

**THE CAMP HILL EXPERIENCE:  
CONCEPTS OF WELLNESS AMONG PEOPLE WITH ENVIRONMENTAL  
SENSITIVITIES**

by

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at

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### **Dedication**

To my husband Frank, who has been there as a constant source of patience, encouragement and support throughout the years, thank you with love. In answer to your question, I want to be an anthropologist and teacher when I grow up!

For my children, Gayle, Lauren and Brendan, who have kept my feet firmly planted in reality, your mother loves you.

And, to my mother, Jeannine Watson, whose voice has been ever present, offering me love, encouragement and the ever needed, “you can do it”, thank you.

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## **Abstract**

As a health issue, environmental sensitivities generates much debate while still remaining enigmatic. Medicine struggles to place this health problem within existing classifications based upon current bio-medical paradigms. At the same time this illness contradicts the accepted societal norms for the sick role. This may be due, in part, to the paradoxical nature of this illness. The individual experiences symptoms indicative of a health problem yet, the symptoms are not consistent with any known medical diagnoses, thus, the individual must not be sick.

In struggling to conform to existing bio-medical paradigms individuals with illnesses outside of the socially and medically accepted parameters often find themselves failing to 'measure up' remaining trapped within the sick role. Success in moving towards the attainment of health and well-being requires a shift in their beliefs, attitudes and values. More importantly, this shift would be facilitated by a move within the medical model to incorporate a more holistic and less mechanistic approach to health and disease.

Socio-cultural factors play a significant role in determining the health outcome for individuals suffering from environmental sensitivities. Since the epidemiological approach has failed to sufficiently provide causality as to why some individuals remained unable to return to work I undertook research utilizing a phenomenological approach. Environmental sensitivities emerged as a health problem as a result of an indoor air quality problem at the Camp Hill Medical Center, Halifax Nova Scotia between 1987 and 1993. Prior to the indoor air quality problem all staff had been healthy, highly functioning adults.

All participants reported symptoms consistent with environmental sensitivities. They indicated that their lives had been significantly altered as a result of the exposure and subsequent development of symptoms. Through questions centering around perceptions of health and illness, both before and after symptoms began to emerge; relationships with health professionals, family and friends; and the illness experience I was able to capture the sense of environmental sensitivities. The twelve participants were drawn from three groups. The first group to be affected consisted of kitchen and housekeeping (four). The second and third groups did not report symptoms until approximately two and a half years later. They were nursing and administrative staff (four) and physicians (four).

From the interview process it became apparent that the participants held similar beliefs, attitudes and values resulting in the emergence of three significant shared social factors: de-legitimation, anger and self-awareness. These factors played a important role in impeding the individual's progress along the continuum towards health. When individuals fail to have their symptoms acknowledged by health professionals they become caught in the sick role, unable to escape. They seek affirmation of their experience in order to move through the socially defined sick role. Subsequent failure generates anger at the system, health professionals and themselves. And finally, if the individual fails to accept themselves, in spite of the limitations that may be placed upon them, they remain as 'sick' or 'disabled', unable to move forward towards health and well-being.

## **ACKNOWLEDGMENT**

I would like to extend my thanks and gratitude to the participants in this study who gave so willingly of their time in order that my project might come to fruition. Without your words our understanding of environmental sensitivities would be limited. I only hope I have done each and every one of you justice in providing voice for your story.

To my advisor, Marian Binkley and the members of my committee, Erica van Roosmalen and Liz Townsend, thank you for your words of encouragement, support and advice. Without your guidance this project might never have been completed. Marian, your enthusiasm and positive attitude are contagious.

A thank you goes out to the Nova Scotia Environmental Health Center for permitting access to their patient population. Also thank you to Dr. Roy Fox and Dr. Michel Joffres for words of advice and interest in this project.

To Ms. Jolene Muise, I owe you a debt of gratitude for helping in the typing of these transcripts. You made this work much easier for me to complete.

## **Chapter One**

### **Setting the Stage**

People say what we're all seeking is a meaning for life. I don't think that's what we're really seeking. I think that what we're really seeking is an experience of being alive, so that our life experiences on the purely physical plane will have resonances within our innermost being and reality, so that we actually feel the rapture of being alive in our bodies.

(Joseph Campbell in Levine, 1992: 106)

#### **1.1 Defining the Research Question**

As we enter the next millennium science finds itself grappling with a myriad of new and perplexing diseases such as HIV/AIDS, Ebola, Hanta, Chemical Sensitivities, environmental sensitivities, Chronic Fatigue Syndrome to name but a few. In dealing with these new and emerging health problems, the hard sciences have chosen to focus on the pathophysiological understanding of the mechanisms of disease etiology rather than seeking to incorporate socio-cultural factors confounding these new diseases. Seeking answers solely based upon direct causality and incorporating technological advances pacifies the fears associated with the unknown. Technology provides the tools whereby physiological and environmental factors may be measured, vectors classified, and genes mapped. Yet it is not enough to understand etiology, one must understand what illness and disease mean to the sufferers<sup>1</sup>, what stressors may exacerbate the disease or place the individual at greater risk of

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Although the use of the word sufferer reflects a lack of agency I felt it was necessary to employ this choice for a number of reasons. The first relates to the illness experience itself. The individual did not actively choose to have environmental sensitivities. Part of the symptomatology reflects a dis-inhibition beyond the control of the individual. Secondly, society, health care institutions, and health professionals contribute to the lack of agency and autonomy by failing to acknowledge the experience. For some individuals, the illness experience places them in a passive role. For others, the illness experience provides them with the opportunity to escape from daily life and the choices inherent



opportunistic infections and disease states and what social and cultural influences impact upon health and wellness outcomes. In order that society may better equip herself to handle the ramifications of diseases, a greater understanding of the far reaching implications that extend beyond the pathophysiological to incorporate the more subjective socio-cultural concepts becomes necessary.

At a time when society and science have come to rely upon technology and its affiliates as mechanisms through which we come to understand disease, where do the social and cultural factors influencing disease risk, causation and outcome fit? How do those who experience these newly emerging diseases come to assign meaning to the experience particularly in light of the fact that medicine and science do not have the answers to explain the process? Marginalizing illnesses such as environmental sensitivities are so poorly understood and accepted that to fully comprehend the event one must transcend the pathophysiological. In order to answer these questions this thesis looks specifically at the socio-cultural factors that determine perceptions of health and how those who have the illness assign meaning to the experience.

Within the structure of the medical paradigm of health and disease there exist specific references to empirically measurable and observable data facilitating the classification of symptoms. Embedded within the medical system are dualistic constructs between disease and illness and health and wellness. Both illness and wellness represent cultural concepts framed within the context of the individual experience. Illness and wellness draw upon the

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within that role. For these reasons I believe employing the use of the word sufferer captures the experience of environmental sensitivities, certainly in the initial stages.

socially constructed concepts of health/disease, integrating and interpreting them into a functional framework familiar to the individual and group, within a particular subculture. Practitioners within the health care system, are taught to interpret the illness experience in order that it may conform to existing medical policies and procedures. This interpretation recreates illness as disease moving it from the cultural to the scientific paradigm. Grand rounds<sup>2</sup> exemplifies a perfect example of the process wherein the subjective illness experience becomes medicalized.

The bio-medical model fails to reflect the complete experience. In so doing the story depicted becomes a partial truth. We are more than mere muscle and bone, tissue and blood. Through the interactions and reactions of our biological and socio-cultural worlds we come to interpret our experiences therein affirming our existence. In drawing these experiences into our being we shape our worlds. In effect, we embody life and all its experience.

The paradigm of embodiment stresses that the body is a subject of culture or in other words "is the existential ground of culture" (Csordas, 1990: 39). Margaret Lock and Nancy Scheper-Hughes (1987) refer to 'three bodies,' the self, the social and the politic. The body self is the life we experience. The body social is representative, symbolically, of all that we learn, socially, culturally and innate. Last, the body politic refers to the regulation and control of our bodies collectively, as well as individually, by our socially constructed health care

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In a sense, like walking tours, specialists, physicians and their entourage, usually composed of interns, residents and other health professionals, visit patients to assess and diagnosis. As part of this learning experience discussions will be conducted, particular centered around interesting, unusual or puzzling cases. These discussions are an effort to reach a consensus on diagnoses, treatment and projected health outcomes. Emphasis is on capturing the patient's experience within the bio-medical model.

system, the media's representations of health (which reflect the bio-medical paradigm), and the ideology incorporated within the scope of the health professional's practice, their texts and rationale. Once we acknowledge the adverse symptoms of illness as part of our reality and incorporate the definitions and behaviours outlined within socio-cultural norms pertaining to health and illness, we then hand over control of our body and its processes to the physicians and practitioners working within our health care system. These individuals tell us what and how we will and should experience the illness process, what is acceptable behaviour during illness and the ramifications if our symptoms fail to comply with existing illness identities. In any illness, especially one with an ambiguous or nebulous etiology such as environmental sensitivities, constructing meaning for the illness and perceptions of health and wellness would impact greatly on the 'three bodies'.

## **1.2 Scope of the project**

Miners used to carry canaries when they went underground into the mines. Though the birdsong might well have cheered the dark world in which they labored, the yellow birds were not there for that purpose. Theirs was a sacrificial role. When the dank and dangerous gases crept silently in from the stopes, it was the canaries which alerted the miners that something was dangerously amiss. When the yellow songbirds toppled over and died in their cages, the miners knew it was time to abandon their posts. The canaries were, in effect, an early warning system. Those among us who suffer from environmental illness – and there are many – may well be the canaries whose response to our chemically enhanced environment perhaps should sound the warning of what may perhaps be ahead for us all.

(Webster, 1994, May 12: A9)

Imagine yourself experiencing symptoms you may have never felt before and that these symptoms defy current medical identification, symptoms so bizarre, at times, that you begin to question your sanity. Perhaps it is only a nightmare and if you pinch yourself you will wake

up and the experience will be over. For the countless individuals with environmental sensitivities this scenario becomes their reality. The experience reduces previously highly functioning individuals to shells of their former selves. These are individuals whose short term memory no longer functions. Their sense of self escapes the normal boundaries of the body to be experienced as surreal, 'floating', bodiless. They report symptoms referred to as 'brain fog,' a type of fuzzy-headed feeling (cognitive difficulties) which are more intimidating than many commonly understood physical maladies.

Environmental sensitivities may best be considered a syndrome encompassing multi-body system symptomatology. The illness eludes the tidy fit required by the highly ordered classifications of medicine and disease. Unfortunately, due to its poorly understood nature and the fact that no causal links explaining the etiology have been made, environmental sensitivities remains an enigmatic entity existing outside of valid disease classifications.

With the inability to classify environmental sensitivities within current medicine we are faced with looking beyond bio-medical paradigms to socio-cultural factors as explanatory models. One may hypothesize that this illness emerged out of lifestyle changes made subsequent to WWII, when technology changed the way we lived, worked and managed our home and work environments.

The indoor air quality problem which occurred at the Camp Hill Medical Centre, Halifax, Nova Scotia between 1987 and 1993 was just such an example of the use of technology and chemicals in the work place. What emerged was a health problem, environmental sensitivities, that affected a significant number of staff. Over ten years after the problem first came to light medicine still finds itself unable to diagnose, define and treat the

health problem effectively. Society, as a whole, remains sceptical about the very existence of such an illness. For this reason, I chose the opportunity to investigate the meanings people attach to health and illness as it related to environmental sensitivities and how the socio-cultural factors underlying the production of meaning influenced their quality of life and ability to return to work.

As we increase the use of chemicals in the home and workplace the risks for potential health problems increases. Add the low dose, chronic chemical exposures to other underlying health risks such as stress, genetic make-up, age and one has the prelude for a 'Camp Hill Medical Centre Incident.' In effect, the problems at Camp Hill arose out of indoor air quality problems thus classifying it in the category of 'sick building syndrome' (SBS). There has been some conjecture that SBS may have developed secondary to an amine-type compound being placed in the ventilation ducts for the prevention of rust and fungus or mould growth. Within the kitchen, the causal factor was an air-borne irritant identified as sodium hydroxide from the detergent in the dishwashers (Fox, Shires, Fox, and Reudy, 1996: 352). The exhaust vent was positioned within close proximity to the fresh air intake vent.

