bring scientific rationality and formal logic, into the measuring of physicochemical information about the patient. Any discourse by the patient would be " 'decoded' by relating symptoms to their biological referents in order to diagnose a disease entity" (Helman, 1994:03). The whole process is a decontextualisation of the patient's experience, and an attempt to objectify the physical features into a set of clinical components/ realities that can be categorised and fitted into a model of the disease. The condition can then be attended to by discovering the causal flow. Once this has been isolated it can be rectified. Investigation takes the form of sophisticated examinations and series of tests. These have become highly proficient and are heavily relied on to arrive at a prognosis. In all this, observers have been able to gain a consensus of explanations and are thus able to work from specific guidelines (Gerhardt, 1989; Helman, 1994; Mishler, 1984; Tuckett, 1976).

Numerical data is supplied from these tests and can be quantitatively analysed and interpreted. This, it is suggested, takes away any reliance on subjective understandings or experience of both patient and doctor because the data provide a means for an objective, and thus more accurate, diagnosis. The numerical data are seen to have a range from normal to abnormal, and according to where the patient's results lie in this continuum, the degree of disease/health is assessed.

Practitioners, however, are not trained to be self-reflective interpreters of distinctive systems of meaning. They are turned out of medical schools as naïve realists, like Dashiell Hammett's Sam Spade, who are led to believe that symptoms are clues to disease, evidence of a "natural" process, a physical entity to be discovered or uncovered. (Kleinman, 1988:17)

Therefore the implication for treatment is that there needs to be a "search for physical evidence of 'disease' or dysfunction, as in the use of physical treatments (such as drugs, surgery or radiation) in correcting these underlying abnormalities" (Helman, 1984:107). This medical model has attained spectacular success in

many areas over the past  $\pm 20$  years. There has been the development of sophisticated computer-controlled diagnostic technology that enables doctors to look inside the body to determine how it is functioning. Surgical procedures have advanced into the realm of laser treatments enhancing the repair work that can be done. Molecular biology and genetics have progressed to the development of many new drugs to control/counteract previously untreatable disorders. Not surprisingly, the western world has traditionally arrived at a tendency to reify the biomedical system – seeing the doctor as expert and as saviour – and accepted the emphasis on disease having objective, physical features (Kabat-Zinn, 1996; Mishler, 1984).

It has been customary in our society to agree that the solution to our illness is therefore, through objective diagnosis and physiological/chemical treatments. If no such course is found for us after exhaustive testing, we tend to be fobbed off with statements such as "it's all in your mind", and this makes us feel blameworthy for our condition. The discourse that one tends to engage in here is that one needs the doctor to give advice and make a prognosis regarding the illness. When the doctor fails to do this, it seems like a negation of the illness experience, and there is a sense that the patient is malingering and needs to pull him/herself together – to get better. The patient experiences intense stress when the malady persists and no amount of trying to improve his/her mental response has any effect on the ailing body and its illness symptoms.

## 5. 2.2 UNIVERSALISM

From the above understanding of disease, it is a natural step to assume that each observed organic abnormality (disease) has its own unique pattern of causality and clinical intervention. An example of this type of thinking is given by Helman :

'tuberculosis' is known to be caused by a particular bacillus, to reveal itself by certain characteristic symptoms, to display certain physical signs on examination, to show up in a particular way on chest radiographs and sputum tests, and to have a likely natural history, depending on whether it is treated or not (1984, p104).

This medical understanding of etiology, treatment and course of disease arrives at the model that assumes, "diseases are universal in form, progress and content, and that they have a recurring identity; that is, it is assumed that 'tuberculosis' will be the same disease, in whatever culture or society it appears. It will always have the same cause, clinical picture, treatment and so on" (Fabrega and Silver 1973, in Helman, 1984:104). As a result of this understanding doctors have developed a particular style of approach to clinical interviews with the patient. Here the doctor is seen, "to ignore the causally structured and temporarily-ordered connections that (the patient) describes. He focuses on one element in the account, the 'objective' symptom, removes it from the grounding she gives it in her life, and isolates each element from the others" (Mishler, 1984:120). The individual is thus the focal point, and the context in which her/his life is lived is seen to have no relevance to the diagnosis and treatment. Swartz expresses the dangers of this viewpoint, "it tends to look at disorders as existing 'out there' to be discovered" (1998, p.13). This means that the patient is stripped of power to effect healing because it is suggested that only the medical treatment, reliant on the doctor, can be trusted to do this. The patient is in a true sense thus seen to be a victim of the disease that has 'attacked' her/him.

### 5.2.3 IMPLICATIONS

The stress that results from the struggle to attain medical healing is evident in the feelings of frustration, impotence and hopelessness with which the patients described their battle to find a medical cure. For instance, P9 remembers, "in retrospect looking back now it was probably one of the most terrible times in my life. Um, and, and it was like a black hole. Certainly, I had no, no, it was like just no control you know, um, over making myself better. But I did what I could to make myself better and my, my symptoms just never seemed to improve". The importance of the medical intervention is acknowledged by P1 who feels that at last she has found a brilliant doctor (this is 9 years into her illness):

And at the moment I see a psychiatrist who is actually my GP, we've decided. Because I've never ever found a GP who's believed in (CFIDS). He totally believes in (CFIDS), thinks it is so devastating. Um, we talk

about my symptoms and he gives me advice. And we try different things. I see him once a month. Now he's, he's suggested now that the next thing I have to try is testosterone.

For this patient it is important that she feels there is ongoing medical intervention, and that a cure will be found through this.

All the patients expressed the need they felt to gain acceptance of their symptoms as bona fide – both from doctors and society – and had to grapple with feelings of anger, helplessness, frustration and isolation as a result of the scepticism they had to face. P8 describes his relief on having his symptoms named and thus acknowledged as valid. “Then I went to see Dr R at Groote Schuur who did a completely mechanical thing on me, but kind of proved invaluable because I got a diagnosis from Groote Schuur of Chronic Fatigue Syndrome. Which, ja, it's an important thing to have, I mean it's bizarre to say it, but it was so important to get that”. The helpfulness of being believed is expressed by P9. “It was extremely painful for my husband as well, but he was a tremendous support to me. And, um, he never doubted once that I was ill”. In contrast, P10 describes how she realised, “my husband was totally unable to help me. He didn't know at all what was going on. Um, he bought a house, he just thought I was going to work. I mean I was too sick, I could not work. And, and he went his own way in that I was very tired, quite sad, sore person to live with”.

They suffered a deep sense of loss of identity in this quest for acceptability. P1 expresses her grief at this loss of identity when she reflects that, “It's really more – a grieving thing because you haven't got your life and it's ongoing”. And P8 explains his experience of loss of identity as, “I feel like I'm a champagne cork, surrounded by ocean liners. My sense of self is very diminished, and my boundaries and my ability to say this is me first of all”.

None of the medical interventions they received resulted in long-lasting relief from the syndrome however, and no attempt was made by the medical profession to address the question of social/familial support systems. Thus they

were forced to discover the actuality of the limits of medicine when dealing with this chronic illness as they battled through on their own. P6 says she thinks that, "isolation is part of the main problem. I lost many of my friends". And P1 expresses the aloneness and anxiety when she thinks of her long-term future, "I have to be honest, I don't know if I'm ever going to recover, and I, I have no money of my own".

The proliferation of medical research into CFIDS referred to in the literature review, is an underlining of the limitedness of medicine as the sole source of healing and understanding this disease. Medical researchers continue to be baffled and unable to agree on an aetiology that could bring some clarity. These patients were forced to look more widely for alternate sources of healing in order to avoid becoming helpless victims of this cruel malady. Those who were determined to go beyond what the medical profession had conveyed to them, had to break away from the conventional medical type of thinking and be willing to engage with their total life situation in order to arrive at some meaning and a way forward out of the mire of sickness which they experienced. However, the two patients who clung to this view continued to expect an answer to be found from medical intervention, and were left in their status quo – helpless and hopeless.

This observation has been similarly expressed by Illich (1976) in Fox "when dependence on the professional management of pain, sickness and death grows beyond a certain point, the healing power in sickness, patience in suffering and fortitude in the face of death must decline" (1988b, p.2). All this would suggest that there is great need for health care to move beyond this reductionist approach to illness. It becomes clear that there must be alternative viewpoints that need to be addressed, and one of these is the need to understand the importance of the patients' lifeworld in the shaping and responding to their sick status. The remaining 8 participants were able to make this shift, and examine seriously the implications of the influence of their lifeworld on their condition and its progress.

### 5.3 LIFEWORLD MODEL

I use the lifeworld concept that Mishler (1984) introduced. It denotes the comprehensiveness of the variety of influences which shape and guide our sense of identity, beliefs, attitudes, behaviour and understanding, as we interact in the living space that is uniquely ours. It is contended that it is from this lifeworld that we are enabled to see a causality pattern influencing the course of our medical disease histories. I will address the lifeworld under two sections. Undoubtedly, the sociocultural system plays an extremely important role in shaping the particular illness narratives that are told. However, these narratives are equally shaped by the personal history of life experiences of each narrator. These together encompass our lifeworld's influence on our understanding and response to illness, and yet they need also to be understood in their own right. This viewpoint was taken from Spicer (1998) and his words best express the thinking of this section of the discussion:

My larger point, then, is that there are very good reasons to distinguish between culture and experience in order to analyse the way that they interact without reducing the one to the other. What that means is that we can no longer develop interpretations of our data that attend only to culture, only to pragmatics, or only to psychology...the time has long since come for the kind of complex and holistic analyses of life stories that attend to all of these dimensions at once (Spicer, 1998, p.163).

#### 5.3.1 SOCIOCULTURAL INFLUENCE

It is important to note that, "In all societies, the state of freedom from disease, and the well being or capacity to function optimally that is culturally defined as health, are considered to be desirable. What is regarded as sickness of body or mind is viewed as undesirable. Everywhere, illness is apprehensively associated with misfortune, suffering, pain, disability, the ebbing of the life force, and the approach of death" (Fox, 1988b, p.1). However, given this commonality across cultures, it is also true that particular illnesses are responded to differently across cultures, and there are certain illnesses peculiar to certain societies, generally

known as 'culture-bound' illnesses. Together with this goes the fact that ideas of self and illness also vary greatly from one place to the next. So we have to acknowledge that what is discovered in this Western-culture oriented sample, cannot be extrapolated in exact detail to a different sample from a different culture (Estroff, 1993; Fox, 1988b; Helman, 1984; Kleinman & Good, 1985; Swartz, 1998).

Because of the homogenous cultural background of the patients interviewed in this research, we will draw from theory pertaining specifically to the Western-cultural understanding/experience. This will in turn be addressed from two different aspects, viz: medicalised identity and demedicalisation influence.

I would like to put forward the following proposal of the effect of the sociocultural illness perception on those suffering a chronic disorder. "Illness results in alteration and/or loss of self/soul" (Estroff, 1993, p.256).

5.3.1a Prevailing sociocultural beliefs about disease and illness are powerfully internalised by people as they progress through life. In Western culture, with the advances in medical technology, there has been an increasing life expectancy and demand for health and wellness. Gilman, (1984) expresses this as:

Disease, with its seeming randomness, is one aspect of the indeterminable universe that we wish to distance from ourselves. To do so we must construct boundaries between ourselves and those categories of individuals whom we believe (or hope) to be at more risk than ourselves (p. 4).

From this it can be seen that a very powerful concept of 'otherness' has been designated to the sick and ailing. Society has deemed them undesirable. People need to be well, independent, productive, in order to be assured of a place of acceptance in the society. When this is not the case they "desire to overcome it by reconnecting (themselves) with that force of society, which has replaced the mother as the prime determiner of (their) sense of self. (They) thus actively seek to accept society's sense of

(their) own difference in order to recreate (their) sense of oneness with the world" (Gilman, 1984, p.5).

Thus they seek to internalise this new identity, and this is borne out by such statements that , "I am not feeling myself" when they have a niggling sense of unwell ness. This assures them that although they are 'other' at the present moment, they expect to be restored again to self ness. Other people confirm this belief with statements like, "You're looking more yourself again", when they acknowledge a restoration to good health (Estroff, 1993). The belief is that they become 'not themselves' when ill or dysfunctional. The desired "I am" has become "I am not". This loss of personal identity can be seen at a much deeper and more harmful level when, after suffering with chronic illness, individuals tend to change the "I am" concept to "I am the disease – I am a diabetic". With this comes the sense of responsibility for the illness – "I can't attain betterness – selfness". There is also the devastation of hopelessness and helplessness as the illness becomes more fully entrenched ( Estroff, 1993).

Our Western medicalized culture has become streamlined towards maintaining a sickness-free society. The goal is to enable people consistently, "to perform and fulfill their social roles, with their ability to relate to one another In and through these roles (kept intact)" (Fox, 1988b, p.3)<sup>12</sup>. When this goal cannot be attained there is a shattering of roles and a sense of being discarded and useless.

### 5.3.1b IMPLICATIONS:

The CFIDS participants do indeed seem to confirm the above theory to a large extent. In fact P1 and P5 seem to have stopped at the point of feeling discarded. They continue to await the restoration of a place and a purpose for themselves within society. This is borne out by P1 when she comments :

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<sup>12</sup> Bracketed words are my own.

comments :

I don't know I just feel as if I'm not living at the moment.

I just feel that my life is on hold. I just think it is exceedingly bad luck. I just have to live in the moment. But I, I don't regard myself as living a life now. I don't regard this as any sort of life at all. For me I'm just, I'm waiting.

There is the sense they convey that they are unable to move beyond the primal need for mother's approval feel excluded and punished by her. P5 expresses this when she says "Um I definitely think it's, it's a form of punishment. I dunno if it's God punishing me, uh I wasn't the greatest daughter".

The other eight participants all had to face and work through their loss of identity. The question of, "Who am I?" was paramount for them. However, they refused to remain victims of a cruel fate/mother, and painfully learnt to shed their old reductionist role-reliant sense of identity. For instance P7 shares how through the process of coming to grips with her illness she had come to understand:

I cannot build a sense of self that depends on constant uh affirmation from another. My sense of self has to be rooted in my own, you know I have to be committed to my own life. I have to take responsibility for it. Um and I have... to learn how to do that with love and compassion. Um but it's ja, it's just made me realise how easily one gets caught up in this whole, in this whole sense of having to be productive, which means you've got to do a lot.

These patients went within themselves to co-operate with their situation towards establishing new meaning and purpose and sense of personhood.

P8 expresses it like this. "But I think what's very important for me to acknowledge is that when I'm well I can look back and say 'wow!'.

I was heading this way and my ME has brought me here. And my ME has brought me to me". These responses would suggest that our sense of selfness needs to be understood more comprehensively than is the norm within our society. Broom (1997) explains this need clearly:

A person is a cohesive unity, and it is this unified wholeness which needs to be emphasised continually. We could perhaps see the human person as a physical/psychological/spiritual/social/ecological gestalt (p.135).

### 5.3.1c DEMEDICALIZATION

Alongside the highly medicalized approach to illness is growing evidence of a different illness belief taking form within the socioculture of the Western world. The theory underpinning this new paradigm began in response to the observed inequities resulting from the traditional, hierarchical medical paradigm dealt with above. It was noted that:

the characteristics of the hospital and of the doctor-patient relationship increase the 'powerlessness' of the sick person, 'maintain his uncertainty', and systematically 'mortify' and 'curtail' the 'self' with which he enters the sick role and arrives at the hospital door (Fox, 1988a, p.478).

The proponents of this theory understand that demedicalization expresses the belief, that for optimal wellness to take place, there needs to be a balance of responsibility between medical team, patient, and family/home when addressing sickness. There is emphasis on "patient's rights" – i.e. both adequate treatment and participation in decision-making regarding their treatments. This theory thus gives rise to the understanding of partnership rather than the hierarchical doctor-patient scenario (Fox, 1988a).

Advocacy groups for demedicalization emphasise the social, psychic and medical benefits attached to patient involvement. They see patients' need to learn to understand, examine and care for their own bodies. This responsibility-sharing would encourage family and patient to work together in managing chronic illnesses in the home. This, in turn, would provide a source of emotional support as well as ease some of the financial stress resulting from relying solely on 'expert' medical care. A greater sense of

autonomy and responsibility in the patient and family regarding health and illness is seen to be, "an ethically and societally superior state" (Fox 1988a, p.480).

All of the above echoes the thinking of Illich (1976) in Fox (1988b):

Man's consciously lived fragility, individuality, and relatedness make the experience of pain, sickness, and of death an integral part of his life. The ability to cope with this trio autonomously is fundamental to his health (p. 2).

The demedicalization of sickness takes a lot of the stigma of being ill from the patient's experience. In this practice s/he is not merely the 'other' (as discussed above) but in fact has a role to play in participating in society's efforts to deal with the question of illness. The other side of this approach is the inclusion of alternative and folk remedies as acceptable and part of treatment routines. We can see how this has already become a significant factor within the West. Helman (1984) claims that this new form of health care is an overlapping of folk and professional sectors and that each year statistics in most Western country indicate the growing popularity of using this combination of treatments. Both the medical and alternative practitioners have entered into a two-way influence between their sectors. For instance a growing number of doctors are training in one or more forms of alternative healing which they gather into collegial organisations – one example of which is the British Society of Medical and Dental Hypnosis. In turn, the alternative practitioners are organising themselves into institutions which oversee training and supervision in order to maintain the highest standard of treatment possible –the Council for Complementary Medicine is one such establishment (Helman, 1984).

Overall the 'new' emphasis is on enabling the individual to understand and work with her/his unique areas of imbalance/illness in a proactive manner, receiving this enablement from the full spectrum of healing and social resources available. Albert Schweitzer, in Cousins (1979) understood this path of treatment when he said:

The witch doctor succeeds for the same reason all the rest of us succeed. Each patient carries his own doctor inside him. They come to us not knowing that truth. We are at our best when we give the doctor who resides within each patient a chance to go to work (p. 69).

#### 5.3.1d IMPLICATIONS:

P2 could almost have been repeating the above theory when she reflects "I think there's a way of healing myself. I really do. Doctor Hoffman says stop listening to other people. He said listen to yourself. You know that one has to start healing oneself and I think that much more and more these days. I've actually started looking at things completely differently". She has learnt the importance of co-operation, rather than having to rely on someone else entirely for her healing treatment. In fact, the alternative route was tried by all of the participants. It was once P8 had received kinesiology treatment that he started out on his journey of recovery. "And so I went and had some kinesiology and I felt much much better." In fact he has gone on to become trained in this healing process. He also uses homeopathic interventions and hypnotherapy, "I'm actually going next week for some hypnotherapy again, because that's what's helped me in the past to actually get me to a stage where I can study and focus and whatever". P1 says "in the second year I tried the alternative route. We did homeopathy with two different homeopaths – no success with all the little powders. Acupuncture – I went to an acupuncturist in Plumstead. Reflexology was excruciating – for me everything in my feet was just exceedingly sore". She also tried diets and all of these she has discarded unlike P2 who was able to see through the pain she experienced in her treatment and allow it to take her into suppressed affect needing to be accessed. P1 would not allow such a journey. In the words of P2:

No. no if I hadn't met Dr H. I definitely – he changed an awful lot. But it was, in the beginning it was a lot of chaos because he brought up, I had deep tissue massage and that, and he brought a lot of uncomfortable

things and emotions started coming very much up front.

It is important to note that although all 10 participants tried alternative treatments of one sort or another, there was a distinct difference between the two groups' responses. P1 and P5 were only able to allow the treatments to be a physical experience (the pain in P1's feet, for instance, was not allowed to lead to the pain that lay within and needed to be brought into the conscious experience and faced). All of the others were willing to listen to their bodily responses and allow them to guide them into a place of co-operation with and understanding of buried affect. P4 gives this example. "There often is lots of forgiveness that needs to be going on. Um so the body alignment therapy's been very good. It, it's just brought things to life. You know little things that I've been aware of, but at the same time I haven't been".

I suggest that the reason the eight were able to move on into new understanding, sense of responsibility, and co-operation lies in their personal history and life experience that I shall address in the following section of this chapter. The provision of certain amenities and the sociocultural pattern of illness treatments are thus not the only influence shaping a person's response to an illness experience. It is suggested the influence of the personal lived experience of each person plays a crucial part in her/his ability to receive the enabling treatment offered and not remain stuck in a place of chronic impairment. The need to learn to understand themselves in new and richer ways – in fact to own the "doctor within" – was clearly expressed through the progress that these eight patients were able to make.

### 5.3.2 EXPERIENCE

What is it that enables some people to respond co-operatively to their illness experience? Why are some able to access "the doctor within"? And why do others seem to crumble or stay in their ill state? This section will address these

questions with a view to fleshing out an understanding of the responses made by our CFIDS patients to their illness. As was indicated in the literature review, the theoretical model I shall be working from is the Salutogenic Model (Antonovsky, 1990; Strümpfer, 1990). It grew out of the observation that against all odds, people continued to stay alive, get well and respond co-operatively to momentous life stressors:

Given the ubiquity of pathogens – microbiological, chemical, physical, psychological, social, and cultural - it seems to me self-evident that everyone should capitulate to this bombardment and constantly be dying (Antonovsky, 1979 in Strümpfer, 1990, p.267).

This led to Antonovsky asking the questions, "How anyone ever stays alive ... Whence the strength?" (Antonovsky, 1979 in Strümpfer, 1990). It is in answer to these questions that the salutogenic model came into being, and has become a well-received model by many in the healthcare professions as it is seen to complement the more established pathogenic model. These models are seen as being able to enrich each other, as Strümpfer explains it:

The benefits of the pathogenic approach are visible in all clinical fields and it is exceedingly important that research directed at the discovery of pathogens and the effects of stressors should continue... The salutogenic paradigm is vitally important to new insights and new growth in the social sciences; it holds promise for integration of knowledge at a new, higher level (1990, p.268).

It is important to gain an understanding of the two paradigms, and so there will be an overview of both in the next section. Following the overview the salutogenic understanding of how life's experiences shape people's dispositions towards illness and all types of stressors will be examined in more detail. Finally, a comparison with what has been discovered about the dispositional responses of the participants in the sample interviewed will be made.

### 5.3.2a OVERVIEW OF PARADIGMS

We begin by noting a basic contrast in their understandings of disease and illness. This echoes the dualistic vs mindbody approach we have been examining earlier on.

*Pathogenic* understanding claims that there is a clear dichotomy in that people are either well or diseased. *Salutogenic* understanding states that there is a "health ease/disease continuum" (Antonovsky 1987 in Strümpfer, 1990, p. 267). People are thus seen as mainly being somewhere between the two points of ease (totally well) or disease (terminally ill).

From these two bases the models move on to fundamental questions that need to be addressed. The pathogenic model asks why people become ill and what causes a particular illness to develop. It then asks how the disease can be combated and/or prevented. The salutogenic model questions why people maintain their health and where they get the strength to do so.

There is then the need to answer these questions, and thus the core of each model emerges. The pathogenic model answers that there is a multifactorial set of agencies inducing disease, and attempts to ascertain and then address their risk factors. An example of this is:

Type A behaviour pattern is viewed as a psychosocial risk factor for coronary heart disease, along with standard medical risk factors like elevated serum cholesterol, hypertension, and heavy cigarette smoking (Strümpfer, 1990, p. 266).

The task of the health practitioner would then be to work at reducing these risk factors in order to prevent the onset of the disease.

Disease is viewed as being abnormal and a disruption of the normal healthy state of homeostasis (constant condition or balance of entities functioning within the bodily system). It is pathogens and stressors that

disrupt this state of homeostasis, and unless they are controlled, the regulatory mechanisms of the system will not be able to function adequately and disease will result. It is thus important to do away with these pathogens and stressors as far as possible. In this model stressors are mainly viewed as harmful to our health.

The salutogenic model answers that stressors are omnipresent and therefore the human organism is, "prototypically being in a dynamic state of heterostatic disequilibrium" (Antonovsky,1987 in Strümpfer,1990, p.266). This understanding grew from observing overwhelming incidence of morbidity within a population via statistical analyses, so that it was valid to say that:

At any one time, at least one third and quite possibly a majority of the population of any modern industrial society is characterized by some morbid condition,... deviance, clinically or epidemiologically defined as "normal" (Antonovsky,1979 in Strümpfer,1990, p.266).

This means that the given is ubiquitous stressors resulting in majority illness prone, and the investigation becomes that of discovering why the deviant are able to resist this ill status. Following on from this we see that human life is essentially stressful. However, there are grades of intensity as introduced by Fried (1982) in Strümpfer, (1990). These are categorized as catastrophic stress which results from disasters and is population-wide; acute stress arising from crises or extreme stress in a particular area of life, and which people have a sense of urgency to overcome; finally there is endemic stress, "a condition of continuous and manifold changes, demands, threats, or deprivations, frequently small in scale and embedded in daily events" (Fried,1982 in Strümpfer, 1990, p. 266). However, instead of trying to eradicate stressors because they are viewed as harmful, the salutogenic model prefers to see stressors as neutral in their health consequences. It is a person's response to the stress that determines the consequences for health or illness, thus a stressor could

open the way for disease if not well handled, or it could either remain neutral or life enhancing when well handled (Strümpfer, 1990). We are urged then to ask the question together with Antonovsky, (1984b), "How can we learn to live, and live well, with stressors, and possibly even turn their existence to our advantage?" (in Strümpfer, 1990, p. 267).

In order to answer the above question it follows that we need to discover what it is that enables the deviants to do well, i.e. we need to discover how wellness functions. The understanding that the salutogenic protagonists have arrived at is that there is a certain dispositional response to stress that enables them to function at the wellness level more consistently than most. Right back in 1939 Goldstein, a neurophysician arrived at the conclusion that, "experiences with patients teach us that we have to assume only one drive, the drive to self-actualization" (in Strümpfer, 1990, p. 266). The salutogenic paradigm expresses the key component somewhat differently, and yet it points to much the same understanding. The disposition they have isolated is a Strong Sense of Coherence (SOC). We shall examine this concept in more detail in the next section.

### 5.3.2b STRONG SENSE OF COHERENCE (SOC):

SOC is formally defined as:

a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement (Antonovsky, 1987 In Antonovsky, 1990, p.160).

It can thus be seen that the SOC has three core components each of which will be examined:

*Comprehensibility* “refers to the extent to which the person perceives the stimuli from both within and without as clear, ordered, structured and consistent information”; a person with a strong SOC “(would) expect these stimuli to in the future continue to be orderable, explicable and even predictable”; a person with a weak SOC “would perceive these stimuli as inexplicable disorder and chaos, and as unpredictable in the future” (Strümpfer, 1990, p.268).

*Manageability* “refers to the extent to which a person perceives the events of his/her life as experiences that are, at least, bearable, or better still, can be coped with, or even better, challenges that can be met”; a person with a strong SOC would be aware of resources available, “under the person’s own control but also under the control of legitimate others who have the power to resolve matters in his/her interest, for instance, a spouse, relatives, friends, a physician, leaders, formal authorities, the trade union, the political party or God”. If they should perceive that no resources are readily available, they would choose to avoid the situation; the person with a weak SOC “would experience the events of life as unfortunate things that happen to her/him and victimize her/him unfairly” (p.268-269).

*Meaningfulness* “refers to the extent to which the person feels that life makes sense emotionally, rather than cognitively”; a person with a strong SOC “would feel at least some of the problems and demands of living as welcome challenges, motivating her/him to invest energy”; a person with a weak SOC “ would feel that nothing in life mattered much, or worse, it was full of unwelcome demands and wearisome burdens” (p.269).

It is important to note here that the model does not claim that the entire world would be comprehensible, manageable and meaningful – but only that part which lies within the boundaries that the individual has set her/himself. Anything outside such boundaries would hold no interest or threat.

SOC can therefore be viewed as a “dispositional orientation not a state or a trait” (Antonovsky, 1987 in Strümpfer, 1990, p. 268). This means that it is established as a result of learning a way of being in relation to life’s stress and strain. The understanding is that everyone, starting in early childhood, is exposed to a variety of life experiences. Those that have the potential to facilitate growth towards a strong SOC, are known as generalized resistance resources (GRRs). They cover a wide range and provide constant feedback for a person which enables her/him to become orientated within the lifeworld, and have a sense of integration there. In order to clarify exactly what these GRRs are seen to be, we will look at the range described by Antonovsky (1979):

- physical and biochemical GRRs, like immunosuppressors and potentiators;
- artefactual-material GRRs, particularly wealth, that can buy, for example, food and clothing or safe abortion for an unwanted pregnancy, but also power, status and services;
- cognitive GRRs, particularly knowledge-intelligence, contingent on education, which includes skills, but also knowledge, for example, about avoiding AIDS or carcinogens, or of one’s legal rights;
- the emotional GRR of ego identity;
- coping strategies, as overall plans of action for overcoming stressors;
- interpersonal-relational GRRs, like social support and commitment;
- and, lastly, the macrosociocultural GRRs, of ‘ready answers provided by one’s culture and its social structure’ which includes religion (in Strümpfer, 1990, p. 268).

The converse experiences would be seen as generalized resistance deficits (GRDs). These would be negative aspects, for instance, poverty, low self-esteem, low social class, cultural instability, and would provide contrary experiences to the GRRs (Antonovsky, 1990). The person having a resultant weak SOC would have a view of isolation in the lifeworld. It is the balance between the experiences of GRRs and GRDs, which will

determine outcome – the stressor itself is rarely a decisive factor in this regard.

When making the decision of what boundaries need to be set in a person's life, however, Antonovsky (1987) in Strümpfer, (1990) maintains:

There are four spheres that cannot be excluded if the person is to maintain a strong SOC, namely, his/her own feelings, immediate interpersonal relations, the major sphere of activity (work, really) and the existential issues of death, inevitable failures, shortcomings, conflict and isolation (p. 269).

Antonovsky (1987) in Strümpfer (1990) also states the importance of being able to be flexible with the boundaries that you set in your life areas. He claims that by being able, temporarily or permanently, to contract out of areas that are becoming more demanding and less and less comprehensible or manageable, you are more likely to maintain your level of coherence.

### 5.3.2c ILLNESS IMPLICATIONS:

It is obvious that no-one's SOC is an assured protection against ill health permanently, but when illness occurs, a person with a strong SOC will be able to respond co-operatively because of her/his inherent ability to discover comprehensibility, manageability and meaning within this situation. There will be no basic change in the level of her/his SOC. However, those who have relatively weak SOC will experience illness as yet another life stressor difficult to cope with. This reinforces the belief of life as incomprehensible, unmanageable and meaningless. The SOC level is once again weakened and the person experiences helplessness and a sense of victimisation (Antonovsky, 1990).

A person with a strong SOC also has more of a chance with coping with the inevitable tension, physiologically and emotionally, that goes along with all of life's stressors. A strong SOC mobilizes the person to cope with the demands posed on him/her by the stressor. When this coping is successful, the resultant gratification will cause a salutary release of the

physiological and emotional tension. The person will not become stressed. A person with a weak SOC is likely to be unsuccessful in coping with life stressors, and this means that the tension associated with such stressors will be maintained. This inevitably becomes transformed into stress (physiological and emotional), and this is a pathogenic state (Antonovsky, 1990).

Finally, because persons with a strong sense of manageability believe that they have all the resources they need available, they are wont to seek these out. They do not have to rely on their own ability, and readily turn to whichever source of help is suitable. They have no fixed method of coping and are able to respond flexibly to stressors. They seek out feedback and are willing to modify their behaviour accordingly. Where they are not able to tap adequate resources to enable them to cope, they choose to avoid the stressful situation. They are in fact, working co-operatively with their illness. However, a person with a weak SOC, having no sense of resources available, tends to be unable to act co-operatively and is afraid to make modifications (Antonovsky, 1990).

#### 5.3.2d CFIDS IMPLICATIONS:

P1 and P5 have a history stemming from their childhood, where they were unable to develop adequate resources to deal honestly with their emotions and their immediate interpersonal relations were superficial. P5, for instance, remembers her childhood family as completely devoid of intimacy. "I would say we were termed a very loving family. But there was no love. There was no communication. We were all looked after and we had everything we wanted materially, but it never went deeper". When I asked her how she and her siblings expressed anger or pain she said "I never expressed it." And there were no fighting or emotional outbursts from her siblings either. "We were wonderful children". In response to the question of talking intimately with her parents and siblings she said, "Nothing, never". From their formative years they had learned to fend for themselves and, unable to work through existential issues of failure,

conflict and isolation, had established a pattern of seeking distraction from these in their social and work contexts. P1 tells how "Friends have always been the most important thing in life. I left varsity in the middle of my final year because I turned 21, and my mother said I had to stay home until I was 21. I wanted to escape from home, they were very strict my parents, Irish Catholics". When she fell pregnant out of wedlock her mother told her that "I had broken my father's heart. He could, he'd never be able to speak to me again, so they didn't speak to me for four years. Since I had Sean and I wasn't married and I got this illness, you know I'm an embarrassment to the family. So I've actually, the battle with the family has been horrible". P1 and P5 have developed a self-reliant stance in life as P1 says, "I'm the strongest person I know. In fact I don't know anyone who could have lived with these and still be open and chatty and whatever". They have not learned to trust in any outside help and have thus developed a weak SOC. Their experience as adults of an abusive husband (P5), and abandonment by two significant others (P1) exacerbated their choice of self-reliance. Antonovsky explains how this type of choice leads to the development of a low SOC:

The person with a strong sense of mastery or an internal locus of control will consistently tend to avoid turning to others and will persist in seeking to control the situation (1990, p.162).