The first reported symptoms occurred among kitchen staff in 1987 in the Veterans Memorial Building (VMB). Over the next two years approximately 127 of the 160 kitchen staff were affected to varying degrees (Fox et al. 1996: 352). Issues surrounding indoor air quality were addressed but staff continued to report symptoms. At the same time other staff throughout the hospital began to report symptoms which were not linked, at that time, to problems in the kitchen. In late 1989 the first cases of staff, outside the kitchen, with similar symptoms were reported on the second floor of the Veterans Memorial Building. The severity

of symptoms progressed along with the number of staff reporting them. Between 1991 and 1993 approximately 700 of the total workforce of 1250 reported symptoms. Over 300 workers were off work for periods ranging from three months to three years (Fox et al. 1996: 351). As of this writing the unofficial statistics at the Nova Scotia Environmental Health Centre have approximately 100 Camp Hill staff unable to return to work due to health problems stemming from the initial indoor air quality problems<sup>3</sup>.

During the course of this epidemic, it became apparent that the symptomatology or clinical features manifested did not fit into any one widely accepted disease category or syndrome. Unfortunately this problem persists today, stoking the debate on whether or not environmental sensitivities actually exists since it defies current medical definition. What may not be discounted is the fact that these individuals have, in some way, been affected by the indoor air quality problems of the building. As the Nova Scotia Environmental Health Centre continues to see individuals from all walks of life who exhibit symptoms similar to those reported by Camp Hill staff, observations have been made that lead the Centre to believe that environmental sensitivities is a multi-system dysfunction due to multi-factorial influences, biological, psycho-social, emotional and spiritual in nature. Most importantly though, regardless of the factors implicit in the underlying cause of the phenomenon, the majority of individuals exhibit clinical features consistent with an inability to tolerate low level irritants in the everyday environment.

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The numbers are estimates taken from our patient population at the Nova Scotia Environmental Health Center. Dr. Roy Fox has approximated these numbers in co-operation with the Occupational Medicine Department at the QEII, Camp Hill Medical Center.

Pathophysiological changes leading to the multi-system health problems are not well understood. Rather than making the claim that environmental sensitivities is a new disease or that the individual has concurrent multiple idiopathic conditions (Fox et al. 1996) the Nova Scotia Environmental Health Centre proposed that 'environmentally induced dysfunction' (EID) be considered as the operational definition for this state of ill health. (See definition classifications Figure 1.1). Because of the exacerbation of symptoms in multiple systems upon exposure to environmental irritants EID patients classically present with two major historical features:

1. The gradual but unremitting descent into ill health, usually over a period of more than three months by the time of presentation;
2. The development of distressing symptoms in more than one organ system aggravated or precipitated by exposure to environmental irritants.

(Fox et al. 1996: 353)

### **Figure 1.1 Defining environmentally induced dysfunction (Fox et al. 1996: 356)**

Pre-existent or associated conditions like asthma, irritable bowel syndrome, arthropathy, migraine, etc., are included.

1. Chronic ill health > 3 months.
2. Evidence of dysfunction and absence of definite pathology.
3. Symptoms and/or signs.
  - a) in multiple systems
  - b) wax and wane
  - c) provoked by exposure to certain environments (e.g. school or workplace)
  - d) ameliorated upon removal of triggers or irritants
  - e) clear or significantly improve in a very clean environment
4. Most patients have nervous system dysfunction or cognitive impairment such as poor memory, difficulty concentrating, dizziness, irritability and mood swings.
5. Most patients have evidence of autonomic nervous system dysfunction, such as inability to keep warm, cold extremities, Raynaud's phenomenon or night sweats, inappropriately warm, vasodilated extremities and flushing episodes.

These reactions occur upon exposure to irritants considered to be of insignificant dosage level to produce symptoms in the average individual. When the individual removes themselves from the offending irritant, or avoids the irritant, symptoms subside. Complicating the problem is the inconsistency of the production of symptoms to identical irritants.

Perhaps one of the most challenging aspects facing health professionals working in the area of Environmental Medicine is to define environmental sensitivities. Many definitions have been put forward, some more descriptive in nature than others, but all fail to adequately encompass the etiology and symptomatology of this illness. The most frequently cited definition has been put forward by Dr. Mark R. Cullen which states that 'multiple chemical sensitivities'

is an acquired disorder characterized by recurrent symptoms, referable to multiple organ systems, occurring in response to demonstrable exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. (Cullen, 1987: 657)



Not only is it an issue of how to define this problem but what to call this illness. Names range from Multiple Chemical Sensitivities, to Environmental Hypersensitivity Syndrome, Environmental Illness, Environmental Irritant Syndrome and more recently environmental sensitivities<sup>4</sup>.

Statistics indicate an increase in chronic or long-term health problems within the Nova Scotia population. *The Nova Scotia Health Survey 1995* reports Environmental Sensitivities at 3 percent of the provincial population—2 percent male and 3 percent female (Nova Scotia, Department of Health 1996: 45). In *The Archives of Environmental Health* Meggs et al. state that individuals with allergic symptoms comprise 5.3 percent of the total population. They further state that individuals reporting both chemical and allergic problems made up 16.9 percent of this population and those with chemical sensitivities made up 18.2 percent (1996: 275-282).

Symptoms may range from the mild to significantly disabling. The severity is not always consistent with exposure as well. Much depends upon the 'overall load' of the individual. In conceptualizing 'load' a rather non-scientific term, we consider all factors or stressors that may impact upon an individual's overall health at that given point in time. Increase the stressors and you increase the risk and severity of the symptoms experienced.

In considering environmental sensitivities within the framework of increased 'load' or body burden and attributing this to stressors which may be biological, psychological, social,

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Multiple Chemical Sensitivities is rarely used today partly because of the limiting characteristics of the name. The NSEHC prefers to use the name environmental sensitivities as it is more reflective of the nature of the illness and possible triggers—multi-factorial, multi-system problem.

cultural or emotional the stage is set to examine health within a broader context. With this in mind I chose to explore the issue of health within the context of environmental sensitivities. More specifically, to look at health and illness and its meaning for staff at Camp Hill Medical Centre who had been affected.

### **1.3 Methodology and ethical considerations**

Since I had researched the material on environmental sensitivities and worked with patients with environmental sensitivities in the capacity of a Clinical Nurse Specialist at the Nova Scotia Environmental Health Centre I felt semi-structured interviews would provide me with an understanding of the phenomena from the perspective of the narrator. I wished to have people with environmental sensitivities reconstruct their experience and explore their meaning of health and illness<sup>5</sup>. The importance of capturing the experience of environmental sensitivities will be achieved through the use of open-ended questions as opposed to the more limiting structured survey question. This was necessary to gain insight into a poorly

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Initially I had hoped to include a participant observation of the support group CHEVS (Camp Hill Environmental Victims Support). Unfortunately I was unable to include this aspect as part of the study because of difficulties within the group. The President felt that my research would find nothing of relevance by observing their group. Concurrently, this group is undergoing significant changes regarding the mandate, agenda and membership. Rather than force the issue, even though participants were more than willing to have me observe, I felt it was preferable to abide by her wishes. I still contend that support groups play a valuable role in assisting individuals to move forward. They may also have an adverse effect upon members dependent upon the dynamics and agendas within the group. I had also intended to access health records to compare patient and health professional interpretations of the experience. Due to the logistical difficulties of gaining access to charts at the QEII Health Sciences Center I chose to leave this aspect of the study out. The Nova Scotia Environmental Health Center is in the process of meetings with the QEII to address concerns for those staff who continue to remain off work. To seek access to the charts might be construed as interference at this time.

understood illness.

The purpose of a stratified sample was to sample the widest variation of sites and people within the limits of the study. The prerequisites set for this study were as follows:

- ◆ the participant must have been employed at the Camp Hill Medical Centre between 1987 and 1993
- ◆ the participant must have documented symptoms consistent with a diagnosis of environmental sensitivities.
- ◆ the participant must have been off work for a minimum of three months as a result of environmental sensitivities.
- ◆ fifty percent of participants will have returned to work in some capacity and not necessarily at the Camp Hill Medical Centre
- ◆ the participant will have been or is currently a client of the Nova Scotia Environmental Centre

What became apparent, once I began to search for participants was that the prerequisites were too limiting for some groups. Physicians, for the most part, did not take time off, nor were they clients of the Nova Scotia Environmental Health Centre, although they did report symptoms consistent with a diagnosis of environmental sensitivities. Another group that presented with problems was kitchen, housekeeping and maintenance. The majority of staff from this group remain off work today.

To enhance the understanding of environmental sensitivities personal interviews were conducted. It was not a simple matter of walking in off the street and asking to speak to individuals who had been employed at Camp Hill during 1987 to 1993. This required enlisting

the cooperation of staff at the Nova Scotia Environmental Health Centre. Nursing staff at the Nova Scotia Environmental Health Centre identified potential participants based upon the aforementioned limitations, contacted and informed them of the nature of the study. Confidentiality had to be ensured. Once the initial contact had been made I was then able to explain my project to potential participants. Consent forms were signed acknowledging their understanding. They were provided with the opportunity to choose pseudonyms to be used for the purpose of the interviews. Nothing would be included that would identify the individual in any manner. Staff were not allowed access to the transcripts or tapes. Tapes and transcripts have been kept in a locked and secure fashion. Once the project has been completed the tapes will be erased. By ensuring anonymity and confidentiality the individuals were more comfortable to take about the experience. The information was far richer than it would have been if I had not taken these measures.

An initial appointment was set up for me to make first contact, inform them of the purpose of the research project and receive their informed, signed consent<sup>6</sup>. I interviewed twelve people who were divided into three categories listed below. It was my goal to have two participants who were 'well' and two who were 'ill'.

The groups were chosen based upon the events as they coincided with the reporting of symptoms:

- kitchen, housekeeping and maintenance staff (1987)
- nursing, ancillary health professionals, clerical (1989-91)

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<sup>6</sup>

For ethical considerations see the section of ethics. For a copy of the consent form see the Appendix.

- physicians (1989-91).

(For further rationale regarding group selection see the Appendix).

Initially it had been by intention to have two individuals who had returned to work and two who remained off because of the illness, within each group. The purpose of structuring the interview population in this manner was to provide a representative accounting of the illness experience. Unfortunately this proved to be problematic. Finding physicians who remained off work due to environmental sensitivities resulted in only one member rather than two. Within the category of kitchen, maintenance and housekeeping I was able to have access to one individual out of four who had returned to work. (See Figure 1.2 for Participant information).

**Figure 1.2 PARTICIPANTS AT A GLANCE<sup>7</sup>**

<b>Name</b>	<b>Age</b>	<b>Job Status</b>	<b>Onset of Symptoms</b>	<b>Off Work</b>	<b>Return to Work</b>
Sylvia	50-59	Nurse	July 1991	Sept. 1992	July 1997 FT
Patricia	40-49	Head Nurse	summer 91	Nov. 1991	no
Greta	50-59	Physician	March 1992	Nov. 1992	no
John	30-39	Housekeep	late 1991	June 1992	no
Phyllis	40-49	Kitchen	fall 1989	Dec 1991	no
Diane	40-49	Admin	1989-1990	Jan. 1993	no
Lewis	30-39	Housekeep	Nov. 1990	early 1991	no
Alexis	30-39	Nurse	1990	Feb. 1992	1996 FT
Chloris	30-39	Kitchen	1991	Dec. 91-93	1993 now FT
Philip	50-59	Physician	1990/91	1991	1994 FT
Moirra	30-39	Physician	1991	no	FT
David	40-49	Physician	1991	no	FT

Once the participants agreed to the study a time was established for the interview. The study was conducted at the Nova Scotia Environmental Health Center. I felt that the Center would provide a unique and 'safe' environment for the participants during the course of the interviews. Since part of the illness experience comprises reacting to very low level irritants, which the average individual cannot detect, it was imperative that a safe environment be utilized to promote the functioning of these individuals at an optimal level cognitively,

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7

Due to the small population and the close relationships that many of them share I have chosen to keep characteristics to a minimum in order to protect the participants from identification.

physically, and emotionally. Although the Nova Scotia Environmental Health Centre was offered as the site of choice individuals were provided with the opportunity to change the location to a more comfortable one. Four individuals preferred to have the interviews conducted off site. All but one participant agreed to have their interviews taped (interviews ran approximately 1.5 to 2 hours) and requested copies of their transcripts upon completion of the study. The tapes were transcribed by a research secretary at the Nova Scotia Environmental Health Centre and myself. The research secretary was informed of the issues surrounding confidentiality and that she should not discuss the material with anyone other than myself. Once completed the text was categorized based upon common themes that had emerged and then organized<sup>8</sup>. The process of marking and sorting passages was done manually<sup>9</sup>.