When they were unable to keep going successfully in their work and social contexts, they seemed to have lost their sense of identity and given up. Because their method of coping was rigid – social and work competency and involvement – they are unable to become flexible in their response to their CFIDS experience, and choose to keep waiting for a cure that will dispel their physical isolation and enable them once again to take up control and be acknowledged as important and successful in these contexts.

The other eight participants had developed, to a lesser or greater degree, sufficient flexibility and trust in their coping resources, so that they were

able to turn to others for feedback enabling them to modify their behaviour patterns, both physically and emotionally. They were therefore able to make progress towards an overall new life experience. They were able to respond with a sense of comprehensibility, manageability and meaningfulness to their illness experience and the changes that it demanded from them. P2 is a good example of this. Her start in life was very dysfunctional (physical and sexual abuse) culminating in her removal from home at the age of 10 by the local authorities. She was placed in a couple of state children's homes where they had the system of house parenting. "The last one I was in the people were incredible. You know they actually treated me like their own child, they had a daughter of my age and we were the best of friends. And you know we both got married on the same day". This experience of being helped and loved enabled her to learn trust. "I passed my 11+ in England, and I played chess for my school. You know everything was ok. Um and I had a normal teens. I loved school". She visited her parents during school holidays only and found "things were much better when I went home, because obviously they'd been spoken to. So they, you know it wasn't so bad at all". She was experiencing the reality of outside facilitation enabling her to overcome the stress of her first ten years of life. She was learning that she could draw on others for support and that she could trust this support. She went on to become a children's nanny where again she experienced warmth and acceptance. When I asked her how she got on with the people she worked with she said, "yes very well. Very well, in fact I'm still in contact with some of them". Her marital relationship has been fulfilling and happy lasting 33 years to date and she has loving relationships with her two adult children. Throughout her illness she received support from them all. So when her illness hit her, she was able to look for coping resources outside of herself as well as try to learn from the experience.

Sometime after I had the illness, I actually suddenly thought one day when I was very, very angry and very upset, I actually suddenly, it suddenly dawned on me that maybe what the reason – the reason I got this illness is because uh – God wanted me to listen and slow down.

I don't know. I just thought, that was sometime into the illness and I hadn't slowed down you see and I'd got worse and worse and worse. And I think maybe if I'd slowed down and listened to God at the beginning I'd have got better much sooner.

She embarked on meditation at a Buddhist centre as well as learnt to practise guided visualisation from a tape made for her by her psychologist. Because of her Christian background she decided to move into a Christian Centering Prayer group. "I think it keeps one very much in touch with God more than the Church even does. I find it more spiritual. You know it helps one on one's path through life". Obviously her GRR experience had been adequate enough to establish a good SOC thus enabling her not to stay victim to her ill health, but grow into a new experience of meaningful living. In fact she says "I wish I had had all the knowledge I have now, in my middle 30's. It would have been very, very good. Very, very good".

The basic difference between the two groups was that in the four crucial areas of SOC development (mentioned above) from childhood onwards, P1 and P5 had experienced inadequate GRRs resulting in weak SOC levels, whereas the others had experienced sufficient GRRs to establish them in a stronger SOC thus enabling them to take hold of a way forward in their illness experience.

As has been noted, together with the flexibility of coping patterns, the flexibility of life areas that a person establishes adds to the coping abilities. It was this very inflexibility in their life boundaries (only successful work and social interaction being valued) displayed by P1 and P2 that prevented them from making meaningful adjustments to their life experience. They were unable to move into a new place, but saw themselves as waiting for life to come back to them.

There is certainly no doubt that life experiences play a major part in the shaping of a person's disposition towards life's stressors and illness more specifically. As Antonovsky(1984b) in Strümpfer states:

Resistance resources, whether generalized or specific, are only potentially available: it is up to the person to actuate them in combating and overcoming pathogens and stressors.

Regardless of differences in the availability of resources, people differ in the extent to which they kinetically transform potential into actuality. What makes the difference is the strength of the SOC; people with a stronger SOC are more likely to show a 'readiness and willingness to exploit the resources that they have at their potential disposal' (1990, p.269).

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## CHAPTER 6

### MIND-BODY MEDICINE

“Like information, then, the emotions travel between the two realms of mind and body, as the peptides and their receptors in the physical realm, and as the feelings we experience and call emotions in the nonmaterial realm.

Information! It is the missing piece that allows us to transcend the body-mind split of the Cartesian view, because by definition, information belongs to neither mind nor body, although it touches both” (Pert, 1999, p. 261).

In this section we will be examining the theory of psychoneuroimmunology (PNI), seeing how it explains psychosomatic medicine. It offers a very clear connection between the medical and lifeworld models in that it explores the interdependence of the physiological processes and the feeling/perceiving reality derived from lifeworld experiences. We will also examine the growing field of energy medicine, another important link in the mindbody theory of healing. Consideration of the way in which these theories shed light on the illness experiences of the CFIDS patients in this research will conclude the chapter.

#### 6.1 PNI

It is important to review the structure and functioning of the Immune System as a basis from which to proceed onto a discussion of PNI. By the mid 1960s medical science had established that there were three autonomous systems within the body – Central Nervous System, Endocrinal System and Immune System. Each of these systems was understood to work independently of the other, specializing in a particular function. The Immune System was seen to be the body’s defense against potentially harmful substances leading to disease - bacteria, viruses, fungi or neoplasms – (Booth, 1990; Pert, 1999). It is thus seen as important that the immune system be kept optimally functional. It has become common practice

that many diseases are explained by inadequate immune functioning. The immunity process is summarized as follows:

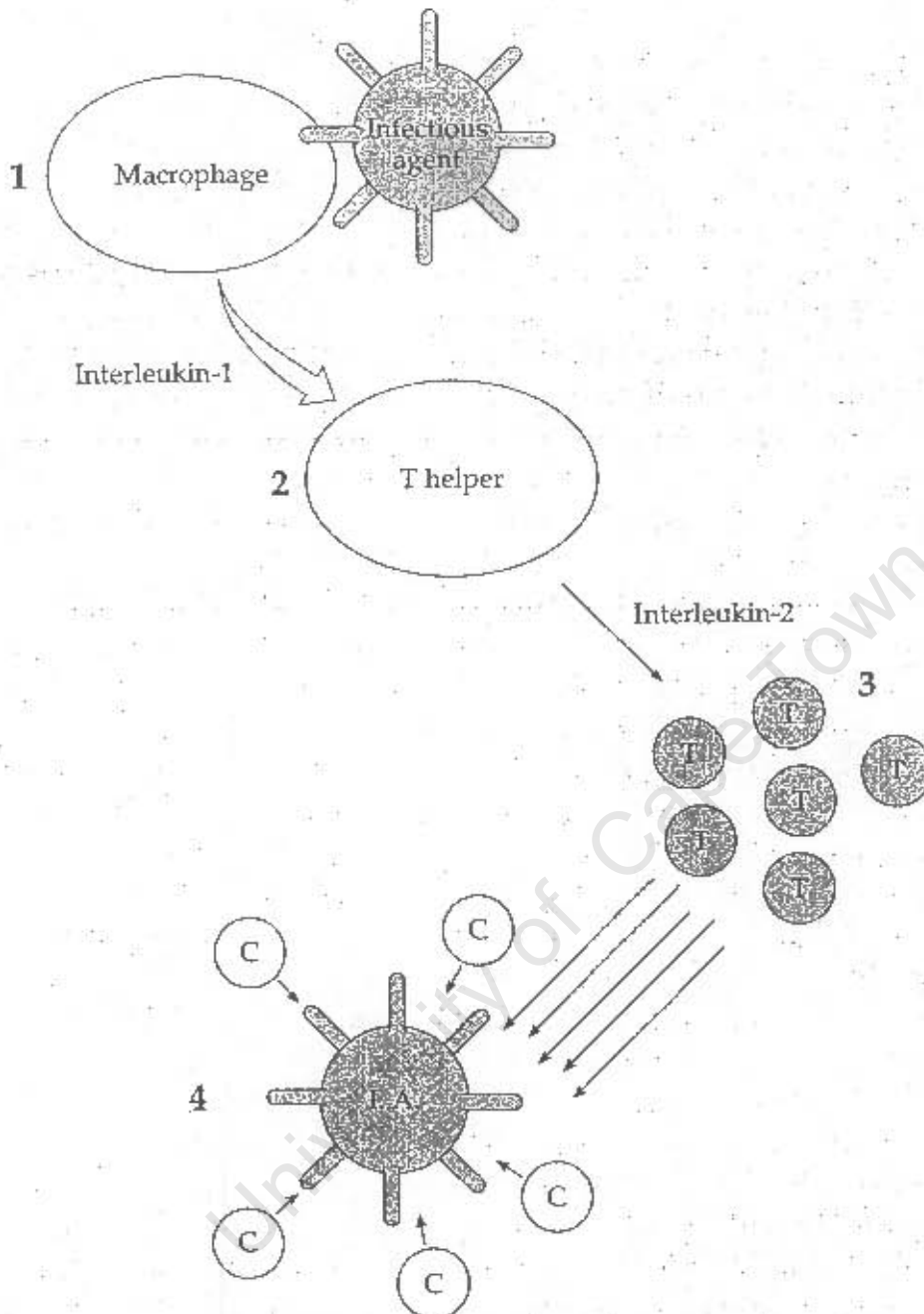
- (1) Disease is an unnatural state which must be fought or resisted.
- (2) Diseases are caused by infectious agents, genetic factors and /or environmental conditions.
- (3) The role of the immune system is defence.
- (4) The immune system discriminates between foreign material and normal constituents of the body (nonself as opposed to self) and destroys or disposes of foreign invaders.
- (5) The healthy state is maintained through a continuous battle between the immune defences which protect the body, and foreign material attempting to overwhelm it.
- (6) The immune system is autonomous and essentially self regulating.
- (7) At the extremes of life the immune system is unable to fulfil its function adequately (Booth, 1990, p.314).

How, then, does the immune system operate? Sapolsky (1994) has expressed the two basic modus operandi in very effective diagrammatic form which needs no further commentary. <sup>13</sup>

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<sup>13</sup> See Figures 4 & 5.

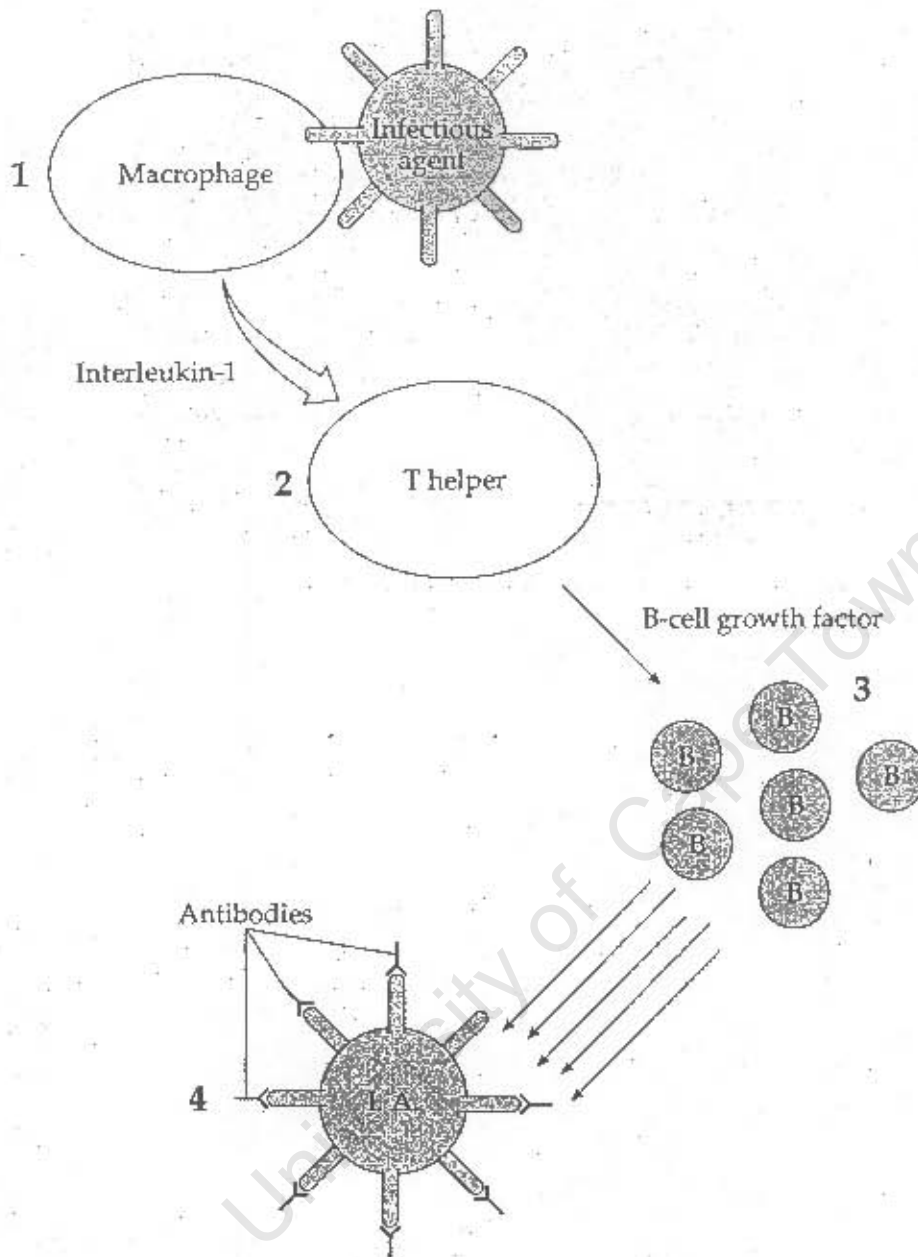
FIGURE 4



*The cascade of cell-mediated immunity. (1) An infectious agent is encountered by a type of monocyte called a macrophage. (2) This stimulates the macrophage to present the infectious agent to a T helper cell (a type of white blood cell) and to release interleukin-1 (IL-1), which stimulates T helper cell activity. (3) The T helper cell, as a result, releases interleukin-2 (IL-2), which triggers T-cell proliferation. (4) This eventually causes another type of white blood cell, cytotoxic killer cells, to proliferate and destroy the infectious agent.*

( Sapolsky, 1994, p.135)

FIGURE 5



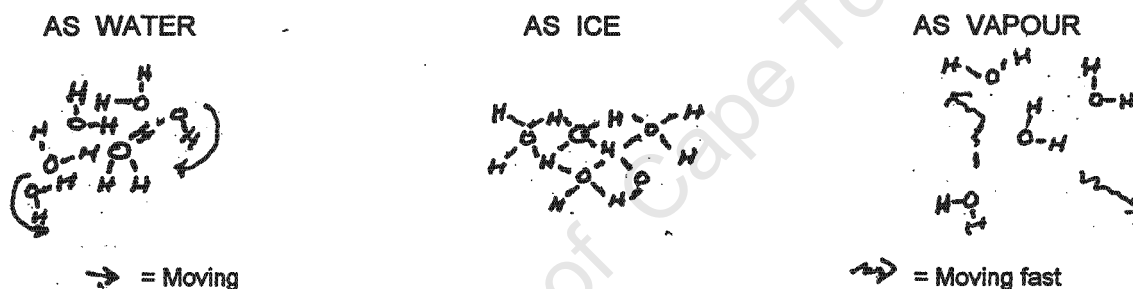
*The cascade of antibody-mediated immunity. (1) An infectious agent is encountered by a macrophage. (2) This encounter stimulates it to present the infectious agent to a T helper cell and to release interleukin-1 (IL-1), which stimulates T helper cell activity. (3) The T helper cell then secretes B-cell growth factor, triggering differentiation and proliferation of another white blood cell, B cells. (4) The B cells make and release specific antibodies that bind to surface proteins on the infectious agent, targeting it for destruction by a large group of circulating proteins known as complement.*

( Sapolsky, 1994, p. 137)

It is also necessary to understand how communication within the systems of the body takes place. To explain this process I will be drawing exclusively from Pert (1999). The basic building blocks of all matter are known as molecules, and a very clear definition is given by Pert. "A molecule is the tiniest possible piece of a substance that can still be identified as that substance. Each and every molecule of any given substance is composed of the smallest units of matter – atoms such as carbon and hydrogen and nitrogen – which are bonded together in a configuration specific to that substance, which can be expressed as a chemical formula, or, more informatively, drawn as a diagram:

FIGURE 6

MOLECULES OF WATER DIAGRAMMED:



(Pert, 1999, p. 22).

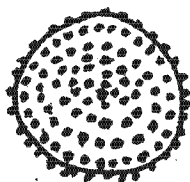
At the start of the 20<sup>th</sup> century, pharmacologists maintained that for drugs to act on the body they had to have something of the body to which they could be attached and so released into the system. They gave this something the name *receptor*, but it was merely a hypothetical supposition at that stage. Today their theory has been confirmed and the receptor has been isolated as a single molecule and perhaps, the most complicated type of molecule there is. The receptor is made up of tiny amino acids strung together in chainlike fashion. A typical neuron (nerve cell) may have millions of receptors on its surface. Molecular biologists are now able to isolate, weigh and crack the chemical structure of these receptors, and have been able to diagram each specific

receptor they have been able to sequence. The basic function of a receptor is that of scanning or sensing in much the same way as eyes, ears and nose but only on a cellular level. These protein receptors remain in the cellular membranes, vibrating whilst they await the arrival of a matching vibrating chemical organism known as a *ligand* to diffuse through the fluids surrounding the cell. The receptor has a particular shape (cf a lock) and this can only be penetrated by a matching shaped ligand (cf a key). Once there has been a successful connection, termed *binding*, the information being carried can enter the cell:

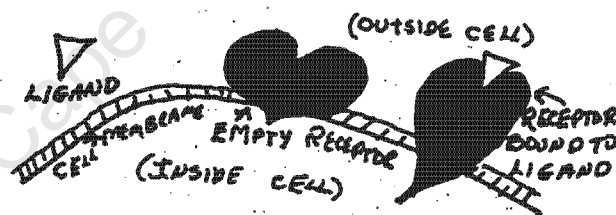
## FIGURE 7

### BINDING PROCESS DIAGRAMMED:

CELL FROM ABOVE STUDDED WITH  
MANY RECEPTORS



CLOSE UP OF EDGE OF CELL



(Pert, 1999, p. 23)

"The process of binding is very selective, very specific! In fact, we can say that binding occurs as a result of *receptor specificity*, meaning the receptor ignores all but the particular ligand that's made to fit it. ...It is this specificity of the receptors that allows for a complex system of organization and ensures that everything gets to where it's supposed to be going" (Pert, 1999, p. 24-25).

Ligands are generally much smaller molecules than the receptors, and there are three chemical types. The first is known as a *neurotransmitter*. These are the smallest and simplest molecules and they carry information between one neuron and the next. The second type are *steroids* and include the sex hormones testosterone, progesterone and estrogen. The third category is the largest of all, constituting 95% of all ligands. It is also the category that relates specifically to the immune functioning and these ligands are known as the *peptides*. These

chemicals regulate practically all life processes. To summarise the process thus far Pert refers to the following concept: "If the cell is the engine that drives all life, then the receptors are the buttons on the control panel of that engine, and a specific peptide (or other kind of ligand) is the finger that pushes that button and gets things started" (Pert, 1999, p.25).

It is important at this point to trace briefly the history of peptide discovery because these peptides are central to the development of PNL as it is currently understood. The first peptide was discovered at the turn of the 20<sup>th</sup> century, but was then classified as a hormone. It revealed the ability to stimulate the secretion of pancreatic juices and so was given the name secretin. This discovery was astonishing to physiologists of that day who had believed that all physiological functions were controlled by electrical impulses from the nerves. A second peptide was isolated a few years later, also in the gastrointestinal area, and its function was to carry messages from the pancreas to the gall bladder. It was named gastrin. In the early 1950's oxytocin was seen to contract the uterus in labour and also produce the uterine contractions of sexual orgasm in females. It was also seen to act in the brain to produce maternal behaviour as well as enable certain male rodents to establish long-term monogamous relationships. This led to the observation of the unifying function of peptides, "coordinating physiology, behaviour, and emotion toward what seems to be a coherent, meaningful end, very characteristic of humans and animals" (Pert, 1999, p.68). An offshoot of this discovery was a milestone accomplishment in 1953 when a synthetic form of oxytocin was made. This is currently used by doctors when they decide that the speed of labour needs to be induced in order to ensure the safety of mother and child. A revolution in the form of synthetic peptide production was thus ushered in. One of the most far-reaching discoveries was that the endogenous substance that had been isolated as key to the body's opiate receptor, was found to be a peptide. It was produced in the brain and the receptor was also located in the brain. This indicated that experiences of local bodily pain relief were mediated by the brain. The question then arose whether this phenomenon was in fact common to all types of peptides. Thus a new investigation of the way the peptides interacted within the brain to bring about

many of the body's internal processes had begun. Currently, the observations have resulted in the discovery that neuropeptides are made in many parts of the body – including the brain. For example the same peptides binding to kidney receptors in order to change blood pressure are also able to operate receptors in the lung and the brain. All this led to Pert and her colleagues researching the assumption that “any peptide ever found anywhere, at any time, was potentially a neuropeptide, with receptors in the brain...we found that peptides existed in all parts of the brain, not only in the hypothalamus, where endocrinologists had classically predicted they would be confined” (Pert, 1999, pp. 71-72). And so the distribution of peptides throughout the nervous system was established. Currently, it has been established that peptides are distributed in the gastrointestinal tract in addition to the nervous and immune systems. “Thus, intercellular communication throughout networks of neuropeptide-rich nodes which extend from the brain to the endocrine and immune system, integrate the internal milieu of the whole organism” (Pert *et.al.*, 1985, p.823s). The stage had now been set for the step into formulating the theory of PNI.

The basic premise of PNI is that the peptides form a *network of communication* throughout the body. (Booth, 1990; Neimark, 1997; Pert *et.al.*, 1985; Pert, 1999).

This implies that:

The three classically separated areas of neuroscience, endocrinology, and immunology, with their various organs – the brain; the glands; and the spleen, bone marrow, and lymph nodes – are actually joined to each other in a multidirectional network of communication, linked by information carriers known as neuropeptides (Pert, 1999, p. 184).

Darwin (1872) in Pert *et.al.*(1985) believed that a physiological basis of emotions would be understood because of their invariance and identifiability in all peoples as well as in other primates. A concentration of neuropeptide receptor distribution has been identified in the mood-regulating areas of the brain. This, together with their role of networking communication throughout the whole organism, makes neuropeptides an obvious candidate for a physiological, biochemical mediator of emotion (Pert *et.al.*, 1985).

Darwin also surmised that because of this universality of emotions, they must be the key to the survival of the fittest (Pert, 1999). This would suggest the paramount importance of well-regulated and controllable emotional content within each human being. It seems pertinent to clarify what PNI means when using the term emotion:

(This) includes not only the familiar human experiences of anger, fear, and sadness, as well as joy, contentment, and courage, but also basic sensations such as pleasure and pain, as well as the "drive states" studied by the experimental psychologists, such as hunger and thirst. In addition to measurable and observable states I also refer to an assortment of other intangible, subjective experiences that are probably unique to humans, such as spiritual inspiration, awe, bliss, and other states of consciousness that we all have experienced but have been, up until now, physiologically unexplained (Pert, 1999, pp. 131-132).

It thus becomes important to answer the question of how significant psychoneuroimmune interactions are to the immune system functioning, and the health and well-being of each individual. Much research has shown that changes occur within the immune system when subjected to stressors and that, depending on their seriousness, affect disease processes (Booth, 1990; Pert, 1999). For example, a one-year prospective study of 40 medical students conducted by Glaser *et al.* (1987) in Booth (1990), revealed a strong relationship between examination stress, increased incidence of illness, and depression of certain immunological measures. The important factor was that, although all the students were undergoing the same examination stress, they showed different perceptions of stress level. Those who perceived the situation to be extremely stressful showed a much greater association with illness and altered immune measurements. This indicates that it is not the stress *per se* which causes harmful change, but the person's attitude or disposition towards such events (cf the concept of SOC in the previous chapter). Braun (1983) in Booth (1990) found that the psychological disorder multiple personalities influenced the patient's

immune responsiveness. One personality manifested severe allergic symptoms, and these disappeared entirely when the other personality was present. So PNI has "added another dimension to our understanding by revealing the important controlling influence on immune responsiveness of what we believe and feel" (Booth, 1990, p. 315).

Another way of expressing this theory has been used: "Every change in the physiological state is accompanied by an appropriate change in the mental and emotional state, conscious or unconscious, and conversely, every change in the mental emotional state, conscious or unconscious, is accompanied by an appropriate change in the physiological state" (Elmer Green in Pert, 1999, p.137). A concrete example of this process is to be seen in the practice of breath training – for instance mothers in labour using the Lamaze breathing technique, have been able to control their pain levels (Pert, 1999). The physiological process that is taking place is that the person is able to plug into his/her periaqueductal gray<sup>14</sup> with conscious intention and so able to reframe the pain threshold. It is possible to access the PNI communication network from any nodal point and quickly get to another nodal point. "All locations are equal as far as the potential to 'rule' or direct the flow of information" (Pert, 1999, p.186). There is much data to substantiate the belief that the rate and depth of breathing produces both quantitative and qualitative changes in peptides released from the brain stem and vice versa (Pert, 1999).

This means that you can cause "peptides to diffuse rapidly throughout the cerebrospinal fluid, in an attempt to restore homeostasis, the body's feedback mechanism for restoring and maintaining balance" (Pert, 1999, pp.186-187). Many of these peptides are the body's natural opiates amongst other pain-relieving substances, and so it is possible to achieve a diminution of pain. There are many modalities of meditation that are used to gain such mastery over breathing, (in the following section of this chapter the mindfulness meditation technique will be examined). We could thus say "that mind doesn't dominate

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<sup>14</sup> "A brain-stem region of neurons and fibres surrounding the aqueduct at the top of the spinal cord in the brain stem. Functionally it serves as a nodal point, enriched in peptide receptors, and processes ascending sensory information arriving to the brain from the extremities. As such it is an early way station by which pain and other perceptual thresholds may be regulated" (Pert, 1999, pp351-352).

body, it *becomes* body – body and mind are one” (Pert, 1999, p.187). Once again, the concept of mindbody is arrived at. This also leads to the theory that “emotional memory is stored throughout the body” (Pert in Neimark, 1997, p.73). In addition, “Since emotional expression is always tied to a specific flow of peptides in the body, the chronic suppression of emotions results in a massive disturbance of the psychosomatic network” (Pert, 1999, p. 192). All these concepts underline the inadequacy of the Cartesian dualistic model of illness and disease and dovetail exactly with the new understanding of integration of bodymind and therefore of the need to approach the treatment of disease from a holistic and co-operative stance. I will end this section with Roger Booth’s proposal of a PNI model of disease:

Instead of disease being seen as an unnatural state which must be fought, it could be considered as a source of information about the dynamic process of our existence and an opportunity for adaptation, evolution and transformation. In such a model, disease is promoted by disconnection, disorientation, alienation or separation, and health depends on maintenance of optimal connectedness or coherence within and among all levels of a person and his or her environment. It may make more sense then, to consider the information content or meaning of disease rather than seeking its cause or mechanism (Booth, 1990, p. 315).

This comparatively new PNI understanding of how well-being can best be attained, has spawned much of the recent research into stress-related impact on the course of CFIDS.

## 6.2 IMPLICATIONS:

Booth’s concept stated above of the importance of “connectedness or coherence within and among all levels of a person and his or her environment” (1990, p.315) is borne out by the pattern of recovery that was experienced by the eight patients in the sample. I will take P10 as an example. She became ill with CFIDS at the peak of her career as a diet therapist and lecturer at the local university. She had

a thriving practice and a small child back home. Her husband complained about the intensity of her work involvement – clients calling her at all hours – and she began to feel the strain of this lifestyle and a failing marital relationship. This was expressed in her body by extreme fatigue and arthritis. After a bad dose of flu, she failed to recover and experienced the acute symptoms associated with CFIDS. She was put in hospital for tests and was diagnosed with the illness. She was sent for psychotherapy and put onto a course of pain killers, antidepressants and sleep therapy. She was also instructed to close her practice. At first she fought the medical treatment but says, “I just realized that I couldn’t cope really, I needed, I needed something to help me”. Gradually the intensity of the pain subsided, but she was left cognitively impaired, physically weak and dizzy, and unable to resume her old lifestyle. After a move to a new town where her relationship with her husband became unbearable because of his refusal to recognize that she was ill, she left her home and went to stay with her parents. Here the pattern of caring for the body and being aware of the environmental needs was established. All this time she was in psychotherapy as well and was working with her inner truths. She expresses this part of her journey into recovery:

Um and I mean I was devastated, uh I think I cried for a week. This was the end of it all, this perfect picture of who I was and what I had achieved and everything. I mean I was now on my way to divorce and ja staying with my folk, I was totally now dependent. But it was real, and you know, I think it had been unreal there, and this at least was real. And I started to realize I had suppressed so much. I tended to, to anything that was not nice must just go away, and I must always be nice. Uh so I just realized ok, so with the psychotherapist, it really challenged me to just deal with reality. For the first time in my life, not being the perfect child, the perfect daughter, the perfect dietician. I was not and that was ok.

Her environment also played the part needed to facilitate her on this self-discovery and allowing her body to inform her activity levels as her parents “just took me as I was, and totally loved and cared, and were fantastic. I couldn’t have wanted more, more, you know more wonderful parents”. This pattern of becoming connected continued and eventually there was a reconciliation with her

husband and she returned home – but to a new home where her husband allowed her to be ill and unable to work for the extra income, wanting her just to get better. “This was the turning point of my illness, because I had that support. I could just love him and love my child and potter around, and manage to do just the daily things. And my pain gradually dissipated”. A year later she began to work again, but this time at a different pace and with a different attitude. “I was very real to everybody. All the people who met me just knew who I was. And if I battled in a day I didn’t pretend it was alright. And that was refreshing – to be just me”. As her body became less exhausted she was encouraged to do some exercise, and she went back to ballet just to have fun – dancing with a standard 6 group, and doing only as much as her body would allow. “And I think this was one of the major factors in me getting better. Because it brought me so much joy, it was mine, uh my time.” Her muscles began to strengthen and her sleep improved so that she was eventually able to come off all her medication. This ability and willingness that P10 displayed to consider and attend to the information she was receiving from her mindbody, enabled the restructuring of her entire being into a new place of health and a new lifestyle. This certainly confirms the suggestion from Booth in his illness model above, that illness could be “considered as a source of information about the dynamic process of our existence and an opportunity for adaptation, evolution and transformation” (1990, p. 315). Most certainly P10 experienced a newness and a transformation in every area of her existence, and now lives her life fully but differently.

However, there is also the area of alternative healing practices, alluded to in the previous chapter that features in the health-seeking surrounding CFIDS. The theory behind these practices will be addressed under the broad term of Energy Medicine in the following section of this chapter.

### 6.3 ENERGY MEDICINE

Although this form of medicine says much the same about the course of disease as does PN, it is grounded in ancient medical practices and belief from Chinese medicine through indigenous shamanic practices to folk and alternative

therapies. The methods and particular paradigms adhered to may be legion, but they are all based on the understanding of energy systems in the human organism. In order to focus more effectively on the concept of energy systems,

this thesis will examine the theory behind the practice of two energy practitioners who work closely with the medical profession in the area of chronic illness. They have much to say that elucidates why this form of healing practice is being increasingly sought out by patients – the sample of CFIDS patients under investigation in this research most particularly.