Environmental sensitivities fails to be classified within current disease nosology<sup>10</sup>

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8

Reisman (1993) advocates that textual material be organized through the use of profiles or through categorization based upon common themes. This facilitates the researcher in making sense of the story at a social and individual level. I chose to organize my transcripts by categories.

9

I had started to use NUD\*IST, a qualitative data analysis software package, but due to time constraints opted to forego the process, in part because of my lack of complete familiarity with the program. Rather, I chose to employ a method of manually coding the transcripts looking for emerging themes. I then compared the themes among all the transcripts identifying those shared by all participants. Themes that were consistent to all individuals based upon the frequency within which they appeared, the prevalence and emotion attached to them were then discussed within this thesis.

10

Nosology is the medical discipline's method of classification for existing disease entities. Those symptoms that defy classification may be assigned the designation of syndrome. At the time of this writing, Environmental Sensitivities has yet to be classified or adequately defined except in the broadest sense. By World Health Organization (WHO) standards

utilized by the medical profession to define the parameters of illness. Nosology defines, objectively, through specific symptoms that which constitutes a valid disease. The sufferer defines illness subjectively through the interpretation of symptoms based upon the lived experience. This distinction between 'being representative' of disease, through the objective meaning attached to symptoms, and 'being-in-the-world' through the subjective lived experience, presents a duality in ascribing meaning to illness<sup>11</sup> (Csordas, 1994). As a result of these distinctions a duality exists between science and experiential knowledge, between object and subject. Inherent within this dualism lies a dichotomy between positivistic and humanistic epistemes. Positivism is considered a science and by its nature has universal applications. On the other hand, time and space influence humanism. How we embody health and disease becomes a function of living and experiencing all that acts, reacts and interacts with us both past and present. This sense of 'being' is integral to the conceptualization and re-conceptualization of illness, health and wellness eluding homogeneous applications.

I believe that to understand the issues underlying environmental sensitivities the voice of the sufferers must be heard. To explore documented evidence alone would have provided a very narrow picture of this issue. This was a unique population having experienced the same

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environmental sensitivities has been designated a syndrome with a definition that is more a listing of possible symptoms than an explanation of the significance of its character.

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In the former the symptoms are accepted as an indication of a valid disease (such as frequent urination, increased thirst and weight loss is associated with diabetes) as predetermined by medicine. The latter would be the less specific symptoms reported by the individual, who themselves knows that something is amiss, but as yet is unsure as to what (such as 'I just feel off' or 'I am tired and I find it difficult to concentrate'—this from an individual who was previously a workaholic and well-organized individual). The former is science the latter is not.



initial exposure. Their symptomatology was quite similar as a result of the indoor air quality problem at that time. Many of our patient population, diagnosed with environmental sensitivities come from a variety of work and social backgrounds. In examining Camp Hill, we had people working in the same building albeit, in a variety of jobs. This provided an opportunity to examine whether or not socio-economic status and education played a role in how the individuals assigned meaning to the same illness.

#### **1.4 Placing the project in a theoretical context**

I felt that the most appropriate method to come to a clearer understanding of the issues of health and illness, as they relate to environmental sensitivities, was to focus on the ideology of embodiment. The body has been visualized as comprised of three arenas. The first arena, the body self represents the perceptions of illness as experienced by the staff who became ill. Their interpretations were based upon life experiences temporally and spatially located up to the time of the interview.

Two other arenas, as part of the holistic body, also exerted influence on interpretations of health and illness. The first of these entailed the impact of socio-cultural norms, beliefs, values and attitudes on the perceived sense of health and wellness, or body social. Included in this category were the interactions of the sufferers with other members of their peer group as well as family, friends and society at large. Last, health care institutions, specifically Camp Hill Medical Centre, government institutions such as Workers' Compensation Board (WCB), Medical Service Insurance (MSI), and health professionals represented the socially constructed, medical epistemology of health and wellness. As a health care institution espousing socio-cultural norms, rules and regulations, the body politic is embodied here.

It is not enough to analyse the health-illness experience from the perspective of the individual body or phenomenological sense of the lived experience. One must seek to determine the impact of the social body and body politic upon the lived experience in order to achieve a clearer understanding of how environmentally sensitive individuals come to conceptualize wellness. In what way do people with sensitivities incorporate, or attempt to incorporate, belief systems (i.e. sick role) or definitions of health and illness embedded within the larger culture into their individual experience?

Evans and Stoddart (1994: 47) define health as the individual's perception of his/her physical, mental and social functional capacity. A summary of the effects of impairment or disability on the individual's quality of life<sup>12</sup> is included within this perception. Rather than health, Dossey et al. (1995) prefers to look at wellness as a subjective measure of optimal health which hinges upon the life process. Illness, on the other hand, is the sufferer's interpretations of a set of symptoms for which they seek meaning. Disease is the objective assignation of poor health or biological dysfunction by the medical community, which can be recreated based upon theories of disorders (Kleinman, 1988). Disease constitutes the validation of the lay interpretation of symptoms (Kleinman, 1988). The interaction between all four concepts leads to the production of a health-wellness-illness-disease paradigm.

Boundaries concerning what constitutes the health-wellness-illness-disease paradigm within environmental sensitivities remain enigmatic. Scientists and health professionals have yet to come to a consensus on the definition and symptomatology of this newly emerged

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The ability to enjoy and participate in life to the fullest of their ability (Spilker 1996: 364).

phenomenon. For those experiencing this illness it becomes the centre of their reality as a result of medicine's failure to be able to recreate the diagnosis in a set of specific symptoms. The tenacious nature of this illness, within the bio-medical paradigm, gives rise to a dichotomy between the subjective reality of physiological symptoms experienced by the individual and the objective socially constructed reality of disease.

In Western medicine, a dualistic and reductionist social construct, the practising physician places greater emphasis on the rhetoric of scientific rationality than on the subjective, value-laden illness experience of the patient (Kirmayer, 1988; Gordon, 1988). A powerful ideology exists within medicine conceding disease as fundamentally biological. In actuality, the practice of medicine revolves around the body and pathology (Good, 1994: 70). Should a sick person's symptoms defy existing medical explanatory models or if the disease state can not be alleviated, the science of medicine may 'disqualify the patient's suffering or moral agency' as of little consequence or non-existent (Kirmayer, 1988). Little attention is given to the psychological, emotional, behavioural or spiritual influences that may impact upon the sick person. This strict adherence to empirical rules about the human body as a fixed, material entity, unchanging and subject to the rules of hard sciences fails to embrace the very essence of human nature, that of being in the world. Our experiences, both internal and external to the human body endure and reflect the illness event.

Within the context of environmental sensitivities little research has been conducted pertaining to the phenomenological experience of illness. The sick person attempts to construct an objective reality, a socially defined and accepted reality, within the context of the subjective experience of illness. Coexisting within the phenomenological certainty one finds

an ideology of the body. To separate the body from the experience would be to separate the conscious from the unconscious, the mind from the body (Descartes' dualism). The body reacts and interacts to the symptoms that present and represent the illness. These symptoms may range from the physical to the metaphorical but regardless, all carry with them meaning which defines the experience.

Medical Anthropology has made broad generalizations concerning how the embodied experience, the subjective reality of the illness and the divergent, socially constructed, objective reality of medicine interact to support the construction of the health-wellness-illness-disease paradigm (Good, 1994; Kleinman, 1988; Csordas, 1994; Frank, 1995; Morris, 1991; Lock and Scheper-Hughes, 1987). Unfortunately, although current literature exists on the embodied experience for diseases such as neurasthenia, psychiatric disorders, pain, cancer, and HIV/AIDS I have been unable to locate specific references or studies to the cultural and sociological aspects of illness-wellness meaning for people with environmental sensitivities. Since this illness does not occur in isolation but, rather as the result of complex, myriad sets of interactions incorporating the personal, subjective life experience, group interaction and conceptualization of the illness-wellness process, physician-client relationships and societal perceptions of illness and wellness, it becomes necessary to explore all facets of the health continuum. By incorporating the ideology of the embodied experience, within the context of environmental sensitivities, my thesis elucidates how people with this illness conceptualize wellness.

### **1.5 The Debate**

The staff at Camp Hill Hospital began to experience symptoms and to question the

hospital's Department of Occupational Medicine and their family doctors. As a result the ensuing controversy surrounding diagnosis and treatment of environmental sensitivities began to emerge. Numerous newspaper articles, reports, physicians and specialists interpretations of the situation brought the public's attention to this medical crisis. In my reading of the articles and reports it became evident that significant polarities existed. Those who supported the concept of environmental sensitivities ascribed to a more liberal and open-minded approach to medicine and disease nosology. At the same time the textual construct still closely paralleled the biomedical rather than a more bio-cultural model. Those in opposition to the acceptance of such an illness tended to fall within positions of power such as the health institutions and medical and insurance boards. To accept something that defied scientific rationale would be to challenge their existing belief systems which had, in the past, appeared to work well for them. Bruce Collins, a spokesperson from the Workers Compensation Board stated that the board would not pay for treatment of an illness it doesn't recognize.

"We don't recognize multiple chemical sensitivity or total allergy syndrome and neither does MSI [Medical Services Insurance] or any [workers' compensation] board in Canada.

(Mellor, August 22 1992: B1)

Even Camp Hill was trying to isolate the problem to staff only and released a report to the *Mail Star* in 1991 in which Kevin McNamara, vice president of human resources for the Camp Hill Hospital stated

he doubts that the two patients – one of whom had dry eyes and another a rash that subsequently disappeared – have been affected by whatever has bothered staff form many months, but they want to be sure.

(Staff Reporter, October 9 1991: A5)

The papers reported that many of the affected staff at Camp Hill believed that “traditional medicine has failed to help them, so they sought treatment from holistic doctors, whose services are not covered by MSI [Medical Services Insurance]” (Tibbetts, April 8 1993: A6). Nurses reported feeling betrayed, let down and ignored by the medical community and the provincial government, areas that as a society we have come to rely upon for support in time of need.

The [Premier] Savage Liberals, after definitively stating last May that environmental illness exists, are no longer certain about its definition or diagnosis. The new-found uncertainty might be defensible, were it not for the effects it will have on about 180 suffering employees of the Camp Hill Medical Centre.

(Editorial, November 25 1992: C1)

Without definitions and diagnostic tools illnesses that fall outside of text book medicine result in the sufferer being doubly penalized. The first as a result of the illness and the second by society and the medical community who deny its existence thereby stigmatizing those individuals reporting the health problem.

When Ann Thompson (a nurse from Camp Hill) won her appeal for compensation relating to environmental sensitivities a sense of vindication was felt, not just by this nurse, but by many other Camp Hill sufferers. By this time the staff had been battling for recognition of this illness by the medical community, health care institutions and society for nearly eight years. Their belief, albeit short-lived, was that their symptoms and the cause had finally been recognized. Although “WCB is forced to accept environmental illness as real and employment related, and the decision validates the treatment and therapies these people need” (Peters, August 16 1995: A5) this ‘acceptance’ did not last. Denials, recriminations, and outright

rejection of the illness, prior to this decision led to much anger, helplessness and frustration not only with bureaucratic institutions such as Workers' Compensation Board, MSI, and Camp Hill, but with family physicians and colleagues, individuals considered to be a support network to legitimate the experience. This decision was not to be the victory that many had thought it would be. For all intents and purposes it was just a further example of the lengths to which medicine and bureaucracy would go to deny the existence of such a health problem. WCB failed to recognize this compensation award as precedent setting thereby putting all individuals through the same process, many who have since been denied their claims based upon insufficient understanding of the illness and a reliance on an archaic medical model whose scope is far too reductionist to address the diseases that have emerged since WW II.