Dr Caroline Myss has been working as a medical intuitive for many years in close association with her medical colleague, Dr Norman Shealy, a neurosurgeon and leading American expert on pain management (Myss, 1998). She explains that the goal of the medical intuitive is to work co-operatively with the body's intention to promote its own health by noticing energy fluctuations that point to imbalance or disease within a person. The energy fluctuation is seen to be a 'message' from the body attempting to bring unhealthy habits of mental or emotional dimension into consciousness. They can then be dealt with and changed and thus the source of the disease formation will be eradicated. The process of intuiting the meaning of the energy pattern presenting itself is arrived at through picking up on childhood experiences, superstitions, personal habits, behaviour patterns, moral beliefs, preferences in literature and music, and also from symbolic impressions. Myss claims that, "our cell tissues hold the vibrational patterns of our attitudes, our belief systems, and the presence or absence of an exquisite energy frequency or 'grace' that we can activate by calling back our spirits from negative attachments" (Myss, 1998, pp.25-26).

There are three basic principles that are adhered to:

The first is *biography becomes biology*. The understanding here is that every facet of our histories – events, relationships – is recorded in bodily cells. This is so much the case that biological health is a statement of personal biography as it has impacted within the person. In other words emotional energy converts into biological matter, and this happens through a clearly defined process. Each

organ and system of the body is calibrated to receive/transmit specific emotional and psychological energies on detailed frequencies (cf PNI). Health results when these function "in tune". Discord in the particular areas that are not functioning properly will indicate illness and the location of the problem. The human energy field is compiled of positive and negative emotional frequencies, the intensities of which indicate change in the progress of an illness. The frequencies influence the physical tissues of the body, forming a bank of life-experiences. They are encoded in the biological systems and influence the cell tissue formation which then generates a congruent quality of energy. The energy patterns are understood as a 'readable' energy language and form a 'memory' in cell tissue and the energy field. Memory storage is an ongoing, daily process and when there is disorder of energy, symptoms of continual/chronic exhaustion or depression arise.

Illnesses develop as a consequence of behavioral patterns and attitudes that we do not realize are biologically toxic until they have already become so. Only when illness forces us to review our attitudes do we come close to comprehending that our day-to-day fearful or bitter attitudes are, in fact, biologically negative substances (Pert, 1998, p.43).

The second principle is *personal power is necessary for health*. Here the human energy system is conceived of as an expression of personal power, thus for energy medicine to be effective the patient must have an awareness of internal power. This is the ability to draw on inner resources of energy which arise from a sense of self-esteem and a belief in the ability to work with and through the situation. Personal power awareness is seen to be developed in a specific pattern. (a) *Revolution* which entails separation from group thought and the recognition of the need to establish a personal code. (b) *Involution* is finding answers to questions such as, 'What else do I think? What is my core desire?' The answers to these will lead to making new choices and expressing new behaviour patterns. (c) *Narcissism* which is seen as the stage of giving self a new image. A new pride in personal appearance is one of the traits of this stage. Here the energy present gives strength to re-create the self and set new boundaries in

order to live more realistically within energy parameters. (d) *Evolution* is when a sense of internal integrity guards the energy flow. The external environments tend to yield to its force.

"Power is at the root of the human experience. Our attitudes and belief patterns, whether positive or negative, are all extensions of how we define, use, or do not use power. Not one of us is free from power issues. Our relationship to power is at the core of our health" (Myss, 1998, p.45). It follows, then, that it is important to become conscious of what fosters a sense of power in order to live co-operatively with the body and its functionings.

Thirdly, *you alone can help yourself heal*. A strong distinction between curing and healing is made here. Being cured implies a passive role of patient being fixed by the healer, "A 'cure' occurs when one has successfully controlled or abated the physical progress of an illness. Curing a physical illness, however, does not necessarily mean that the emotional and psychological stresses that were a part of the illness were also alleviated. In this case it is highly possible, and often probable, that an illness will recur" (Pert, 1998, p.48). Contrastingly, healing is understood to be an active co-operation. The patient reviews his/her attitudes, beliefs and memories in order to release all negative energy patterning thus making way for emotional and psychological healing to take place. It also encourages the patient to choose to recreate the way s/he uses her/his energies and so cultivate love, self-esteem and health.

It seems appropriate here to illustrate the theory that has been examined in an example of a patient's experience. A young woman named Kate, recently widowed, presented with extreme exhaustion and the resultant feeling that she could not go on living. During the course of the interview an ovarian cyst was diagnosed, and Dr Myss encouraged Kate to go for a physical check up with her physician. In addition to this Kate was asked to embark on a small task that would symbolize her intention to rebuild her shattered life. "She was to visualize that task as bringing new energy into her life. That she would have a growth in her ovarian area was not surprising, because not only had she lost her mate, she had lost a way of life and was now confronting her ability to survive physically

and financially” (Pert, 1998, p.136). Kate chose to do gardening and plant new flowers as a symbol of new life, and told herself with each flower she planted that this planting was the planting of a new life for herself and her children. She chose to consciously keep her energy in the present moment and not dwell on the life she had lost. The doctor confirmed that she had a benign cyst that would have to be removed sometime. This encouraged her to transform the weeding process into a symbolic action of pulling the cyst out of her body. After six weeks she began to have ideas for generating income in the form of sewing and took on a job making costumes for a local theatre production. She saw ways to improve on the design of the costumes. She implemented these changes and the costumes were a great success. This led to more work with theatre productions as well as requests for personal design work. All this resulted in her having opened her own design shop and receiving a plentiful income. In addition, at a later check up with her doctor the cyst had disappeared.

Kate’s story illustrates how creative energy can propel us along paths that we may never have anticipated and enhance the power of our positive choices. A creative idea has its own energy field and can generate the synchronistic involvement of people and circumstances required to carry the idea through to the next stage of life (Pert, 1998, p.137).

Jon Kabat-Zinn practises his form of energy medicine with patients sent to him by doctors at the University of Massachusetts Medical Centre. He uses mindfulness form of meditation to reduce stress and help patients cope with anxiety, pain and illness. His programme is based on the principles of *wholeness* and *connectedness* and their importance for medicine and health care. He also draws heavily on the PN1 understanding of well-being, but it is not necessary to include this principle as it would be inappropriate repetition.

“The choice of meditation training as the central and unifying practice in the stress clinic was not arbitrary. Meditation training has unique characteristics that distinguish it from the many relaxation and stress reduction techniques in common use, The most important is that it is a door into direct experience of

wholeness, experiences not so easily tapped and deepened by methods that focus on doing and getting somewhere rather than non-doing and being” (Kabat-Zinn, 1996, p. 164). Meditation is *consciousness discipline*. From this perspective the ordinary state of consciousness is seen to be suboptimal. This discipline of consciousness believes that it is essential for a person to develop meditation practice so that s/he can be freed from the distortions of emotional and thought processes that undermine the experience of intrinsic wholeness. The stress clinic uses the writing of Einstein as a basis for expanding the understanding of this intrinsic wholeness:

A human being is part of the whole, called by us “Universe,” a part limited in time and space. He experiences himself his thoughts and feelings as something separated from the rest – a kind of optical delusion of his consciousness. This delusion is a kind of prison for us, restricting us to our personal desires and to affection for a few persons nearest to us. Our task must be to free ourselves from this prison by widening our circle of compassion to embrace all living creatures and the whole nature in its beauty. Nobody is able to achieve this completely, but the striving for such an achievement is in itself a part of the liberation, and a foundation for inner security (Einstein, 1972 in Kabat-Zinn, 1996, p.165).

From this we can extrapolate some of the understandings which underpin the clinic’s basic motivation. Firstly, wholeness is seen as more fundamental than separateness. The experience of separation and isolation is an imprisoning delusion. Secondly, if we neglect the perspective of wholeness and connectedness we have a truncated experience of being alive. Thirdly, it takes a discipline to cultivate compassion for all life, and this leads to healing – freedom and inner security.

“When we use the word healing to describe the experience of people in the stress clinic, what we mean above all is that they are undergoing a profound transformation of view. This transformation of view creates an entirely different context within which we can see and work with our problems. It is a perceptual

shift away from fragmentation and isolation toward wholeness and connectedness. With this comes a shift from feeling out of control and beyond help to a sense of the possible, a sense of acceptance and inner peace and control" (Kabat-Zinn, 1996, p. 168). This understanding of healing thus offers the exploration of a way of living and paying attention that is like starting afresh, and is liberating in its effect. It is a way of awareness where each moment is the first moment of the rest of your life. It is a way of engaging consciously in every aspect of life and of discovering a unique personal way to be in this world.

In order to enter such a way, however, it is needful to acknowledge the need for personal responsibility in maintaining this commitment to being mindful by regular practice. The way of mindfulness meditation is through taking notice of the breathing process, and this discipline encourages observation of all aspects of life and bodily experience thus facilitating a co-operative participation in maintaining healthful attitudes and actions. In the words of Kabat-Zinn this way of awareness "is connected to health and healing, to stress, pain and illness, and to all the ups and downs of the body, the mind, and life itself. It is a path to be traveled, to be cultivated through daily practice. Rather than a philosophy, it is a way of being, a way of living your moments and living them fully. This way only becomes yours as you travel it yourself" (1996, p.443).

#### 6.4 IMPLICATIONS:

The understanding of mindbody reality that informs energy medicine is shown in the progress that was made by those patients who were willing to engage their total being in the process of dealing with their illness experience. For instance, P2 learnt to listen to herself and get in touch with the healer within as she engaged in meditation and visualization techniques because they opened her to a new awareness. She reflects on her understanding of the new awareness that she experiences in her daily life:

Awareness is actually, it's awareness that we actually can feel ourselves. You know there are certain things that we actually need medical doctors for but you know really basically, we could, we can, can heal ourselves. Obviously through diet and lifestyle, and , look

meditation and spirituality, listening to the inner self. And being in touch. It's not easy to be in touch with one's emotions in this fast life. No you override so much.

She tells how she practices meditation at home and is learning techniques for relaxation with her psychologist. "I do these techniques with her for relaxation, where I can actually physically free my body of stress completely, my whole world and to release all the stress toxins and that out of one's body". In fact not only is she learning to be aware and in touch with her inner being, she also finds that physiologically her body is changing. "You know it's, it is very therapeutic to me to do meditation. They say it's a good...well my blood pressure recently uh even this physician I went to he said now after suffering from high blood pressure, I have got the blood pressure of a 20yr old". Each of the participants in this research had to find her/his own way of co-operating with the illness experience. But the common thread of becoming conscious of their unique inner truth, of seeking counsel and support, of developing a new behavioural and perceptual stance, of taking responsibility for choices that needed to be made, of practising the new discipline of listening to their bodies and responding to the messages they were receiving, is apparent throughout. It took a lot of struggle and commitment for all those eight patients who ventured into the inner journey and learnt to take responsibility for their ways of being. It was only once they had confronted unhealthy attitudes, beliefs and feelings, that they began to experience a lessening of their illness symptoms.

Where there was an inability to take this participative stance as we have noted previously to be the case with P1 and P5, the messages of the illness symptoms were not investigated and the patients remained stuck in their old dispositional patterns. Their experience remained that of seeking a cure, looking to the professional to find a way to free them of their malady, giving up their sense of power and remaining imprisoned in their sense of isolation and disconnectedness. As an example of the result of an inability to engage with new meaning and discovery for beingness, I'd like to share P5's reflections on the meaninglessness of it all for her. "You see if you can explain it, I always say it would be better to get cancer because then they cut off your arm or they cut out

your boob or whatever it is, they'll do it and you know there's an ending. You know you're gonna die. Or you know you're gonna survive. With me I don't know anything. I mean it's now five years. How long does it go on? There's no ending to it".

The analysis of the illness experiences of these CFIDS patients certainly seems to confirm the theoretical models that have been investigated so far. There is one model left for investigation, and in chapter 7 the psychodynamic model of illness will be addressed as a final examination of the theory underpinning the CFIDS research covered in this thesis.

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## CHAPTER 7

### PSYCHODYNAMIC THEORY

The language of the body should not be dismissed as primitive, or excluded from legitimate therapeutic discourse. To insist that patients find something 'more interesting' than their physical symptoms to bring to therapy not only excludes a source of rich symbolic material, but also sets up the potential for empathic failure, or therapeutic impasse. On the contrary, given a warm, accepting place in which to share their experiences of their bodies, patients seem eager to make the links between body and mind (Swartz, 1997, p.15).

In this discussion I intend to examine the concept of body/affect as it is seen within the framework of psychoanalytic theory and experience with patients.

An examination of the current thinking and experiences in this field will be covered in this chapter, and its implications for bringing added insight into the illness experience of the CFIDS patients being researched will be proposed.

#### 7.1 PROPOSED AFFECT ETIOLOGY

Grotstein (1997) states "the mindbody constitutes a single, holistic entity, one that we think about and believe that we can imaginatively experience as being separate but that is mockingly nonseparate all the while" (p. 205). This is yet another way of expressing the inescapable interconnectedness of the human psychosomatic beingness which has been examined as a common thread throughout most of the theoretical models of illness that have been examined in this thesis in order to shed deeper insight into the research findings regarding the process and meaning of CFIDS. It is in agreement with this dual-track theorem that I build my argument as to the formation process of affect. If we unpack this theorem more specifically, we arrive at the understanding that humans relate to themselves in two basic ways - mindbody or bodymind - never separating the two entities, but actually expressing dialectic and dialogue both in an intra and

intersubjective manner. The image of "Siamese Twinship" (Grotstein, 1997, p.206), expresses symbiotically the relating as being one of wholeness and particularity. The tendency is to particularize the bodymind and to see the mindbody as the underlying holistic matrix. When the mindbody, for instance, fails to process, say, affect appropriately, the bodymind is left to 'carry the can' and becomes the scapegoat bearing the 'unmentalized'<sup>15</sup> affects causing deep distress to the soma. In other words, affect that should have been desomatized<sup>16</sup> through conscious confrontation becomes resomatized. When this process occurs, the affect remains unprocessed in the unconscious. The need to establish a link between the unconscious affects (there because of a failure to complete the normal cycle of formation) and their disruption of bodily homeostasis (way of getting attention directed towards them in the 'hope' of receiving release) needs therefore to be established in order for a healing process to be initiated. It is as if the soma in these states is 'calling out' for attention to be turned towards enabling the mindbody to effect the necessary desomatization of the unwanted affect. Another way of expressing this is in the concept of emotion schemas - the integration of somatic, sensory and motoric processes. To the extent that such integration fails to be achieved by the individual, somatization of affect will occur (Bucci, 1997; Grotstein, 1997; Krystal, 1997).

## 7.2 EMOTIONAL SCHEMAS

In the most general terms, the emotion schemas constitute the desires, expectations, and beliefs one has about people, which develop through interactions with others from the beginning of life. These schemas include representations of objects<sup>17</sup>, parts of objects, and relations between them in all

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<sup>15</sup> A consciously experienced/remembered affect.

<sup>16</sup> Affect is stored in bodily tissues (somatized) where it causes disturbance if not integrated into the conscious experience and thus released (desomatized).

<sup>17</sup> The ego develops its identity as a result of interaction with objects. For instance, the primal 'object' would be the mother and her breast. Sometimes the relationship with this object will be satisfying (good) and sometimes unsatisfying (bad). In order to protect against the confusion of this, ego internalizes the object in split-form - 'parts of object', i. e. good breast and bad breast. These internalized relationships with objects form the basis from which the emotional schemas we live by are formed (Fairburn, 1963).

sensory modalities, as well as patterns of activation associated with motoric actions, and visceral and somatic states (Bucci,1997 p.156-157).

If we unpack the above statement more thoroughly, we can say schemas include images of the object of the emotion (person or situation either desired or feared); response actions towards object associated with particular types of emotion (fight, flight, embrace) and feelings experienced either viscerally or somatically in response to specific emotions (love, hate, fear).

These schemas begin formation within the preverbal (unconscious) stage and then become part of the conscious experience as they are linked with language. When an emotion structure has been activated - such as terror, loss, joy - it tends towards displaying physiological effects which mirror the experience itself. "Any component of emotion schema may be activated by any other...any component of an emotion schema, like any mental representation or process, may occur within or outside of the focus of awareness" (Bucci,1997, p.157). Emotion schemas start their development in earliest infancy. Through subsymbolic<sup>18</sup> and symbolic separate perceptual functions - smell, taste, touch, sound, and sight - the infant's developing "knowledge" of its mother (caregiver) is being formed. This occurs as mother emerges in the form of eyes, mouth, breasts, reaching-out-hand and so on. 'These sensory experiences occur in consonance with somatic and visceral experiences of pleasure and pain, as well as organized motor actions' (Bucci, 1997, p. 161). They use bodily actions for example the mouth for sucking, and through this process of interaction an expectation of 'mother' is formed. This means that an emotion schema relating to mother will be directing and integrating the baby's emotional life long before language is acquired.

Emotion schemas vary from the very beginning according to the nature of the interaction from which they are being formed. For example, a visceral discomfort

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<sup>18</sup> Symbolic perception entails the capacity for dual recognition. A symbol is thus two things at once. "The word 'apple' on the page is a black pattern of ink on white paper; it also means a fruit which can be eaten, looks green or red and so on" (Hinshelwood, 1994). In some emotional-somatic disorders, there is a subsymbolic perception where the patient is without symbols for the somatic state.

such as crying and tense tummy muscles, might arise from the schema of need; if this need is followed by a caring, empathic response such as a loving voice, a comforting cuddle, and a satisfying suck on the breast, the somatic experience will be one of satisfaction and pleasure. This schema would differ in the case of an unsympathetic scenario of interaction where a bottle is propped alongside for feeding, resulting in a completely different emotional meaning and somatic experience. "It is the particular interpersonal context in which the somatic activation occurs that determines its emotional meaning, not the physical arousal or need satisfaction alone" (Bucci, 1997, p.161). There needs to be an empathic intersubjective experience with mother so that the physical action and satisfaction can translate into feeling that can be experienced and understood.

Therefore we can say that an individual comes to experience affect as mind (conscious interaction and ideation), when s/he has been the recipient of a facilitative intersubjective context. To the extent that this has not been the case, affects continue to be experienced primarily as bodily states. It would follow then, that in order to rectify any arrest in the desomatization of affect, one would need to experience a facilitative (attuned, accepting, affect articulating) intersubjective presence. The analyst/therapist becomes established for the individual as such a presence through the transference process. In this way the regulation of affect can be achieved towards lessening of 'division' and consequent whole-making of the mindbody (Stolorow, 1992). Wrye (1998) stresses the importance of making contact with the inchoate, preverbal body (of both analysand and analyst) in order to include the body as the subject of experience thus being able to include an awareness of primitive bodily states of mind.

Though it is not easy, we can attune ourselves more to the body-mind in the analytic dance, if we not only listen with the third ear but consciously feel with our skin, our bones, and our viscera our patients' narratives of desire. That capacity to resonate with patients' total subjective and sensory experiences enriches our patients' self-awareness and contributes to therapeutic change. So much of our psychic health, our sexual identity and expression, and our capacity to function well in love, work, and play – in other words, dancing with our dustmops on – depends

on the integration of enlivened, body-conscious self-states that can be returned in analysis that relinks this early bodymind ( 1998, p. 115).

In similar vein, McDougall (1989) says:

As time went on I became more attentive to the psychic functioning of those of analysands who, in addition to their psychological problems, suffered from allergies, heart and respiratory illnesses, gynaecological disturbances, and other such maladies whose onset or reappearance appeared to be related to events of psychological importance to the individual concerned. Clinical observation slowly taught me that all analysands (and analysts as well) somatize at one time or another, particularly when stressful events override their usual ways of dealing with mental pain and conflict. When I came to recognize the unconscious need, in a number of my patients, to *pr̄eserve* these illnesses, not only as a reassurance of one's bodily limits but also as proof of psychic survival, this was for me a notable discovery. With the passage of time I have made it a practice in initial encounters to invite future analysands to talk about their physical as well as their mental suffering (pp. 20-21).

In summary, in the process of affect formation an intersubjective facilitating environment is of paramount importance for an infant to be able to move into a "mind" experience of affect. If this is in any way withheld, the affect content is likely to be somatized to the extent of the psychic component remaining unconscious. This suggests that at any stage in life where an appropriate intersubjective context is unavailable, a person will be likely to relegate the psychic component of the affect into unconsciousness in order to protect him/herself, (cf. patient Elizabeth in next section). This in turn will mean that the affect is experienced somatically only. If we are mindbody it would follow that affect is both a somatic and psychic entity, meaning there is always a physical content to our experience of feelings.

### 7.3 STIMULUS ENTRAPMENT

However, we need to ensure that the psychic component is also given attention in order for the affect to be kept in a balance that will promote healthful experience for the individual. Meares (1997) has noted the condition in which a

person becomes obsessed with the external surroundings and bodily states to the exclusion of any form of reflection or inner awareness. He calls this state stimulus entrapment, and suggests that it arises from a lack of connectedness with selfobject<sup>19</sup> relationships within the social environment leading to a sense of dissociation and loss of sense of self. The development of an inner life becomes retarded in such circumstances and with it also self-awareness. At this point it is important to establish an understanding of what it meant by 'self object relationships within the social environment. This environment is seen to be an intersubjective field in which there is a system of reciprocal mutual influence. For instance, the child would anticipate selfobject experiences from its caregiver, and the caregiver would in turn anticipate selfobject experiences from the child. There is a system of mutual regulation in the child-caregiver relationship. In fact in this framework, a child's psychological organization would always be seen as an aspect of a changing and maturing care-giver system. Here the conception is that affect is the primary motivational source, and it is within the person's history of dyadic processes of intersubjective sharing, that her/his affective core is derived.

It is as a child experiences the validating attunement of a caregiving environment, where both positive and negative experiences are shared, that a child develops a sense of the world and self as real (Stolorow, 1992). The importance of attunement with a selfobject is stressed in order that a playspace can be provided in which the child can begin to examine and name the sensory experiences coming its way. If this does not occur s/he becomes "addicted to stimuli" (Meares, 1997, p.226). For instance, a child when lost in play is said to be 'filled' with the experience. This attunement results in a sense of vitality and meaningful engagement in the happening. When chronic misattunement with the environment occurs however, the child's development is disrupted. In such an environment the child would be unable to connect with others as selfobjects and becomes "constantly confronted with the threat of emptiness should the stimuli cease. This emptiness is beyond mere vacancy. It implies nonexistence. In order

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<sup>19</sup> It is important to note that the selfobject is a function. The self is evoked as a result of the interaction a person has with an object. "Any experience that functions to evoke the structured self (which manifests as an experience of selfhood) or to maintain the continuity of such selfhood is properly designated as a selfobject experience" (Wolf, 1988, p.52).

to find some sense of existence, however unsatisfactory, the individual must seek sensation" (Meares, 1997, p.226). It is vitally important that such entrapment be taken seriously and work on establishing a connectedness with some selfobject be done. By 'reading' the stimulus and bringing metaphor to play in naming it, one will be on the way to facilitating the mentalizing of the affect that is being expressed only bodily.

All this underlines the importance of the inextricable interplay of affect somatically and psychically, and that this needs to be held in a healthy balance within the individual. Where there is inadequate mentalization of the affect the soma will be under inordinate stress if made to 'carry' the affect alone, hence the need to examine bodily symptoms of stress and illness from a total perspective of mental/physical functioning. As we have noted in the PNI model, affective stressors have a negative relationship with immune functioning, and thus with the progress of illnesses resulting from inefficient immune reactivity (Brosschot, 1994; Brauchli & Zeier, 1997; Finerman & Bennet, 1995). With this in mind it seems appropriate to examine the influence of unconscious affect on the soma from the following perspectives.

#### 7.4 INFLUENCE OF AFFECT

It could be said that there is a variation from traumatic bases of affect somatization to general 'nagging' conditions of this process. The following reflections will explain my suggestion.

Firstly, a case study provides a good example. Elizabeth presented for therapy because she was experiencing extreme stress in her job. Together with this she was aware that she seemed to be actively sabotaging the graduate studies that she was engaged with. She acknowledged that this pattern of behaviour towards her studies was not a new experience as she had acted in this way in the past. Four months into therapy her boyfriend broke their relationship, and this catapulted her into a tumultuous experience of extreme disorganization. She suffered from a variety of somatic complaints during the course of her therapy as she became more and more able to trust in the therapeutic relationship. It was as

if layers of unconscious 'protection' were being uncovered. It is important to focus on one of these in order to support the suggestion that imbalance of somatic and psychic affect interaction will result in dis-ease being expressed by the soma. In fact Elizabeth would experience these physical symptoms as precursors to remembering traumatic events. For instance she "would have pain and sensations of a penis moving or not moving within her vagina, choking sensations, inability to swallow or to breathe, pain in her neck and back, tightness and heaviness in her chest, and painful pulling sensations in her arms, among others" (Droga, 1997, p. 180). These "somatic memories" enabled her, in unpacking their content with her therapist, to mentalize her father's sexual abuse of her as it became accessible to her conscious mind. Gradually, these memories became more affect-laden resulting in a period of hospitalization. "The process of remembering was intermixed in an overall direction toward integration of somatic, cognitive, and affective components as Elizabeth gradually came to know, feel, and remember her childhood experiences and to weave them into the fabric of her developing self" (Droga, 1997, p. 185). This story is an example of a traumatic basis for unintegrated affect.

What I refer to as "nagging" affect is the stress caused to the soma by the individual constantly behaving in a certain manner, for instance the pattern of striving for excellence as a result of insufficient mirroring and affirming from significant others in the infant/early childhood stages. Here an emotion schema of experiencing a sense of personal general unworthiness has been established and 'buried' in the unconscious. The resulting behaviour pattern is an attempt to create an experience of the affects of self-esteem and acceptance within her/his consciousness to counteract the somatic experience of unworthiness. The constant watchfulness and desire to please which characterizes this behaviour, would also be experienced as stressful to the soma. It is as a result of such constant pressure being placed on the soma, that the very real situation of bodily disturbances of a chronic disease such as CFIDS can be set in motion when life stressors accumulate to a state of overwhelmingness. These bodily disturbances certainly need to be treated and researched, but, if the underlying psychological process of affect somatization is not also restored to a suitable integration by

becoming mentalized, there will be a continuance of the waxing and waning CFIDS phenomenon within the individual's life, according to the intensity of stressors present. CFIDS can be seen therefore as a cry for help from the bodymind for the unintegrated affect in the unconscious to be integrated within the mindbody, so that wholeness and renewed health can be established.

It has been shown that CFIDS can occur in both an acute-only onset form as well build towards such acute symptomatology out of a chronic state of ill health. The somatic response to a recent trauma could well be so stressful to the affect of the soma that it results in the CFIDS condition, or the somatic subjection to a behaviour pattern resulting from unmentalized affect and causing stress on the soma, could also make way for CFIDS symptoms to be established within the organism.

At this point it is needful to underline what has been said in this section with the hypotheses set out by McDougall (1989) because they succinctly encapsulate the psychoanalytic standpoint regarding the influence of unmentalized affect on the individual's life-experience that has been examined above:

1. Certain allergic, gastric, cardiac and other such reactions may be a somatic expression of an attempt to protect oneself against truly archaic libidinal and narcissistic longings that are felt to be life-endangering, much as a small infant might fear the threat of death.
2. To achieve this purpose, the psyche in moments of danger sends, as in infancy, a primitive psychic message of warning to the body which bypasses the use of language. Therefore, the danger cannot be thought about.
3. This may result in psychosomatic dysfunctioning, such as the urgent need to empty the body of its contents (as in ulcerative colitis), to hold one's breath (as in bronchial asthma), or to produce violent skin reactions (as in excema and urticaria). Alternatively, the psychic message result in increased gastric secretion, heightened blood pressure, quickened pulse rate, and so on. Or again, the message may give rise to disturbances of such normal bodily functions as eating, sleeping, eliminating, etc.

4. The body, like the mind, is subject to the repetition-compulsion. It may be recalled that in *Beyond the Pleasure Principle* Freud linked this manifestation to the destructive impulses. In the somatic sphere a complex body-mind reaction also tends to be inexorably repeated whenever the necessary stimulus (often of a visual, auditory or other perceptual-sensory nature) arises or when certain relationships with significant others are felt to be threatened.
5. The emotion aroused is not recognized in a symbolic way (that is, within the code of language which would have allowed the affect-laden representations to be named, thought about, and dealt with by the mind), but instead is immediately transmitted by the mind to the body, in a primitive nonverbal way such as fight-flight impulses, thus producing the physical disorganization that we call psychosomatic symptoms.
6. Psychosomatic maladies come to acquire, secondarily, a beneficial significance. The physical suffering they cause is liable to be compensated by the unconscious conviction that the illness is serving a protective function, such as defining one's body limits. Fears of merging when in affective interaction with others (recalling unconsciously a disturbed mother-infant relationship and the fear of being engulfed or abandoned by her) are thereby alleviated. Communicating a state of despair through organic illness may also give access to care taking people. Analysis often uncovers one further fantasy, namely that the physically attacked body is at the same time a way of attacking the body of the internalized mother, thus providing a further secondary gain from illness.
7. In some cases physical illness may also be experienced as a reassuring proof that one's body is alive. The self is therefore reinforced against a feeling of inner death that stems from disturbed infancy. Such inner feelings frequently give rise to unacknowledged depression, since the individual takes this to be a normal mode of experience (pp. 28-29).

In order to "put flesh" onto the above hypotheses, I will refer to two incidents of somatic symptoms proving to be a "cry" for engagement with unconscious affect in order that a new balance of health of bodymind could be established.

Mrs A was referred to psychotherapy by her physician who had failed to contain attacks of severe ulcerative colitis which were threatening her life. During the process of Mrs A telling her story to the therapist in a facilitative, caring, intersubjective context, she was enabled to access her deep-seated unmentalized affect of a lack of sense-of-self. Over the years this affect had "demanded" that she find her sense-of-self within her relationship with her daughter who became her life. When her daughter "escaped" to another country and marriage, the colitis episodes began. Once Mrs A was able to access her feeling of emptiness she was able to address it with her conscious mind, understand it, and plan action she could take to fill the emptiness for herself by engaging fully in her own life. The colitis attacks completely disappeared after this. She went on to live a healthy and increasingly fulfilling life. The hidden affect had been accessed, and was no longer exclusively experienced in the soma but was being worked with within the context of the whole mindbody (McDougall, 1989).

Marie Cardinal had never been able to experience an adequate connection with another person from mother through to husband. This lack of a caring, nurturing and affirming context eventually resulted in her experiencing a bleeding which could not be stayed even after the best medical care possible. Not only did this condition exhaust her physical resources, but also wore away her ability to function normally in her psyche as well. It was only once she had been established in her first facilitative and caring intersubjective relationship with her therapist, that she was able to make conscious contact with the pain of abandonment and rejection buried within her soma, and mentalize it. Her bleeding stopped overnight never to return and she was slowly able to confront and understand and deal with the pain that had been buried in her unconscious all her life. She went on to be restored to a full and normal experience of life, and became one of the most powerful writers of our age (Cardinal, 1996).

These examples underline the need that we as humans have to experience appropriate intersubjective relationships so that we can freely allow our affect to be part of our mental as well as our physical experience. Without this integration

we are unable to function healthily, and are likely to be plagued by somatic disorders that need to be attended to in order for us to confront affect which is hidden. This confrontation is essential, but how do we achieve it?

### 7.5 ACCESSING AFFECT

From all that has gone above there are some generalisable processes that can be extrapolated.

Firstly, if it is true that the crucial factor in the mentalization of affect is a good-enough fit with a caring other, then it would follow that such a relationship would also be key to the unlocking of affect which had been suppressed or not ever formed within the conscious. In order for caring there must be adequate intersubjective selfobject experience that provides space in which a healthy sense of self is able to develop. As a person shares his/her story with a receptive, empathic other, the enabling towards seeing metaphor and thus understanding the hidden occurs. It was as the patients already mentioned, were able to tell their illness narratives to a caring, enabling other that they were freed into health. It is thus suggested that talking about the illness experience is a powerful means of accessing unconscious affect – it is often referred to as ‘the talking cure’.

Secondly, the therapeutic relationship offers a balance between positive and negative selfobject experience essential for facilitating a medium through which patients are enabled to experience their self-regulating capacities being reinstated. For instance a disruption to the relationship with the therapist leading to a certain state of retrogression within the patient, and the subsequent working through to a new place of equilibrium, serves to create a strengthening of the self. The patients gradually learn to rely less on the selfobject and evidence a greater capacity to sustain empathic failures both within the therapeutic relationship and the outside world.

Thirdly, it is especially important to patients that they are able to recognize and name their affective experience. Where they have been unable to mentalize their

inner states before this, it is of greatest importance that such affective experience actually be named and consciously felt. Once these steps have been taken, the somatic symptoms are no longer needed as pointers to inner disturbance, and they disappear leaving the patient with a new sense of control, belonging and direction in her/his life.