Newspapers are not the only forum in which to address the Camp Hill phenomenon. A number of reports have been written stemming from the Camp Hill Medical Centre experience. Two of the more frequently cited are the often referred to 'Cullen Report' (Nova Scotia Department of Health, 1996) and the Report of the advisory committee on environmental hypersensitivity (1986 and 1997)<sup>13</sup> sometimes referred to as the Langley Reports. Dr Cullen had been contacted by the Nova Scotia Nurses Union subsequent to the health crisis at Camp Hill. His initial role was therapeutic rather than diagnostic in that his role was to educate, conciliate and provide therapy for affected staff. His assessment was that of a chemical exposure of some form which affected individuals but that other internal and

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This committee penned an initial report in 1986 which denied the existence of environmental sensitivities stating that other health conditions were the actual cause. In their updated report in 1997 they acknowledged that the individuals were ill but that further research was required in order to determine exactly what the health problem was.

external factors such as work place stress stemming from institutional structure and policies, management and fear (message sent out to people about the problem) all had an additional impact on health outcomes for the individuals (Cullen transcripts in the Nova Scotia Department of Health, 1996: 13). Cullen's comments indicate that, without dispute, the individuals had their health adversely affected and were indeed ill.

Contrast this with the initial report from the Advisory Committee on Environmental Hypersensitivity, chaired by Dr. Ross Langley, which depicted the individuals as more psychiatric in nature (1986). The second report by this committee (although some of the members had changed), in 1997 concluded that the individuals "are ill, and some are seriously disabled" (Advisory Committee on Environmental Hypersensitivity, 1997: 49) They identified the causal agent(s) and pathogenesis of affected individuals as unknown, stated the extent of neuropsychiatric involvement requires further empirical studies, called for treatments which included supportive measures and treatment of concurrent illnesses (Advisory Committee on Environmental Hypersensitivity, 1997).

Many affected individuals have given up the fight from sheer exhaustion and financial hardship. Perhaps this was the intent of these institutions from the onset. In listening to the debate and the voices of those who feel they have been ignored, it becomes apparent that it has changed their very lives.

It has been a terrible thing to have to fight. I'm really a very placid individual...but this has changed me, having to fight every step of the way.

(Mellor, December 1 1993: A1)

It's our livelihoods they're talking about; it's our health that's being frigged and we don't have a say.



(Ward, October 29 1993: A6)

If medicine and the establishment do not pull their heads from the sand and reevaluate their approach in order to address the issue the likelihood of this scenario improving is doubtful.

One might also wish to ask if a relationship exists between the meaning we seek in life and illness? How do we arrive at meaning? Do we base this meaning solely upon the epistemology of bio-medicine or does culture play a significant role in the production of disease and outcome trajectories for the individual affected by environmental sensitivities? The previous pages have set the tone for this discussion. It has become apparent that all players, sufferers, health professionals and society have an investment in the illness process, meaning and outcome. The manner in which each interprets meaning may be attributed to cultural influences, socio-cultural norms and belief systems pertaining to the sick role and behaviour.

By taking illness and disease beyond the epidemiological greater insight emerges into the very nature of environmental sensitivities. This thesis illustrates that humans and the illness experience do not exist in a vacuum to be explained away on the basis of bio-physiological causality. Culture shapes and influences the meaning of environmental sensitivities, contributes to outcomes and bestows power and control on those capable of interpreting its significance.

In the following chapters a literature review will reinforce the view taken by this author that a greater understanding of the illness experience and how individuals perceive wellness is reflected through the concept of embodiment. Further, the voices of the participants will be heard in the case study as they talk about the experience of having an illness that is poorly understood and accepted, both medically and socially. Through the participants we gain

insight into the emergence of an illness, the impact of the experience on their lives, and the social and cultural influences effecting their health outcomes. Finally, I discuss the implications for research, health professionals and health care in taking into account these experiences in order to understand marginalizing illnesses.

## **Chapter Two**

### **A review of the literature**

**Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick.**

**(Susan Sontag, 1978: 3)**

At some point in our lives each and everyone of us will experience illness of one form or another. This experience provides the common ground for communication, empathy and understanding. Illness becomes something that we may all relate too; that subjective intangible something that defines who we are in relation to others, that orders, or more importantly disorders 'normalcy'. Carolyn Myss talks about 'woundology' whereby we use the exchange of or revelation of wounds as a form of "relationship currency" (Myss, 1996: 209). This sharing of experience of loss, injury, illness or tragedy provides a common language enabling those with similar circumstances the ability to support and to validate others in their 'group.'

At the same time, for those of us considered as non-sufferers, it provides a mechanism by which we come to understand the depths of the experience, an experience that reaches far beyond the physical realm to encompass all that is human. It is our 'body' and how we view it that comes to life in woundology.

"It is said that prison fabricates delinquents.." (Foucault in Schatzki, 1996: 55) but does medicine fabricate patients? Practices inherent within the bio-medical model create the sick role through the shaping of our existence and, by default, the perception of our self. One such practice, intrinsic to medicine, affords physicians the ability to confer a diagnosis of disease which carries with it all inscribed behavioural patterns delineated by medicine and

society. Second, a fundamental episteme of medicine is the Cartesian dualism of the mind-body split separating the experience or subjective construction of the illness process from the objective verifiable corporeal body. Finally, medicine establishes the appropriate mechanism of communication between the physician and sufferer. By seeking to conform to a given paradigm the individual becomes the patient and the experience is legitimated. For some this experience is not complete and the sense of self, of embodiment, of who they are is caught up in the struggle to achieve the legitimation of the process. Their disease impedes completion assigning the individual to the realm of an anomaly by virtue of lack of verification.

This sense of in-completion of the process has created an internal struggle for the person with this disease. To understand the illness and its impact on the individual requires an alternative method – one that may step outside the scientific realm of medicine to explore the meaning of health and disease through the theories of phenomenology and embodiment.

## **2.1 Understanding Phenomenology: the embodied experience**

What is phenomenology and how does grounding a research project in this process increase our understanding of disease entities? Specifically, this methodological tool provides a philosophical foundation free of presupposition, descriptive in nature as it endeavours to uncover the intention, consciousness and life world (*lebenswelt*) or meaning of that which we study in the social or applied sciences. It is the lived experience. To understand the social world (itself a construct) requires interpretation. Those who engage in phenomenology attempt to ‘construct objective accounts of subjective reality’. In essence, the lived experience is no more than a construct of a construct (Kuper and Kuper, 1996: 603).

As illness is a lived experience, an experience that “threatens to undo our senses of who

we are” (Morris, 1998: 237) meaning becomes quite apropos in the interpretation and comprehension of this state. Illness forces the sufferer into a foreign reality that bears no resemblance to the everyday world they are familiar with. The foray into an alien environment may be temporary or prolonged. For some, illness requires the construction of a new reality, a new framework from which ‘normal’ becomes redefined and experiences re-conceptualized. In order to adequately comprehend this existence one must look further than the test-tube, X-ray or other modern technology. It requires the sufferer and researcher to explore new terrain, to toss out universality in favour of heterogeneity. Existing benchmarks from which we previously conceptualized health and disease no longer apply.

## **2.2 Through the Eyes of the Sufferer: the body self**

Historically, the body has been omitted from the scholarly work of anthropology except to reflect the empirical rules of nature, that of the body as a fixed, material entity subject to the rules of biological science, exempt from cultural and social influence. A renewed interest in the human body, as a subject of study, extending beyond the corporeal boundaries, to encompass life experience, arose in the 1970's. Feminist theory, philosophy, psychology, sociology, religion began to problematise the body. Rather than focussing on phenomena where they end, such as health and disease, we are seeing a shift from "the end of one kind of body [to] the beginning of another kind of body" (Martin, 1992: 121). Donna Haraway (1988) argued that we have positioned our search for knowledge within the constraints of hierarchical, reductionist thought. The subjective body has been translated to a universal language of the hard sciences precluding the subjective experience. A more critical theoretical approach to "how meanings and bodies get made, not in order to deny meanings and bodies,

but in order to build meanings and bodies that have a chance for life" (Haraway, 1988: 580).

In seeking to incorporate an embodied approach to health and illness the body becomes the subject of culture or the basis for the existence from which culture may be derived. Earlier, I had discussed Margaret Lock and Nancy Scheper-Hughes concept of the human body as composed of three cultural concepts, the individual, social and political. If we think of the integration of these three bodies it becomes easier to comprehend how each and everyone of us come to interpret, understand and assign meaning to all our experiences. We do not draw from one world but from many. Our own personal experiences, the larger social context within which we move and the way we relate to power structures influence the events or illness outcomes that occur. This 'lebenswelt' shifts continually as opposed to remaining in stasis.

To understand concepts of health and illness one has to understand the intricate relationships between subject and object, between perceived and real. Sensory experience or symptoms find meaning only as it "involves a reference to the body" (Merleau-Ponty, 1962: 52). At the core of human experience lies the ability to recognize, to acknowledge the existence of the experience, not through inference or perception, but because one has had contact with that existence. We know we are ill, that our body manifests symptoms incongruent with a state of health, because we *know* what it feels like to be well, to be symptom-free. The sense of embodiment, of experiential knowledge is not "*because* I think I am that I am certain of my existence: on the contrary the certainty that I enjoy concerning my thoughts stems from their genuine existence" (Merleau-Ponty, 1962: 382).

The human body experiences pain, reactions, dysfunctions as a sensation interpreted by the brain. How we perceive the sensation results from our ability to recognize and attribute

a sense of knowing to the experience.

At the root of all our experiences and all our reflections, we find, then, a being which immediately recognizes itself, because it is a knowledge both of itself and of all things, and which knows its existence, not by observation and as a given fact, nor by inference from any idea of itself, but through direct contact with that existence.

(Merleau-Ponty, 1962: 371)

The very experience of illness defines its reality, affords it the status of object rather than subject. The ill person experiences reality bodily and as a result of these feelings or sensations, whether physiological or cognitive, afforded existence. Their visceral reactions are congruent with their perceptions of health and illness but incongruent with the socially and culturally perceived reality of what constitutes health and illness. For them, "whatever is real has meaning [Oakeshott, 1922]" (Kleinman et al. 1978: 58).

The body is imbued with social meaning, as both subject and object, temporally situated, it not only signifies belonging and order, but represents the dual mode of internal bodily expression which is culturally produced and a dialectical exchange with external social life (Lock, 1993: 136). The body exists as an extension of that to which it belongs both, internally as the lived, personal subjective experience and externally as the socially constructed, objective reality. Embodiment is a "turn towards the body represent[ing] a longing for community, for bodily connection and participation in a habitable world of substance and feeling" (Kirmayer, 1992: 324). Sickness places the body in the foreground, as the chalice of experience, challenging preconceived notions within the ontology of medicine which imbues disease as a disembodied reality, a rational, empirically constructed theory that does not entertain notions of subjective suffering (Kirmayer, 1988 & 1992; Kleinman, 1980 & 1988;

Good, 1994).

The concept of illness underlies all disease as the sufferer's interpretation of a cluster of symptoms -- the subjective reality. The sick person infers illness meaning as a direct result of their perception of the 'lived experience'. This lived experience does not arise in isolation but evolves through multi-factorial processes internal and external to the individual. Biomedical and socio-cultural factors, along with personal experience ( memories generated from the life history of the individual ) interact in intricate fashion to construct and reconstruct the illness experience. Individuals experience a subjective reality of bodily symptoms but the objective reality becomes the socially recognized construction of these symptoms as disease. Further, the objective reality predetermines what constitutes wellness. This relationship between the embodied experience of the individual and the socially prescribed, culturally collective experience finds itself imbedded in the empirical, epistemology of the hard sciences which serves to conceptualize wellness for the sufferer.

### **2.3 Society: how interactions shape our world or, the body social**

The social body refers to the representational use of the body as a symbol vis-a-vis science, culture and society. To understand this concept one must view the body as a function of structuralism, of order and control, and of symbolism, of representative of a shared set of beliefs (Lock and Scheper-Hughes, 1987; Kirmayer, 1992).

The human organism and its natural products of blood, milk, tears, semen, and excretis may be used as a cognitive map to represent other natural, supernatural, social, and even spatial relations.

(Lock and Scheper-Hughes, 1987; 18-19)

The body provides a natural source of metaphor, culturally and socially constructed to sustain



particular views of society and social relations. Within these constraints or social norms are the guidelines for health and illness, expectations of specific types of behaviour congruent with the level of illness, compatible outward signs of stigmata that indicate to society at large -- 'this person is sick'. For example, the individual with cancer becomes increasingly thin, bordering on skeletal, their skin sallow or grey, eyes often appear lacklustre. Diabetics exhibit a certain body fat distribution -- heavier around the midline with narrow hips-- and may be seen injecting themselves with insulin or checking their blood sugar levels.

Illness must be identified and meaning established before one may proceed to address any concerns stemming from the illness. Parson talks about the 'sick role' as part of the 'role identity' in the illness process. People feel the need to fulfil expectations within the various roles (Layder, 1994) -- in this instance, the need to fulfil the role of the sick person once the diagnosis is made or legitimated through the medical model. How others perceive the performance of this role influences "the view of think[ing] of [oneself] being and acting as an occupant of that position" (McCall and Simmons, 1978: 65). Behaviour continually changes based upon the perceived interpretations of the performance. This frame of reference within which we assign meaning depends upon these interpretations, yet the interpretations ultimately conform to socio-cultural norms regarding roles, behaviours and scientific definitions of health and illness. With meaning, embodiment may then be derived; without, it becomes the disembodied experience. The lack of validation of the experience increases the likelihood of stigma.

Essentially the sufferer has become one of '*them*,' has fallen into that ambiguous and oftentimes nebulous area of the ill or symptomatic. The illness has changed their ability to

interact with others, relationships, autonomy and control. In its place stigma and shame personify the person. It colors their interactions, establishes the basis for non-sufferers behavioral responses, and determines the health outcome for the individual by default. Often times the result is one of 'victim.' This role becomes increasingly difficult to exit from as the individual increasingly identifies themselves as deviant, as different from the norm, as one of them.

Stigma has come to mean an attribute, possessed by an individual, that separates them from others in the same group. As a result, the individual becomes viewed as tainted and any contribution that they may make, whether verbal or non-verbal discounted (Goffman, 1963). The social identity attributed to the individual becomes real rather than perceived since society establishes the means to categorize and assign attributes. Those participants who have told their stories recount being referred to as 'crazy,' 'wacko,' or various other derogatory comments. Societal norms set the parameters for our interpretation, perception and response, as members of the group, to illness narratives. "Stigma, then, is really a special kind of relationship between attributes and stereotype" (Goffman, 1963: 4).

As a broad and multidimensional concept stigma centers on deviance. Consensus within the literature indicates that stigma, as a socially constructed phenomenon, represents a deviation from some ideal or expectation. At its basic level Goffman perceives stigma as "a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons" (Alonzo and Reynolds, 1995: 304). These attributes result in the individual becoming unable to meet the expectations or norms. Subsequently the individual becomes a discounted person. The "discrepancy between what is desired and what

is actual, 'spoils' the social identity, isolating the individual from self, as well as, societal acceptance" (Alonzo and Reynolds, 1995: 304).

More current symbolic representations between the body and society equate a healthy body with a healthy society; a diseased body reflects a dysfunctional societal system. The ideologies within Eastern and Oriental medicine acknowledge a correlation between the body and the environment, the body and culture. In order to attain a more holistic approach to diagnosis and treatment conventional Western medicine has begun to incorporate some alternative practices within its rubric

Images of what society considers as healthy involve external appearances of the body. For those with 'invisible illnesses' outward appearances belie the incongruence of the experience. This leads to perceptions of the individual as malingering, as hypochondriacal or just plain lazy (Goffman, 1963). The dialectic between symbolic reality and sensorial reality supports the ideology of a social body even if medicine chooses to ignore the experience. We all experience empirical reality through sensorial experiences such as pain but the very necessity of the empirical experience lends credence to the symbolic (Laderman, 1994; Kirmayer, 1992; Lyon and Barbalet, 1992). The symbolic representation of the social body affords a mechanism for interpretation and communication of the illness experience to others. This symbolic structure

allows us to interpret experience in a way that helps us believe that the cosmos itself is meaningful, that things connect, that life has an aim, and that human beings, at least to some extent, can acquire knowledge to deal with the workings of an orderly universe.

(Laderman, 1994: 196)

## **2.4 The Power of Health Care and Health Care Professionals: the body politic**

Relationships between the individual and social body incorporate more than the metaphors or collective representations of culture and science. Underlying social and individual relationships are issues of power and control (Lock and Scheper-Hughes, 1987). Who dominates, who capitulates or becomes subjugated, who controls the boundaries of the group?

Threats to the continued existence of the social group may be real or imagined. Even when the threats are real, however, the true aggressors may not be known...

(Lock and Scheper-Hughes, 1987: 24)

It may come as no surprise that physicians instill a sense of fear and unease in many patients or that health care institutions appear as cold and uncaring, where the human body represents nothing more than a collection of machine parts. It stems from the dualistic nature of the patient-physician relationship, of agency and structure, of dis-empowerment and power, of subjective and objective interpretations of the same experience (Pappas, 1990; Buchanan, 1989).

The medical model contains a built-in antagonism between illness and wellness. The socially constructed, empirical nature of medicine places emphasis on etiology and treatment of disease. You enter the system because of dysfunction not because you are well. How the agents perform their roles are tied into the policies, rules, and regulations established by our culture and society. All participants bring with them individual expectations as well as expectations of the culture within which they reside. Whether the expectations are fulfilled or not impinges on whether or not the experience conforms to existing definitions of disease.

Validation becomes external to the experience rather than intrinsic to it.

Since “illness can only be comprehended, constituted by a synthetic act, by giving larger sense to what can only be experienced in discrete moments and from limited perspectives” (Good, 1994: 164). This failure to acknowledge the reported symptoms of people with new and emerging illnesses as legitimate, whether by health professionals, family or society at large leads to the perpetuation of the sick role. Individuals internalize the experience focussing on physical symptoms until it becomes a way of life for them (Angel and Thoits, 1987). They continue to search for validation of an illness experience that continually changes.

When the sense of social order, of what is appropriate becomes threatened, the boundaries between the individual and political bodies become blurred. Socio-cultural norms take on more importance and the individual strives for conformity. This results in a paradox — the individual’s desire to appear normal, regardless of whether they are well or ill (since that involves less hassles), their need for others to perceive them as normal, and the inner turmoil of their reality that they are, in fact abnormal (Goffman, 1963). Failure to comply, as a result of illness, may result in conflict between the experienced self, the social and political bodies. Illness becomes, in essence, a mechanism for assigning blame or failure to the individual, a sense of inability to live up to the expectations of society.

Within our society norms and mores control images of health, illness and the body. More value is placed on ideals that are, for the average individual, impossible to achieve. Turner talks about ideals or images as categories that include demographic as well as non-demographic classifications “relevant to the world-of-becoming...[as] arbitrary

representations..."(1986: 12). This very arbitrariness results in the limitation of human potential, of 'human essence', of dis-empowerment and disembodiment. The stigma, which emerges from the socially inflicted limitation of human potential, as a result of non-conformity separates the sufferer from others. The social identity attributed to the individual, through the mechanism of the medical institution, becomes an 'actual social identity' as opposed to a 'virtual social identity' (Goffman, 1963: 2). The epistemological and ontological standpoint of medicine establishes the means to categorize and assign attributes of health/wellness and illness/disease. And, these socially constructed medical norms establish the parameters for how the players, within the system, will interpret, perceive and respond to the illness story.

Health care institutions and the practitioners within retain the balance of power and reciprocity appears to be no more than compliance on behalf of the patient rather than an equitable sharing of knowledge. Society establishes and reinforces status, hierarchy, control in the profession, defines disease, determines who is 'healthy' and should return to work, and validates the illness experience. Those working within health care institutions put into practice that which society has constructed as the parameters of health delivery, diagnosis and treatment.

A more effective approach to understanding health might be to look at David Morris's bio-cultural model (1998). This model implies that health is the intersection of biology and culture. Furthermore, health should not be conceived as existing only in the absence of illness. The bio-cultural model (as opposed to the bio-medical model) provides a more comprehensive conceptualization of this state by recognizing the influence of cultural beliefs, values and attitudes on health. In fact, it lays to rest the epidemiological model that depicts discrete

variables as influencing health and illness. These discrete variables are visualized as universal, individual and homogenous—a very modernist, positivist approach which, in its narrow confines fails to address all the issues. In accepting multi-cultural influences a more heterogeneous picture emerges permitting a more complete understanding of various states of health and well-being.

The concept of health as dualistic, in that one may be either sick or well, is both counterintuitive and counterproductive. To ascribe to such a definition precludes a large segment of the population from achieving health<sup>14</sup>. The actual number of people who could state, in all honesty, that they are free of all disease and disability would certainly be a fraction of those who are presently experiencing one form of health problem or another. Current statistics place far more people as suffering from a serious or disabling illness than there are people.<sup>15</sup> It makes very little sense, indeed, to think of health from a statistical and conceptual frame of reference, as the absence of disability, injury or disease.

In considering health from a more integrated perspective, that of both bio-medically and culturally, more people would be able to see themselves in a positive, healthy light. Health would be redefined as the state of living well in spite of disabilities and disease or as Anne

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If one thinks about it, an individual may be considered healthy in their pre-symptomatic state prior to their becoming aware that the illness process has occurred within their body. The alternative to this would be those individuals who report symptoms in the absence of pathology. (This latter state may be referred to as psychosomatic or somatization. [Kirmayer 1989].)

<sup>15</sup>

Statistics from 1994, *Vital Health Statistics*, 10 #193 1995 and *Statistical Abstract of the United States* 1996, projected 391 million peoples as suffering from illnesses ranging from HIV/AIDS to visual impairments. Considering the fact that the United States population at that time was only 260 million it certainly doesn't leave anybody as healthy.

Hunsaker-Hawkins refers to it, a state of 'healthy-mindedness' (1993).

The mythos of healthy-mindedness, even within secularized medicine, stresses faith and spirituality. This optimism derives from an acceptance of the self as of primary importance, of enabling one's self to identify, nurture and attain life-enhancing self abilities in the presence of and in spite of illness, whether the illness is of a minor or life-threatening nature. Secondly, it stresses a belief in the healing power of nature. This has become evident with the increasing public movement towards alternative holistic medicine. Healthy-mindedness emphasizes natural as good, technology as suspect, or even detrimental to one's health. Perhaps the most crucial aspect of healthy-mindedness is the sufferer's active participation in their treatment. No longer are they willing to be passive subjects hanging on the every word of their physician. Instead greater responsibility, self-reliance and activism are the fundamental characteristics of the sufferer.

As we read through the literature on perceptions of health, from an embodied perspective, it becomes apparent that we do not act in isolation. Nor do we attach meaning to our experiences based upon a single event. We interpret and integrate all events within our experiences to define meaning. We play an integral role in the outcome of events through our active participation, wittingly or otherwise. We sense and feel from the conscious and the subconscious taking into account previous actions, interactions, beliefs, values, attitudes and norms. Experience and meaning are closely interwoven within a socio-cultural context. To ignore this aspect when talking about health and illness, particularly as it applies to newly emerging illnesses such as environmental sensitivities, is to ignore a key element in the creation of these concepts.