In this chapter the formation of affect and the necessity for a good-enough intersubjective matrix in which this can take place has been considered. Failure to mentalize certain affect results in inordinate stress being placed on the soma in order for it to cope with that which should be a conscious experience within the psyche. It has been noted how such a situation can be redressed by accessing affect into the conscious mental realm. Through this the importance of affect formation and access has been established, and once again the need for co-operative response to illness has been emphasized.

## 7.6 IMPLICATIONS

It wasn't until the participants had been able to name the underlying affect motivating their patterns of behaviour, that they began to experience an easing off of their somatic symptoms. P3 had been ill since the age of 12 with little variation to her somatic symptoms. It was only when she was able to access the emotional experience surrounding her parents constant strife, her mother's confiding in her and her father's alcoholism, that there was a change. This opening to her somatized affect was enabled through sessions with a psychotherapist and a spiritual counselor. The turning point came when she was able to address the previously hidden emotions openly with her parents and the therapist. She reflects on the importance of this intersubjective encounter for her. "Um...you see my parents have always like not got on. Um and he brought them in and talked to them and talked to me, and that kind of thing. And if that was the problem, I did start getting better after that. Um.. I think it was good. I was just so tired of trying everything. It was right at the end...uh after about 4 years. Ja. That was the only thing that I thought possibly could have helped". It seems that the unprocessed emotional response to the family situation once mentalised and

shared, freed the soma from the excess stress it had been experiencing, and refreshment could begin.

Once P2 had allowed the memory of sexual abuse to surface and was able to engage with it, she too, began to find the ability to co-operate with her symptoms and find a new way of being and living. The process of mentalisation started in her deep body massage treatment sessions and was fully encountered in her psychotherapy sessions as she says:

You know, he (doctor who had been doing the tissue massage) knows that I had a few emotional issues to deal with and it would be more difficult, this is why he, he actually suggested I saw a psychologist to deal with that - who is, who also thinks the same way as he does. She's a very enlightened person, she's a beautiful person and um, she actually is teaching me to start to heal my body through opening up channels in my body.

Here is an instance of the psychotherapist respecting, not only the suppressed affect that needs to be brought into conscious experience, but also acknowledging the somatic content of the affect and its need to be released. The patient is empowered to co-operate with her healing process in a mindbody totality.

When P10 identified the underlying emotional schema (as was referred to in the previous chapter) causing her to push herself to achieve and perform way beyond what was a healthy degree, she allowed her therapist to provide a new selfobject experience in which she was free to confront and release her somatically entrapped affect. Each of the participants had the choice whether to become conscious of their underlying pain or whether to rely only on addressing somatic symptoms. Unfortunately P1 was unable to acknowledge any need for inner affect confrontation. She tells of her contact with a psychiatrist who after her first session with him pronounced her to be manic depressive:

I said are you going to put me on Lithium? He said yes. And I actually was stupid enough...I mean there's no way I'm a manic depressive. And he was so derelict in his duty, just

because I was stupid enough to say I had been manic. Meanwhile I wasn't that sort of manic. I mean I wasn't talking about that sort of thing, and it just goes to show how someone can pounce upon one thing you say, and, and use it against you as it were. He tested my blood, put me on Lithium, and I used to go and see him and then we had nothing to talk about. Because psych, psychologically I was so well. You know he, I didn't have problems with my parents, or my child, or my anything. And so we sort of just used to sit there, and I mean you know it was just a whole waste of time.

She stopped treatment after 3 months. Her state of denial was entrenched. As has already been discussed previously, she certainly did have problems with her family and was sitting on a lot of suppressed hurt relating to broken relationships. She remains, as has already been noted, in her state of waiting to live again. There is no significant change in her physical symptoms after 9 years of illness.

From the above examples, the need for conscious mentalization of affect in order to release the soma from disabling symptoms, has been underlined. It was shown that there is indeed a need for a person to live in a healthy balance of somatic and psychic emotional content. Again, the patient who was unable to allow herself to access hidden affect, is seen to be experiencing a stagnant CFIDS course.

Overall, the various illness models that have been examined have found an echo in the experience of this group of sufferers. All the theories have touched on parts of the whole experience of their illness. It is as treatments arising out of these theoretical models were entered into and were allowed to make an impact on the understanding and behaviour of the patients, that progress, and renewal of energy and purpose began. In the following chapter wider implications for health care will be addressed in the review of what has been discovered in this particular research.

## CHAPTER 8

### CONCLUSION

Currently much medical thinking, and most taxonomic systems, actually exclude from clinical consideration those human subjective 'story' elements which we all regard as crucial to our experience. We must include them despite the difficulties we confront as we begin to do so. Much of the difficulty arises from our Western philosophical heritage, some arises from our individual defensive reluctance to face inner reality both in our patients and in ourselves, and some arises from the fact that if we consider multiple aspects of reality, life tends to become less manageable (Broom, 1997, p. 174).

The *British Medical Journal* published an editorial (Sept. 6, 1997) acknowledging that there is continuing controversy over the illness CFIDS that could well be due to "the remarkable persistence of mind-body dualism which appears to be as prevalent among the medical profession as among the general public" (p.2). It went on to stress the need for a more constructive attitude to medically unexplained physical symptoms. This, it proposed, could come about only if there were to be a change in medical students' training, and a greater dialogue between medical, psychiatric and psychology professionals. It called for professionals to lead the public in positive and non-judgmental acceptance of the role of physical, psychological and social factors in all illness. In this way the door to innovative treatments would be opened.

These sentiments are confirmed by the findings of this research that sees the need for CFIDS to be seen as a total mindbody experience, necessitating the co-operation of professionals from different areas of health care both amongst

themselves and with the patients, in order to bring some meaningful resolution into treatment processes. The complexity of this illness is manifest in the great variety of research that it has spawned. The medical research, although it has been able to isolate specific biological changes that occur within patients, has not been able to pin-point any pathogen for the illness, and the frustration of those who insist on finding a physiological cause that can be treated and eradicated from the patient's system increases. It is certainly important to treat the biological symptoms medically where necessary, but to concentrate solely on this form of intervention has been shown to be inadequate in enabling the patient to cope with the suffering entailed in a way that brings meaning into her/his lived reality. The participants in this research who insisted on seeking a medical cure have remained unhappy and have a sense of having been cheated of their lives. Their symptoms continue to prevent their participation socially and in the workplace and they persist in hoping that the life they had before the illness will one day be restored to them, enabling them to regain their sense of identity and self esteem. They can find no meaning in their illness experience. Kleinman underlines the futility of focussing on the illness from this perspective and urges a very different form of approach:

Chronic illness is nothing if not various, as many-sided and differing as our lives. That is why, if we are to understand the meaning of illness, we cannot focus on the content. Instead, we must inquire into the *structure* of illness meanings: the manner in which illness is made meaningful, the processes of creating meaning, and the social situations and psychological reactions that determine and are determined by the meanings (1988, p.185).

The approach recommended above is the one with which the present research has gone about examining the illness narratives of the CFIDS participants in order to gain insight into the way they were enabled to find meaning and new purpose for their lives from their illness experience. Current research into CFIDS has arisen out of four major theoretical models of illness understanding, and the patients responses were analysed in the light of these models, showing how all

four areas had major impact on their illness process, thus confirming the need for a more comprehensive interdisciplinary mode of intervention.

The *medical model* has traditionally tended to elevate the role of the doctor's responsibility for healing patients. The patient is regarded as being largely dependent on the efficacy of the doctor's intervention. In this model it becomes important that the illness is legitimated by finding specific biological pathogens which can be measured and treated. The Cartesian mind- body dualism that has traditionally pervaded the medical understanding brought this about, and the mental and emotional component of illness tended to be treated as something unrelated to the bodily functioning. Although this dualism is now widely challenged, many patients persist in seeking only a biological cure.

In the journey towards a meaning of their experience, eight participants were able to allow the alternative therapies to boost their medical treatments. They practised new understandings of co-operation with their bodies. For example, the emotions accessed by body alignment therapy were engaged, and working through the negative content of these emotions became part of their treatment process. In this way they were taking control and not remaining passive recipients of biological and chemical interventions exclusively. They were able to acknowledge the areas of limited effectiveness in their medical treatment and then go looking for something in addition. Two participants were unable to shed their belief in the total authority of the medical interventions and so remained waiting with a sense of helplessness for a cure to be found.

The *lifeworld understanding* that it is bad to be other than well and fully participating in the community life had great influence on all the participants. They all struggled with the loss of role identities, social and work failures, and a new emptiness and apparent uselessness. Each came to the place of having to answer the question who am I. Because the two participants mentioned above had had life- experiences that taught them to mistrust others and rely on their own strength to cope with life's vicissitudes, when this ability was weakened they were left still mistrustful being unable and unused to receiving help from others, they found themselves answering the question by saying 'I am nothing, I have no

self esteem'. The other eight participants to varying degrees had known the support of others, and had developed a strong enough sense of coherence to enable them to seek help from others in answering this question. With the help of psychotherapists and counselors they were able to make new discoveries about themselves and the reasons for behaviour patterns they had established but needed to change, and they discovered a deeper place of identity. They were able to answer the question by knowing 'I am me'. In this they were empowered to begin listening.

*Minbody* theory rests on the discovery made by psychoneuroimmunology that the emotions are inextricably part of the informational process that is constantly taking place within the three body systems, and which are crucial in influencing health and well-being. Through a process of attentiveness to the messages being received from the body, a person is led to discover the emotional content that is part and parcel of it all. Thus a response is called forth where the patient is called upon to co-operate with the body and learn ways of accessing inner affect so that the information system within the body can be restored to healthy functioning as far as possible. Meditation and spiritual connecting were very much part of the process. All eight participants embarked upon this listening way of being and gained new perspective and increasing release from the CFIDS symptoms. The other two participants did not venture into this area of understanding, and their symptoms seem to have settled into a chronic debilitating pattern.

*Psychodynamic* understanding of affect formation gives answers about why affect becomes somatised causing the body to 'speak out' for release from this stored affect, in the form of symptoms of bodily discord. Here too the importance of listening to the life story and discovering how the bodily symptoms are metaphors of affect somatisation is stressed. The process of mentalising this affect is facilitated by an empathic intersubjective environment that provides the necessary containment for what is a painful exploration. Five of the participants experienced this form of intervention and all of them are making marked progress into a new way of being and living. Their bodily symptoms have mainly

disappeared except for the 'monitoring' fatigue that keeps them from slipping back into old patterns.

In all of these experiences, the core to the patients being enabled to take hold of meaning and newness was *relationship*. It demanded an ability to trust others to bring about help through alternative remedies as they responded to the direction these remedies were inviting them into. In order to challenge the notion that unless they were fully functioning and achieving within the community they had no identity, there was the need for a sense of coherence that enabled them to trust that others could help them on their journey of self discovery. It was through the practice of learning to listen to their bodies and their inner responses that they became empowered to co-operate with their symptoms instead of fight them. It was in relating to those who offered to teach them that they were enabled to enter this new way of being. And it was in the caring and empathic relationship with the therapist in a containing intersubjective environment that hidden affect was brought into the conscious lived experience, and the body released more fully from the effects of somatised affect. They needed to be heard by someone. As Broom puts it, when reflecting on a relational understanding of a patient's recovery from the somatic metaphor of a facial rash, "the issue is a question of whether anybody listening to her heard what she had to say, that is, illness as a manifestation of inadequacy of relationship" (1997, p.172). Once again the findings of this research are in accord with the understanding of illness purported by Kleinman:

Illness is not simply a personal experience; it is transactional, communicative, profoundly social. The study of illness meanings is not only about one particular individual's experience; it is also very much about social networks, social situations, and different forms of social reality. They are integral dimensions of lives lived together. For the practitioner, as for the anthropologist, an inquiry into the meaning of illness is a journey into relationships (1988, pp. 185-186).

The crux of this investigation now arises – how do we, as health professionals, promote a relational understanding of the illness experience within CFIDS patients enabling them to respond co-operatively with their illness and gain significant release from disabling symptoms and a new way of being in their community?

The findings of this research suggest that first and foremost there needs to be a marked shift away from the independent stance amongst health professionals and a move towards collaboration. This approach is increasingly being called for (Benatar, 1998; Davies, 2000; Margo *et.al.*, 2000; Swartz, L.,1998; Swartz,S., 1997). The idea here is that the importance of the collaborative approach lies in the differences between disciplines that together add up to a fuller understanding and more comprehensive treatment plan. Davies makes a clear case for this:

It is the questions and challenges that arise from the differences that are vital. A diverse group can arrive at a place no individual and no like-minded group would have reached (2000, p.1021).

It proved important for the participants in this research that they availed themselves of a variety of professional help. It would be powerful for patients if this collaboration were encouraged by the health system working from an interdisciplinary base and making such variety of interventions more widely accessible. There is a need to research ways of making such collaboration feasible.

Training of health professionals needs to include new understanding of the importance of communication between practitioner and chronically ill patient. Such skills need to be taught and practised. It is important that trust and co-operation be established to enable the patient to take hold for her/himself of the path of healing. The patient's story needs to be attended to with empathy and respect and patients should be encouraged to share their stories. The progress in medical training in the United States of America that was mentioned at the end of chapter 2 indicates that it is indeed possible to make such changes – especially in this time of the global village where resources can be so easily shared. Techniques of interviewing such as the adapted form of the BATHE

technique also mentioned at the end of chapter 2, make the task of helping professionals with this vital part of their intervention seem less daunting.

Not only is it important for health carers to establish adequate communication between themselves and their patients, it is also most important that they encourage and facilitate the patient's communication with her/himself. The chronically ill need to learn how to listen to their bodies and their inner reality. They need to be enabled to access unconscious affect. Thus again a collaborative approach is essential in that patients need to be given opportunities to discover a way to self-engagement. This research has examined, for instance, mindfulness meditation as a means to this end. Kutz *et al.* (1985) make a strong case for the integration of psychodynamic therapy with meditation and relaxation techniques. Such a course was followed by the psychotherapist in her treatment of P2, and achieved great success in being part of P2's learning to engage the healer within. And Post *et al.* (2000) urge that the medical practitioner needs to allow and respond to a patient's spirituality. The influence of spirituality on health is a growing area of research. Certainly, the sample of CFIDS patients showed evidence of the importance of engaging in a spiritual awareness.

It is also crucial that the chronically ill patient be helped to interpret the meaning of her/his illness experience. One way of facilitating this could be to encourage the patient to form a story about the CFIDS experience, for instance, giving it a character identity that can be responded to. In this way a conversation with the illness can be used to develop respect for the subjective experience of the patient as well as enable the patient to develop a relationship with the illness. Through this dialogue the patient learns to recognise the patterns of the illness and finds ways of working co-operatively with it. The patient's agency over the illness will thus be increased.

I am aware that this research has not addressed the socio-economic reality of the majority of the people in this country, nor explored an African socio-cultural dynamic. The sample of patients I have used represent the minority of South Africans who come from a Western cultural perspective. Research into the illness

meaning of the chronically ill amongst a sample from the majority group needs to happen - perhaps using a different, more epidemic illness-group such as Sugar Diabetes sufferers, as this illness is rife in the Western Cape. This could be used to ascertain what interventions are best suited to enabling this group of people to engage their mindbody reality, and so become co-operative agents in their healing processes. It would be very important to take cognisance of the role of the traditional healers in this instance. Swartz makes this point:

We are living in a country with a substantial set of meanings around the connections between bodies, minds, and spirits. The work of the sangoma or inyanga in treating a range of disorders not easily classifiable as either 'body' or 'mind', might serve as a model and source of inspiration in facing the creative illnesses of our patients (1997, p.17).

I arrive at the end of this thesis back where I started – with the fact of the overwhelming incidence of chronic illness that persists in baffling health professionals and robbing sufferers of meaningful existence. It is vitally important that a new way of viewing and treating the chronically ill become established in our health care system. Kleinman articulates this truth powerfully, and with his statement I end this thesis:

What is clear is that chronic illness is an ongoing process in which personal problems constantly emerge to challenge technical control, social order, and individual mastery. Like the rest of life, though greatly concentrated and intensified, it must be taken in total without valuing one part and rejecting others; we are both courageous and weak. Few of us are heroes in the grand sense, but in a small, quiet way and in a moral rather than a military sense, there are real heroes among the chronically ill (1988. pp. 144-145).

## APPENDIX A

### The BATHE Technique

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Background: "What is going on in your life?"

Affect: "How do you feel about it?"