### **Chapter Three**

#### **Pathographies of Environmental Sensitivities**

**Illness is something to recover from if you can, but recovery is worth only as much as what you learn about the life you are regaining.**

**(Frank, 1991: 2)**

**The status and progress of medicine ought always to be judged primarily from the point of view of the suffering patient, and never from the point of view of one who has never been ill.**

**(Jurgan Thorowald in Buchanan, 1989; cover page)**

Where does illness fit in the grand scheme of our lives? Most of us, do not want the experience nor do we want to have to worry about fitting illness into our lives. More thought goes into understanding ill-health and assigning meaning to it than its more positive counterpart, health. Illness we seek to avoid, whereas health we desire and aspire too. More frequently the emphasis lies in the amelioration and prevention of illness rather than the maintenance of health. Even the images we use reflect the focus on illness rather than health. It seems to me a sad commentary of our lives that we feel the need to emphasize the more negative components of our lives rather than celebrating the positive aspects of our lives.

In talking about the experience of environmental sensitivities, Greta felt very much like a prisoner trapped within a body that refused to accept the 'normal' life. In striving to measure up to this concept we very often fail to recognize how limiting and stereotyping normal can be. For Greta, the body's refusal to behave in a manner appropriate to her age and gender was an experience that "in the eyes of most people...had made me not just an invalid, but also 'in-val-id'." Having environmental sensitivities did not just imply having an illness, it also embodied negative connotations such as the invalidation of the individual as a credible

narrator of the experience. This reality also places the individual outside the boundaries of the socially ascribed 'normal.'

In response to the question I had asked about how she saw her body before the illness and after, Greta provided me with this response.

I've found that the best approach is to stay in the present, in the moment, as there are many beautiful and enjoyable moments to be found in each day. I don't like to look at the past much as the contrast with the present can overwhelm my ability to see the good in each day. And as each day comes only once, I want to live it and not be buried in loss. When I first became ill I decided that somewhere in the world there would be someone who would look at my situation and say "oh, if only I had that life". I decided to be that person. After all, if I must be under "house arrest" I do have a nice home to do it in and a peaceful society in which to live. As for the future, well, no one knows what the future will bring to oneself or to the world in general. I just hope for the best, try to be as prepared as possible for whatever may come, and often hum the tune of "Que sera, sera, whatever will be, will be..."

(Greta)

If we chose to ignore the subjective quality of the illness narrative and its images depicting the impact of the disease process on the human body much would be lost. To describe this experience as a strictly biological phenomenon would not capture the true essence of the sick role as being under 'house arrest.' Accounts of health are often constructed as part of the ongoing identity, shaped by previous experiences, interactions with others, societal and cultural norms. Ultimately what the individual defines, or lays claim to, is their sense of self, their identity as worthy members capable of participating in the larger social world (Radley and Billig, 1996). These descriptions of health are more than mere physical conditions. In fact what they reflect are the person's beliefs, values and attitudes and their ability to articulate their situation in the world.

In trying to capture the reality of the sufferer of environmental sensitivities and how

they define health and illness I chose to structure the questions within the framework of embodiment. I wanted them to tell me about their life before they began to experience symptoms, their perceptions of health and how they saw their body. I then compared these depictions with their stories of life after symptoms began to emerge. I examined the metaphors used to describe the entire experience. They were asked to talk about their relationships with health professionals before and after the symptoms appeared. They were asked about the use of alternative practitioners and whether or not they were instrumental in attaining health. In structuring the questions in this manner I felt that I was able to extract their perceptions of health and illness as it related to their progression along the health-illness continuum.

### **3.1 Case Studies: the voices of the silenced**

In order to understand the experience of environmental sensitivities and its implications for health outcomes I felt it was necessary to approach this from the perspective of the sufferer rather than that of the health professional. Certainly both sides have stories to tell. Both feel that their point of view constitutes the truth. Both sides provide the mechanism to understanding an illness that is poorly understood, often mis-represented, and on the receiving end of little acceptance within the medical community and society at large. In fact, environmental sensitivities bears many of the same social implications as mental illness such as isolation, stereotyping, stigma and powerlessness. It is an illness to be reckoned with but with few advocates in positions of power to fight on the behalf of its marginalized population.

While one may note that the participants are drawn from varied backgrounds what became apparent during the interview process was a commonality of shared themes relating to their experiences with environmental sensitivities. One particular theme, which I have titled

de-legitimation, appears as a consistent theme among all the participants with environmental sensitivities. This may be attributed, in part, to the fact that this illness has yet to be defined within medical nomenclature and therefore falls outside of the scope of diagnosis. Individuals find themselves having to continually repeat their symptomatology to a variety of health professionals, family members, and friends in an attempt to justify the experience. The illness carries with it a double burden, that of being 'victim' of an illness and that of being a 'victim' of the meaning imbued by society on this illness.

Even more significant is the burden of blame<sup>16</sup>. Health professionals have a tendency to perceive the patient with environmental sensitivities as a victim, not just of the illness, but a victim in all aspects of their life. Somehow as a result of their inability to cope with the everyday stressors that all individuals face, or to at least cope in a 'normal' fashion, their emotional needs, unresolved interpersonal conflicts, and spiritual desires are not met. As a direct result of this inability to cope the individual is provided with an excuse to escape the 'healthy life' into illness. This in turn absolves them of responsibility for their present life. When asking the physician, 'why me?', s/he is able to reply even if only implicitly, that 'you have brought it upon yourself'<sup>17</sup>.

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In the context of this paper, self-blame emerged as a sub-theme out of the experience of de-legitimation. Individuals felt that in some way they had contributed to the in-acceptance of their illness and the failure of the medical profession to address their needs. At the same time, self-blame emerged as a sub-theme in the second major theme of anger. They blamed their bodies for failing them.

<sup>17</sup>

It has been hypothesized by some writers that there exists a 'cancer-prone personality'. For these individuals, the inability to cope with stress results in emotional 'blockages' which impedes the normal functioning of the immune system. The dysfunction may then lead to the individual acquiring the illness. In so doing, the physician is then able to shift

A sub-theme stigma, emerged as a direct off-shoot of the de-legitimization of the illness experience. As with many catastrophic diseases such as the Plague, leprosy, and more recent disease phenomena such as the HIV/AIDS epidemic, the underlying sense of fear guides our imaginations, colors our words and inevitably instills meaning in the descriptors we use to represent the illness experience. By creating shame and stigma the illness experience is transferred to 'them' not 'us', to be borne by others who, for whatever reason, have succumbed to the disease for justifiable reasons. Stigma connotes an attribute that suggests a difference from the norm, from the group, and yet, this difference is, in some way, the fault of the individual. Bio-medicine prefers the transference of blame to the patient. In so doing the physician is able to save face when unable to find the answer or cure for the problem.

Another major theme that arose out of the interview experience was anger. Anger was directed at the institution, health professionals, and government agencies as a result of non-acceptance of the illness as a legitimate disease. Anger was also directed at themselves for the perceived failure of their bodies to accommodate to a supposedly 'normal' world. Dealing with anger requires a phenomenal amount of energy leaving few resources for the individual to cope with an already compromised health status.

A third predominant theme was that of self-awareness or spirituality (as opposed to religiosity). Inherent in this theme was the ability of the individual to accept their body for

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blame to the sufferer because of their shortcomings. A similar phenomenon, as I see it, occurs among the environmentally sensitive person. In some way they are considered culpable for the symptoms they are experiencing. They use the 'victim' role as a means of escaping from the stressors of life rather than addressing the issues as they arise – at least in the eyes of bio-medicine and some members of society. See LeShan, 1957, 1966 & 1977; Simonton, Matthews-Simonton and Creighton, 1978; DiGiacomo, 1992 for discussion of the cancer victim.

what it now was and move forward. For others, there was a significant inability to accept the limitations placed upon their bodies as a result of environmental sensitivities. For this group, an intense longing to return to a pre-morbid state of health or 'turn back the clock' inhibited the progress along the health-illness continuum.

### **3.2 What is health?**

How does a concept such as health or illness take on meaning, not just for the individual but for society itself? As an enigma, health depends upon the interpreter of the concept and may actually take on different meanings for different individuals, groups or cultures based upon the referent or paradigm (in North American society—the biomedical model). Further, do boundaries exist impeding the definition of health through the exclusion of certain aspects of daily life? Are some aspects of life more significant than others and these defining characteristics incumbent upon socio-economic characteristics such as class, hierarchy, job, gender, race, and age? These and many other questions influence the perception of health. In themselves, they would constitute a paper but I have chosen to limit the scope of health to the issues arising from the interview process with the participants.

For most of the participants, health as a concept, emerged as something that was taken-for-granted. When asked to reflect back on their health, which appeared to be the most predominant means of assessing the body's situation prior to becoming ill, individuals categorized it within a physical context as opposed to psychosocial, emotional or spiritual contexts<sup>18</sup>.

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Most references to health are inferred as a direct result of retrospection drawing upon comparisons to previous states of being and experience. Studies have shown that most

I was basically very healthy individual. I didn't really think about my health. I just sort of took it for granted. I just went about life very, you know, unassumingly well, didn't have reading problems, didn't have allergies. Could do what I wanted, go where I wanted, eat what I wanted. Had no problems, really, with anything.

(Diane)

It was really important because it...it's the quality of life that you had. Like I really ate well, I watched my weight. I mean I didn't say I didn't have a weight problem because I did.

(Sylvia)

I was very involved in sports prior to working at Camp Hill. Um, all through my whole life I was athletic, outgoing, um participated in a lot of activities...Health's pretty much everything now, you know. Uh, it's number one on my list of things, you know. If you're not healthy, to me, that is the most serious issue in life...I guess when things are really going good you take a lot for granted I find.

(John)

I probably just took it for granted. But look, but I wasn't sick a lot or anything like that.

(Phyllis)

[Health was] getting up in the morning. I mean if you get up in the morning and go to work. I didn't even think about it. Allergies, I never had no allergies or anything like that.

(Lewis)

In a society obsessed with health the incongruence lies in how little thought is actually given to this phenomenon. "Health (in all its variations) is something that happens not so much in the absence of illness as in its presence" (Morris, 1998: 241). Every aspect of life and living the experience focuses upon keeping a healthy and vibrant body. People face a constant barrage of information from the media, newsprint and magazines espousing health as a virtue,

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people think in terms of physicality when talking about health. A secondary form of relating to health is through the negative definition such as 'I rarely or never had illnesses' (Calnan and Johnson, 1985; Spector, 1979; Williams, 1983).

certain body images as the ideal, herbal preparations that will add this, take off that, enhance this, and most importantly, halt the aging process. We have become a society of 'health hypochondriacs' generating a multitude of ailments in the process of seeking the virtually unattainable perfection of health.

No wonder when questioned, the participants have difficulty defining a paradoxical state of being so all-encompassing yet limiting. Even if we accept the World Health Organization's definition of health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or injury" (Evans and Stoddart, 1994: 28) the limitations are still apparent. What constitutes complete state? To one individual it may mean one thing to another something entirely different. How then do we fit within a definition that has such polar alternatives for its structure? At the one end we have the often vague, yet humanist, post modern term, well-being<sup>19</sup>, at the other, the modernist, positivistic medical paradigm's absence of disease and disability. Although health should be constructed as a continuum, medicine (or science) tends to depict this state as occurring at a given point in time. This provides medicine with the ability to assign universality or homogeneity to a state better defined as heterogeneous.

In accepting health as relative and static, rather than as a continuum, individuals then strive to gain control of and achieve what they perceive as attainable. "Health consciousness as a value system has joined the discourse of public policy in such a way that a new civic

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"Wellness is not just aimed at preventing illness but a maintaining the very best possible health and quality of life" (Morris, 1998: 247). The aim here has a tendency to reinforce self-absorption and hence the current trend with the health and fitness craze.



obligation has come into being; ...'the duty to be healthy'" (DiGiacomo, 1992: 122).

Unfortunately, how does one achieve a utopian, fictional state of health and well-being when health is something that happens in the presence of illness as opposed to its absence?

I always see myself healthy and people tell me, 'oh you have environmental illness' and I'd always say 'no, I'm not. I don't have environmental illness 'cause I'm not really ill'. I have some kind of maybe reaction, or I haven't really figured out the proper terminology to use but I never let people say that about me because it doesn't seem like the right label and mostly, you know, we, you struggle of course with friends and going to their house and then trying to impose restrictions on them and people do get very angry about it. So there is some kind of message that you have to give to people that what your needs are and so, then it's just a matter of making sure that those words that you use are not misinterpreted to make you into an actual ill or debilitated person, which I never have been.

(Moira)

I had to see that I had an obligation to, to treat my body well. That, I mean, one of the teachings that I believe is that the body is a temple for the spirit and we have to take care of it and we have to treat it with respect. So I did have that attitude before I became ill and tried to do that. I just don't think that I was so successful then as I am now. I've got more insight now.

(Philip)

Both Moira and Philip imply an obligation to maintain their health. To ascribe to a belief and value system, to see health as a duty. "The imperative of health: at once the duty of each and the objective of all" (Foucault, 1984: 277). Health implies conformity, normalcy, but perhaps most of all, health defines a utopian state that becomes unrealistic in its ideology.

...and I could just say the hell with this. I'm not prepared to do that. I mean I want my life back. I don't think I'm going to be working full time, mind you, and I'm gonna have to, and I don't think that's bad either...I know I can't do nursing like I did before. I can't physically lift people. I know that. So I'm not going to be able to work on a medical floor and I'm not going back to long term care, in that building. There's no way I could me in that building. But I'm going to be a little, a little shit disturber to be honest with you, about where I'm going to go because it's my health. I'm responsible for it. And they're not doing this to me anymore. But I need to have my life back. I need

to be in control. And they are not taking that away from me.

(Sylvia)

...now I have to think about my body as something that is quite vulnerable and something that I really have to work hard to do something about. And partly that was a strong desire to become more vigorous to begin working on it. And I also had to put limits around my time at work, 'cause I mean otherwise I was working all the time. If I wasn't here I was home, if I wasn't at home at work, so in the last couple of years there were all these things going on as well. I really tried to pay attention to a healthy lifestyle...

(David)

I wanted answers. It was the same type of thing. And, but the only problem was or, then again we'll get to that but at the same time I thought they could give me the answers too. So it was a real let down when they couldn't give me the answers and that was probably a good thing. Because then I started to learn and understand that they didn't have all the answers. And they didn't know everything. And they were not god. And they were not up there on a pedestal. And I needed to take the initiative because it was my body and I had to uh, take the responsibility though, to continue to search and find the answers because it was my body and it was my responsibility. And ask questions and seek answers and, you know, not be afraid to ask.

(Alexis)

Healthy-mindedness appears to provide empowerment to those who are ill. It's emphasis on responsibility and control frees the sick from the dependent, dehumanizing role of patient within the medical system. Not only does it redefine the role for the sufferer but it redefines the patient-physician role. As Alexis stated, her physician was no longer a god with all the answers but another human being, frail, limited and in need of education, ultimately no different from herself. This shift, in all likelihood, produces a positive health outcome rather than a reliance on the doctor. In becoming partners the sufferer and physician both feel they have accomplished more in improving quality of life.

### **3.3 De-legitimation**

Inherent in the role of the sick are certain guidelines or rules to ensure that the sufferer

will return to society as a functioning individual, able to carry out previously designated tasks or multi-tasks such as wife, mother, employee, and teacher. A rational patient will adhere to the social norms outlined for the assumption of this role. As Talcott Parsons states, the individual is granted temporary reprieve from their responsibilities due to the illness; the sick person is not responsible for the illness; the sick person must seek help and cooperate with those providing help in order to achieve health and well-being; and finally, the sick person must be motivated to abandon the state of illness (Alexander, 1982: 356). If they deviate from this process they are labeled irrational and in some way culpable for the predicament through intent. If no biological, explanatory model is found or if the disease state is not alleviated the patient may have to carry the burden of blame for the failure. Scientific medicine “disqualifies the patient’s moral agency” (Kirmayer, 1988: 58) as psychosomatic, somatoform or idiopathic (Helman, 1984).

But what happens to the lay sufferer who seeks out help for their symptoms only to find that no answers exist or that their symptoms have been written off as ‘all in their head?’ The first step in the experience of illness is to receive the news from one’s physician that they indeed do have a specific disease. Intellectually we want to hear these words or diagnosis as it justifies the reported experience, but emotionally the individual denies such news for to accept it, one’s perception of self now becomes deviant, abnormal. “When illness arises it creates a sequence of stresses and challenges with the individual, like the ever-widening circles caused by a pebble dropped in a stream or pond” (Stabler, 1993: 303). In fact, that analogy came to light during the course of the interview. The question posed dealt with describing the experience of developing the symptoms of environmental sensitivities. A very similar

description has been attributed to Selye (1956). This description emerged as a very natural way of Diane coming to understand the impact of environmental sensitivities.

But this illness, to me, is the same as if you take a stone and you tossed it into a pool of water. And I am the stone. And then you get all the ripples going around and it's my immediate family. Then there is my family and my brothers and sisters and my mom and dad and my friends and my workplace. It's effected everything in my life in different intensities and in different ways, but it has effected my whole life. And it was just a ripple effect. It just kept effecting everything. And it went out from me and it effected my entire life and it effected the way people treat me. Um, how they perceived me, how I perceived them and some of it was good and some of it was very earthshaking because people that you thought would be supportive sometimes were not and people you thought would have never been supportive sometimes were so. It was a real mental challenge in some ways.

(Diane)

This illness carries with it a double edged sword. The sufferer becomes the victim of a set of symptoms creating the illness as well as a victim of the system that effectively denies the experience for them<sup>20</sup>. Over and over this scenario played itself out to me regardless of the status of the individual. All individuals, whether kitchen workers or physicians, reported a sense of lack of validation from the medical and social community. In turn, these individuals find themselves struggling to achieve the validation in order to move through the societal role of the sick. Effectively, some become trapped within the role going in ever increasing circles to fulfill the role yet never being able to do so.

The following quotations taken from interviews with health professionals depict the

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At the same time one may be justified in asking the question of how people participate in the ongoing de-legitimization process by continuing to seek a medical diagnosis that they know is unlikely to be forthcoming? Further, in what way may this process be used for insurance purposes? I have chosen not to deal with such issues within this paper although I believe that they are valid concerns. What is discussed arises from the experience of the individual with environmental sensitivities.

sufferers attempts to rationalize an experience that appears, for all intents and purposes, to be irrational. In attempting to have a diagnosis assigned they suffer the same fate as any other sufferer of environmental sensitivities.

At that time there was no specialist that you could go to, to say that this is what it is or we can do this test and this is what it is. So it was really frustrating because I knew that there was definitely something wrong with me but the notion of the general public was, you know, 'this is all in a person's head. This isn't real', you know. So it was really, it really took a toll, like. And it really, um, at that time I have to say I was the type of person that, um, being naive, I and uh, not really you know, I had just started my career, um, and I was the type of person I used to worry about what other people thought. So it really bothered me to think that people don't believe that there was something wrong with me and, especially when I would go into emerg. I would be doubled over in pain and I knew there was something physically wrong and then they would say, 'you look fine on paper', you know. It would really bother me because then I started to question, well you know, this isn't in my head but, how come I feel this way and they can't find anything?

(Alexis)

I was wondering if I had a brain tumor. That I had a neurological problem or something dreadful going on. I went, it prompted me to get a family doctor which I hadn't had for some time. And I went and saw him and he was sympathetic and thought I was stressed. Which I didn't think made any sense 'cause from my standpoint this was not stress. Stress was the years of being in internal medicine, not the relaxed happy lifestyle I had now. And so, I mean, that whole interaction lasted 20 minutes. I sort of dismissed that as an option to further think about....finally my wife who said to me, 'you know, why are you so lazy?' 'Cause she was concerned and I was, I've always thought of myself as being terribly hard working.

(David)

It seems to me that it is not just the majority of MD.s who are inclined to dismiss the reality of MCS [multiple chemical sensitivities] and the profound changes it brings to a person's life. My experience has been that the majority of ALL people around me refuse to regard the reality of MCS in the same way that they'd regard the reality of a heart attack or paraplegia. The Langley report and Dr. Fox's initial endorsement of it to the media did nothing to help this. This situation increases the isolation of people with MCS and it makes me feel frustrated, lonely and angry. A few years ago I realized that it was not good for me to be around people who felt it was 'all in my head', that I was

‘milking the system’, ‘malingering’ and who said things like, ‘there’s nothing wrong with you that isn’t wrong with any other woman your age...I tried for about a year to find a way to maintain the friendships but eventually I began to feel that ‘with friends like that, who needs enemies?’ as the saying goes, and ended the relationships completely. At that time I realized that in the eyes of most people, apparently, MCS had made me not just an invalid, but also in-val-id (her emphasis on the 2<sup>nd</sup> syllable)

(In correspondence with Greta)

I don’t know. It’s just this weird stigma, you know, going with un-described problems and seeking help for something that maybe you should understand. It’s a hard role.

(Moir)

Having a medically undefined illness, as well as, socially unaccepted strains the belief system of health professionals who are trained to objectively examine, accept and refute symptoms. Herein lies the dilemma. First, health professionals should be able to identify what occurs within their bodies based upon their training. Second, by the very nature of their role, as health professionals, credibility should be automatically inferred upon reporting the symptoms to their colleagues. Last, the balance between the role of patient and role of health professional has a tendency to lean towards the latter providing a source of role conflict. Not one of the health professionals appeared comfortable in the role of patient, particularly one who was not believed.

In contrast, participants from the kitchen and housekeeping departments found even greater hurdles to jump in an attempt to validate the illness experience. Lack of sophistication in the language of medicine, stereotyping and limited financial resources only served to increase the likelihood of a negative outcome for this group.

A lot of people, you know, don’t understand this illness and uh, their doctors don’t believe in it. And uh, I, people don’t really know enough about it. Like most, a lot of doctors. They look at you like you are, you have a problem, a

mental problem. Well, I've had a hard time. Like when I first got sick I was seeing my family doctor and I had seen him for over 10 years and he said to me, 'I'll see you for anything else but not anything to do with environmental illness'. So I mean my first reaction was probably, like hurt, then it was probably anger. Then I just figured I just would have to find somebody else because, I mean, he's just not going to believe me. So, uh, I still feel bad cause I've seen him for so, you know, like all those years [laughs] and it's like he never gave me a reason. He never explained to me why he didn't want to. Oh.

(Phyllis)

In listening to Phyllis's story, the pain and anguish becomes quite evident. A sense of betrayal that in trusting someone with your body for all those years, the same someone who you believe knows you at your most intimate levels, can turn against you so cruelly. Her apparent sense of self blame, that in some way the responsible lies with her for the break in this relationship demonstrates a significant flaw within health care. It is disheartening to realize that, in becoming vulnerable through illness, one should be forced to carry an additional burden of blame for a fallible medical system.

An even more glaring indication of the inherent flaws within the systems was the blatant abuse of a patient by a physician unable to diagnosis or to believe.

Well I went to see Dr. – for the first time. He's one of the Occupational Health doctors. Um, this was the first time I had seen him since Dr. – had left and things were in disarray there for awhile. 'Til somebody was appointed I guess. And the first time I had seen him, I went in and explained to him exactly what was going on, what I thought. He proceeded to tell me, and I quote, 'I had a fucking problem!' and, um, I went up to see Ms – . So basically I was verbally and mentally abused by that particular physician....Some of these doctors, you know, they got degrees and stuff like that but I kinda find that, in some cases, that doesn't really mean a whole lot...I know in my situation that just because they are a physician that some of them feel that they can pretty well dictate to you everything that they want to even though it may not be in your best interests or whatever.

(John)

For those individuals seeking the assistance of health professionals in the legitimization

process of the illness experience, their symptoms are very real. They have placed their bodies in the trust of the health professional in order to render judgement, to treat, and ultimately to cure. At no time do they perceive the relationship will be an abusive one or that the outcome would be one of abuse. We are at our most vulnerable when we present ourselves to the doctor. The expectation is one of implicit and explicit trust. No wonder when the outcomes are as harsh as these that individuals become lost souls, their belief system shattered and trust forsaken.