Trouble: "What troubles you the most about that situation?"

Handle: "What helps you handle that?"

Empathy: "This is a tough situation to be in. Anybody would feel (down, stressed, etc.). Your reaction makes sense to me ..."

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*Adapted with permission from Stuart MR, Lieberman JA: The fifteen minute hour: applied psychotherapy for the primary care physician, 2d ed. Westport, Conn. Praeger, 1993.*

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## APPENDIX B

"Gramercy", 36 Quarterdeck Rd., Kalk Bay 7975  
Telephone: (021) 7882404

Dear

### CONSENT FORM

I am a psychology MA student at UCT, and am doing a research thesis on the illness experience of those who are suffering from ME. Because this illness continues to baffle health carers, it seems important to develop a wide approach to treatment interventions. My purpose in this study is to investigate the need for helping patients to engage with the meaning of their illness in the context of other life experiences.

In order to do this research, I need to interview ME sufferers. This is why I am approaching you. Should you agree to participate in the research, you must understand that you are entirely free to withdraw at any stage. Your participation is completely voluntary.

I undertake to keep the strictest confidentiality, and any material that I use in my thesis would be presented anonymously.

The process of this research is intended as follows:

- A series of interviews where the patient informally tells her/his illness narrative
- Either a written or verbal record of any significant dreams which occur during the illness

The length of the above will depend entirely on your energy level, and there is no specific expectation on my behalf. I am committed to being sensitive to your individual situation.

I look forward to sharing with you if you should so choose.

Sincerely yours

  
Jenny Gray  
RESEARCHER

I have read this letter and consent to participate:

Signature:

Date:

# APPENDIX C

## SEMI-STRUCTURED INTERVIEW ON THE ILLNESS NARRATIVE OF ME/CFIDS SUFFERERS

### OVERALL FRAMEWORK

1. ILLNESS NARRATIVE
2. BIOGRAPHICAL HISTORY
3. MEANING OF ILLNESS

### QUESTIONS:

#### ILLNESS NARRATIVE

- **Sequence of diagnosis** - *get as much detail about this process as possible,*  
- *ask for their responses psychologically to this experience*
- **Perceptions of** - *responses of those around as supportive or not,*  
- *personal responses to the way of life being forced on self*
- **Information of disease** - *what is understood of the illness,*  
- *sources of information received (internet-doctor-library-magazine etc)*
- **Responsibilities** - *how have these been impacted?*  
- *does the fact of being either male or female affect this situation in any particular way?*
- **Psychological state** - *identify major mood states (depression, frustration, helplessness, anger etc),*  
- *does patient see this as part of the illness or contributory to or resulting from, - i.e. how does s/he understand this state?*
- **Sleep patterns** - *has any change in patterns of sleep and wakefulness been experienced?*

- *is there any difference in levels of concentration (TV, reading, conversation, memory)*

- **Dreams** – *is there an active dream-life,*  
- *any dreams which are particularly remembered*

### **BIOGRAPHICAL HISTORY**

- **Basic Context** – Age
  - Marital Status
  - Family members
  - Presently living with
  - Support systems
  - Functional responsibilities...*capable?*
  - Work involvement...*partial?*  
... *full-time?*  
... *feelings of coping, frustration etc?*
  - Overall perception of present life-style
- **Historical Context** - Major events ... *birth,*  
... *nature of family of origin,*  
... *parents,*  
... *siblings,*  
... *schooling,*  
... *career history,*  
... *relational history*  
... *sexual development*  
- *Illness history ... family in general,*  
... *personal,*  
... *what were these experiences like to live with?*
- **Basic Personality** - Social and interpersonal relations ... *family, friends, colleagues, leader etc*  
- Intellectual activities and interests ... *books/film preference; fantasy-life;*  
... *hobbies*  
- Mood ... *cheerful, despondent etc*  
- Values... *moral, religious, political etc*  
- Self description ... *how would you describe yourself? etc*

### **MEANING OF ILLNESS**

- **Why is this illness happening in me at this particular time?**
- **Is there something new for me to discover about my life and the way to live it?**  
( *Exploring an explanatory model unique to each patient*)

# APPENDIX D

## PSYCHIATRIC HISTORY AND EXAMINATION

This scheme should be followed for the sake of uniformity and accessibility, but the data may of course be collected in the most convenient way. Facts and evidence should be stated in plain language rather than technical terms, and verbatim reports of what the patient says should be included especially concerning auditory hallucinations. Also examples of abnormal speech. Subjective and objective data should not be mixed, nor should details of the history and psychiatric examination. Formulation must be recorded. If information is gathered from relatives or friends, state the informant's name, relation to the patient, intimacy and length of acquaintance, impression of reliability, etc. Do not confuse such accounts with information obtained from the patient.

### METHOD AND REASON FOR REFERRAL

Include the section of the Mental Health Act under which the patient is admitted if relevant. Name and address of the referring doctor or agent.

### PRESENT ILLNESS

A detailed coherent account in chronological order of the illness from the earliest time at which a change was noticed. Ask yourself the question "What has brought this patient to seek help at this time?" Let the patient tell his or her story in his or her own way.

LIFE EVENTS List the events (with dates) which have caused significant changes, impact or disturbance (either positive or negative) in his or her life during the last few years. Indicate the degree of severity (include police or legal contact, work, health, love and marriage, financial, family etc.)

HIGHEST LEVEL OF ADAPTIVE FUNCTIONING achieved during the last year. This should be described in terms of the breadth and quality of inter-personal relationships, occupational functioning and use of leisure time. Depth of involvement is the key note of this assessment. Also assess energy and initiative - sustained or fitful, easily fatigued, decline, etc. (see Appendix 3 for categories of severity)

### FAMILY HISTORY

Construct a geneogram including grandparents and close family members.

Biological parents (and adoptive parents, if any) : Health, age, or age at time of death, and cause of death. Their personalities, relationships, occupations.

Other significant family figures including grandparents, other relatives, foster parents, etc.

Siblings: Enumerate in chronological order of birth with first names, ages, marital status, occupation, health or illness, personality. Miscarriages and stillbirths to be included.

Home atmosphere and influence : Assess family functioning, relationships and values in patient's formative years. Note any source of stress, e.g. marital tension, uprooting, social class.

Familial, psychiatric and medical illnesses : Note particulars which might be needed for further enquiries, e.g. names of hospitals where relatives might have been treated.

### PERSONAL HISTORY

#### EARLY HISTORY

Pregnancy and birth : Mother's health during pregnancy. Date of birth and place. Full term birth? Normal delivery? Breast or bottle-fed? Wanted baby or not? Illegitimate?

Early development : Health and setbacks. Milestones of development, e.g. sitting up, walking, talking, bowel control.

Neurotic symptoms in childhood : Night terrors, sleep-walking, tantrums, bed-wetting, food fads, stammering, mannerisms, fear-states, model child, etc.

Health during childhood: Infections, convulsions, operations.

#### EDUCATION

School : Age of beginning. School changes, standard reached and age of leaving. Evidence of adeptability, ability, backwardness or disabilities. Hobbies, sports and interests. Relationship to teachers and schoolmates. Nicknames.

Further education and training (technical, university, etc.)

PSYCHOSEXUAL MATURATION

Sexual inclinations and practices : Heterosexual experiences apart from marriage. Sexual information, how received. Masturbation - age, frequency, guilt. Sexual fantasies. Homosexuality.

Menstrual History : Age at first period. Regularity, duration and amount. How regarded. Pain, premenstrual tension or psychic changes. Climacteric symptoms. Date of last period.

Marriage : Duration of acquaintance before marriage and of engagement. Wife/husband's age, occupation, personality. Compatibility. Mode and frequency of sexual intercourse, satisfaction, impotence or frigidity. Contraceptive measures. Chronological list of children and miscarriages, giving ages, names, personality, etc.

OCCUPATION : Age of starting work. Jobs held in chronological order with wages, dates, reasons for change. Longest job held. Present economic circumstances and highest level of employment in the previous year. Ambitions. Satisfaction in work or reasons for dissatisfaction.

ACTIVITIES : Religion and religious contact, leisure activities, hobbies, sports, etc.

HABITS : Alcohol, tobacco, drugs; specify amount taken (recently and earlier). Sleeping; excretory functions; appetite; eating fada; weight loss.

PRESENT DOMESTIC CIRCUMSTANCES : Where living, with whom, income, social supports including social agencies involved.

PREVIOUS ILLNESSES

Medical - Illnesses, operations, and accidents (chronological and in detail).

Psychiatric - (detailed account). Dates, duration, symptoms, where treated and the psychiatrist concerned.

BASIC PERSONALITY

Aim at giving a flesh and blood picture of the person. The following are guidelines.

Social and interpersonal relations in respect of family, friends, groups, workmates. Leader, follower, organiser, aggressive, submissive, adjustable, etc.

Intellectual activities and interests : books, films preferred. Fantasy life, day-dreaming - frequency and content. Hobbies.

Mood : Cheerful, despondent, anxious, worrying, optimistic, pessimistic, self-deprecating, satisfied, over-confident, stable, fluctuating (with or without occasion), controlled, demonstrative, etc.

Personality traits : Withdrawn, suspicious, cold, aloof, jealous. Resentful, unstable, aggressive, stubborn. Impulsive, egocentric, overly dramatic, exhibitionistic. Timid, self-conscious, poor self-image. Dependent, passive, unconfident. Always happy, unstable mood, emotionally over-reactive. Strict, perfectionistic, rigid. Narcissistic, envious.

Values : Moral, religious, political, etc. Attitude towards self, others, health, own body, interests, work and ambitions.

PSYCHIATRIC EXAMINATION (MENTAL STATE)GENERAL APPEARANCE, BEHAVIOUR AND SPEECH

A description as complete, accurate and lifelike as possible of what you observe.

Appearance - grooming, neatness, mode of dress and unusual features.

Behaviour - eye contact, posture, psychomotor activity such as agitation, excitement or abnormal slowness, irreverent or embarrassing behaviour, distractability, objective evidence of hallucinations, mannerisms or stereotypes, catatonic symptoms.

Speech - this refers to utterance and may range from muteness through slowness, delayed responses and restricted quantity to rapidity and pressure of talk. Note tone of voice, clarity and speech difficulties. (Content of speech is covered under THINKING below).

AFFECT AND MOOD

Affect (the external manifestations of internal feeling judged from the patient's general demeanour, facies and expressed ideas). Note emotional responses during the interview. Also anxiety, depressive demeanour, hypomanic or histrionic, suspiciousness, perplexity. Restriction, blunting, flattening, lability or incongruity of affect.

Mood (pervasive feeling tone not related to an object) Ask "How do you feel in yourself?" "What is your mood?" "How does the future look?" Enquire for suicidal ideas.

THINKING

(the capacity to manipulate symbols in the form of words, images and ideas)

a) Organisation of Thought

Flow - tempo: retardation, rapidity, flight of ideas, blocking, poverty of ideation, perseveration, echolalia.

Form - abnormalities of structure such as vagueness, incoherence, condensation, loss of direction, distortions, displacement of words and ideas, lack of association of ideas, overinclusiveness, talking past the point, idiosyncratic use of words, neologisms. Give verbatim examples.

b) Possession of Thought

Subjective experiences which the person feels are outside his control such as withdrawal, insertion or broadcasting of thoughts, or thoughts being read or influenced by others. These are commonly delusional in nature. Obsessional thoughts (ideas that enter the mind against the person's will and cannot be resisted although they are recognised as abnormal).

c) Content of Thought

Delusions (false and unshakable beliefs that can cover a wide variety of experiences including ideas, perceptions and moods). For example, a conviction of control by others, ideas of reference or influence, catastrophic delusions, etc.

Delusions may be partial if expressed with doubt or full if held with complete conviction. Note: Check for social and cultural appropriateness.

Hallucinations - These may occur in any sensory modality. Ask, "I should like to ask you a routine question which we ask of everybody: do you ever seem to hear noises or voices when there is no one about and nothing to explain it?"

Auditory hallucinations may occur in the form of non-verbal sounds or mutterings, as voices speaking to the person, discussing him/her in the third person, or commenting. Rate as a true hallucination if heard through the ears or a pseudo-hallucination if heard in the head. Give verbatim examples. Visual, olfactory, haptic (touch) and somatic hallucinations should also be enquired for.

COGNITIVE FUNCTIONS

(Cognition is the process of acquiring, classifying and integrating information)

AWARENESS. Assess level of consciousness and arousal. Are attention and concentration easily aroused and held? Tests (in order of difficulty) - Serial 7's, Serial 3's, or months or weeks backward.

ORIENTATION. Test for identity, place and time.

MEMORY. Ask the patient if his/her memory is failing. Compare his account of his life with that given by others. Test by means of the Mental State Questionnaire (page ). Distinguish between different memory functions as follows:

- Immediate/short-term recall - Ask the patient to remember 5 objects in the room or a shopping list and to repeat them immediately. Check for recall after a short period.
- Intermediate term recall - Ask about events of the previous day e.g. meals.
- Long-term recall - Ask about remote or historical events in the person's past which could be expected to be known. Evidence of abnormality should be further tested by more specific tests.

SYNTHESISING FUNCTIONS

CAPACITY FOR ABSTRACT THINKING: Note the use of abstract concepts or figures of speech. Seek specifically for concrete or idiosyncratic thinking. Test with proverbs:

- e.g. "People in glass houses should not throw stones"  
 "A rolling stone gathers no moss"  
 "A stitch in time saves nine"

Can the person establish relationships between objects, e.g. similarity between orange and banana, orange and ball, etc.

INTELLIGENCE

Assess by school level achieved, speed of grasp, and range and quality of knowledge. An I.Q. test may be necessary.

INSIGHT

A conscious recognition by the person of his/her state of mental functioning and behaviour. There are degrees of insight varying from a simple recognition of change or disturbance ("course insight"), to a more discriminating type where there is deeper understanding of causation and significance. Record what the person believes are his difficulties.

JUDGMENT

The mental act of evaluating choices within the framework of a given set of values for the purpose of electing a course of action. Judgment is said to be intact if the course of action chosen is consistent with high values. This is assessed from the person's ability to draw reasonable conclusions from information or material gathered from experience. It can be tested in terms of action to be taken in social, financial and ethical situations. Also realistic plans for the future.

This is the SYNTHESIS (not a summary) of all relevant knowledge so that effective treatment can take place. It should be presented in such a manner that essential issues can be readily grasped by a third party, and it should flow sequentially and take no longer than 10 minutes.

#### IDENTIFYING DATA

Name, age, sex, race, occupation, marital status, present employment and residence, etc.

#### HIGHLIGHTS OF PRESENT ILLNESS :

Reason for referral  
Main complaints and/or problems

#### HIGHLIGHTS OF HISTORY AND EXAMINATION :

Significant features of personal and family background  
Premorbid personality  
Socioeconomic and cultural factors  
- Positive findings of the Psychiatric Examination  
Positive findings on Physical Examination



#### ESTABLISHMENT OF A DIFFERENTIAL DIAGNOSIS

List the most likely diagnosis first. Justify each diagnosis.



#### FURTHER INVESTIGATIONS

Medical - neurological investigations, endocrine studies, etc.  
Psychological - psychometric tests, etc.  
Social - collateral history, contact with employers, social support, etc.

#### DISCUSSION OF AETIOLOGICAL FACTORS

Distinguish between the following :

PREDISPOSING  
PRECIPITATING  
PERPETUATING  
PSYCHODYNAMICS

Where relevant, include an assessment of ego strength, motivation, intelligence, the accomplishment of developmental tasks and capacity to form a therapeutically useful relationship.



#### WORKING DIAGNOSIS

Justify the diagnosis with criteria either from ICD9 or DSM III. Use all axes if possible.

#### MANAGEMENT

This includes general management and specific treatment. Describe under the following headings :

- Medical
- Psychiatric - specify the particular treatment (ECT, medication, etc.)
- Psychological - the type and aim of psychotherapy
- Social - material assistance, work assessment, dealing with families, rehabilitation,

#### FINALLY

The FORMULATION should be revised in terms of additional information, further investigations and the progress of the case.

FINAL DIAGNOSIS: (ICD9 and DSM III - use all axes if possible)

PROGNOSIS : Express in terms of particular manifestations or functions such as symptoms, independent functioning, relapse, etc. Also in terms of the short and long-term. Specify the degree and nature of residual impairment, if any.

AFTERCARE RECOMMENDATIONS : Specify - medical, psychiatric, social, etc., short- and long-term

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