Bio-medicine was founded on the Cartesian division of body and mind. All function and dysfunction becomes reduced to biological terms which are viewed as the only rational and empirical evidence necessary for allopathic physicians to legitimate the illness experience for the sufferer. Within this paradigm the experience becomes medicalized and the individual formally engages in the illness behavior.

Certainly the less tangible, more subjective aspects which reflect our reliance on the consciousness of the experience are seen time and time again within the illness narrative that patients utilize to document their symptoms. Unfortunately, unless the psycho-sociocultural aspects have a direct bearing on the illness trajectory they are often deleted, by clinicians, in the re-telling of the illness history. The real dualism lies in the patient-physician role. The patient acts as the passive un-knowing in contrast to the active knowing role of the physician. The physician interprets and places the illness narrative within the rhetoric of scientific rationality. The patient forfeits any control when describing their illness experience to medical authority.

“Pain is never the sole creation of our anatomy and physiology. It emerges only at the



intersection of bodies, minds and cultures” (Morris, 1991: 1). This distinction between the experiential body and the exterior, objective institutionalized or medicalized body expresses the ambiguous state of human embodiment as objective and subjective, as personal and impersonal (Bendelow and Williams, 1995). Scientific medicine reduces the experience of illness to a series of ‘signs’ rather than symptoms that fit a particular disease classification (signs belong to the verifiable world of science whereas symptoms are but mere interpretations of sensations experienced by the sufferer) (Good, 1994). Within this framework the illness narrative becomes legitimized or de-legitimized.

The ensuing conflict of internal and external identity role conflict predisposes the individual to the self-fulfilling prophecy. If you put enough faith in words that stereotype and stigmatize the outcome generated will likely reflect inferences from the original context. If I think you are ‘crazy’ and I behave as if you are, eventually the outcome behavior will be aberrant leading one to think you are. It doesn’t mean that I was right, only that I have created a socially iatrogenic phenomenon. Likewise, if I treat you as disabled, or if the physician tells you that you are disabled, regardless of whether the disability exists or not, the emerging outcome will be an individual with a disability.

[in talking about the possibility of going back to work] No, [unable to make out] try to get better, but I don’t worry about that because I took, what you call them, the IQ tests [in actual fact the reference is to neuropsychological testing—to ascertain the individual’s functional cognitive abilities]. Ya, and she told me mine’s so low that, don’t ever look forward to going back to school or learn anything because it just won’t sink in or whatever. [how did that make you feel?] Brain damage. I mean I don’t know, you know. She said, ‘well I can’t really tell until I get your records’. Then she got my records and she says ‘why you are, what they call it, diles? [dyslexic] Dyslexia and then I told her, I said, ‘well you know, I mean what’s that?’ Well she said ‘it’s a learning disability’. So I said, ‘well the, I, she said, ‘well, no not actually’. She says,

I can't swear to it, she says, 'how bad you were, compared to how bad you are now'. I couldn't, but she said for me to go back to school and learn anything 'cause you just won't learn. So that felt [unable to articulate feelings here]

(Lewis)

So yeah, I wasn't getting sick. I didn't have the environmental problem. It was the flu or whatever. And then when, somewhere along there, I can't really describe what it was, probably closer to December, I got chest pains. And then I went on the defense. It's like, ok, you can play with my eczema, you can play with my head, but you can't play with my lungs. You can't do that 'cause, I don't really, I mean, at that time I wouldn't called and said, you know, if somebody asked me, now, oh yeah, but I wouldn't get up and swear, kind of thing. I wasn't going to be a marked person. I wasn't going to fall into that.

(Cloris)

[after having been seen at the Nova Scotia Environmental Health Center] Finally there was this concrete evidence that there was something wrong, you know. It wasn't just that I was, you know, that it wasn't just in my head which I knew all along that it wasn't but it is really difficult when you are at that stage in your life where you don't have the competence yet, you know, and you still worry about what other people think. And uh, then to have a condition like this. And for people to say and label you and say 'well, that's just all in a person's head', 'that's not real', or that, that was really difficult for me. I think that was probably one of the most difficult things to deal with. I think above and beyond the limitations and everything else, that stigma, that was probably the most difficult thing to deal with.

(Alexis)

You know that is much more acceptable if you say you have bad asthma and say this will bother my asthma, then it's accepted. Then if you say, 'I'm chemically sensitive', then you're a 'wacko'. A lot of people will. If I'm on the phone and I'm really having a difficult time understanding what they are saying, I will say 'please explain, I've had a brain injury and I can't understand you'. And they fall all over themselves to help you. But if I was to say 'I'm chemically sensitive and I really can't understand you' then [gestures to her head]. But certain aspects if you explain them differently, they are well receptive.

(Patricia)

Imagine being told that you must resign yourself to the fact that you will never be able to learn anything. I remember the look in Lewis's eyes as he told me. His life was gone as he

knew it. His perception of what the psychologist told him was that he was stupid. Or imagine having to assume the label 'brain-injured,' as Patricia did, to reflect your abilities simply because society does not understand or chooses not to understand environmental sensitivities. Furthermore, imagine continually worrying about what others think, of what image you portray to others as Alexis found herself doing. It becomes apparent how easily stigma emerges from the experience of le-legitimation. Although I considered it to be a sub-theme of de-legitimation, I felt that it carried significant weight when examining possible factors that may impede one's progress towards health and well-being.

In the process of labeling we can defeat, demoralize and dehumanize the individual or group to which we assign the deviant characteristics. The greatest challenge for anyone is to achieve control, not of others, but of themselves while expending energy into socially acceptable behavior (Buchanan, 1989). The sick inherently know the behavior required of them in order to fulfill the particular role. When society or the medical community disallows or disavows the behavior because of stereotyping, stigma, or labeling the individual finds themselves having to resort to practices that are contrary to role performance. Imagine having to fabricate disorders, symptoms illnesses, or play up one aspect of the illness over another in an attempt to have the illness experience affirmed and legitimated; or having to seek outside help for symptoms because of fear of recriminations, and/or derogatory comments from your colleagues. The sense of betrayal becomes quite profound. Add to that the additional burden of trying to return to a state of health and well-being and the outcome will be a less than positive one based upon the stressors.

### 3.4 Anger

Diagnosis and treatment are social rather than biological acts specific to the human population. Illness may be biological in nature but defining the experience as illness is a purely social construct that carries with it specific roles, behaviors, and acts. As we have seen from the previous examples, circumstances do not always follow in neat and orderly fashions. Illnesses are emerging at a faster rate than medicine is equipped to handle. Therein lies the crux of the problem. Simply stated, just because medicine has not been able to define the health problem within the paradigm of cause and effect does not justify stating that the problem does not exist.

All of us want to be believed when we take our stories to the doctors. No one expects to be discounted in the telling of the illness narrative. If it happens often enough the individual will question their own motives, the experience and its reality, learn to distrust, feel betrayed, or just get down right angry. The anger may be directed at whomsoever they perceive to be the center of their problem, whether an employer, the family doctor, a spouse, or even their own body. Rationality does not always enter in to it.

Anger emerges as a natural response to the illness experience, particularly a life threatening or chronic illness. Elizabeth Kubler-Ross outlined the grieving process as denial, anger, bargaining, depression, and acceptance (1969 & 1981). It doesn't necessarily follow that one will proceed from one stage to the next in an orderly fashion. Different people will move through the stages at different rates and in an order acceptable to their being. Some sufferers may never come to accept the situation they have been placed in or may become 'stuck' in one specific stage unable to move forward. If we were to factor in other issues such

as loss of control, lack of connectedness (the inability to interact with people in the same manner as previous to the onset of the illness), isolation, and invisibility (not being seen as a whole person—commonly experienced by patients within the health care system—in this case only see the symptoms or the mask not the person) (Michael, 1996) it would not be unexpected to observe anger in explicit as well as implicit manifestations.

Just thinking about the future. If I stop and think about it for awhile it really gets, it really gets unnerving. What's going to happen, ya know? Where am I going to be maybe five years from now or just how well this treatment or uh work? And just how much will I benefit from it or am I going to get? Uh, Dr. — told me I'll probably always have some sort of deficiency in regard to what happen uh. Well doesn't make me feel, uh, it makes me feel angry. If I think about it which I don't like to think about it too much because it really angers me because uh, just the things I've seen the people that have been told different things and misled and stuff like that. Uh, ya know, the really only people I can put my trust in are the people right here. I don't have any trust in any of my physicians down at the — because I've been told different things and misled and everything else so [paused at this point].

(John)

John expresses anger at the system for having failed him, misled him (based upon his perception of the situation) and the misinformation that he feels he has been given. A sense of no longer being in control of his destiny, of the uncertainty about the future, about the loss of a young life that had previously been energetic, active and vibrant surfaces bringing with it resentment, helplessness and bitterness. For John, his inability to move beyond the anger has essentially stalled any further progress towards health and well-being.

In the beginning I did and I um, the psychologist I was seeing said I was quit lucky because I focused my rage all on one person. I really did. He was the department head of maintenance and I really focused on him and I really hated him. If I saw him I would beat him. Um, and my husband actually golfed with him a couple of times and tried to explain how things were and this man just was awful and my husband said it was all he could do not to beat him. And then he got fired. And then I felt all right (laughs). He got what he deserved.

He was fired because he didn't do his job properly. Um, and I guess I was angry at him because my work ethic was to do your job and do it as best as you possibly can and he didn't do that. And he hurt me because of what he did. Now he wasn't the only one I know but I focused it all on him. And I hated him. I really did. Once he was fired that was good. He got what he deserved. [and you felt you could let go?] Ya, um, and I guess things still, still from Camp Hill make me angry because I wasn't treated properly. With respect as a patient or as a staff person. Or anything. And I wasn't treated with respect and that was wrong. That was wrong. And it's not going to change. I've tried to change things but its not going to change. I think you need to pick up your battles and realize what you can't win. There's no sense banging your head against the wall. It doesn't do any good.

(Patricia)

Here, we have an example of anger arising out of betrayal. Patricia assumed that professionals would espouse the same work ethics as hers. It came as a shock to discover that not all human beings hold the health and well-being of others dear to them. How could one human being do this to another? Morally and ethically we should respect each other and strive to maintain respect for our fellow man. In Patricia's case, she feels justified in her anger diverting it from the institution and placing it squarely on the shoulders of an individual. For her it may be easier, and more personal (and anger is very personal), to be angry with one than with many. Resolution may be easier to achieve. A sense of futility, of having done battle and accomplishing nothing underlies the emotional aspect of anger. The institution continues to treat people with the same cavalier attitude—a lack of respect and disregard for their experience.

Because probably at that time I wanted to deny that there was anything wrong. So between denying it and starting to get angry with what was going on and then finally realizing that there was something wrong and then trying to accept what was wrong. It was a major emotional turmoil. Um, physically it was terrible. Um, I felt like a seventy year old in a twenty some odd year old body. You know, it was just terrible.

(Alexis)

...So I realized that I wasn't very well and then when I actually realized that I was sick I got really angry. I mean, I really got angry about Camp Hill! And the fact that I had become ill in my workplace. And that there were a lot of people who, before I went off sick, there had been a lot of, maybe fifty or sixty females, nurses and kitchen staff, and others that had gone off sick. Very few men. No physicians or administrator or anybody had gone off. So when I refused to see patients in the VMB [Veterans Memorial Building] because I felt that was where my problem was, I got pulled into the administrator's office and told that, you know, if within administration you have to be like a captain. You don't leave a sinking ship, and you should try to set an example to people and you should carry on. you don't want this to be blown out of proportion, you know. And I just looked at them and said, 'you have no idea how I feel. I feel very ill. Other times it's a struggle for me to even be here with you', etc. And so I got pretty angry about the whole process.

(Philip)

Yeah so what trust, what mistrust you had in the people who are not doing anything, and then when they start putting some of this stuff in, you kind of forgive them, you know, their giving you a hard time that you might be missing a few days, or that you're itchy and complaining but when they bring the equipment in you kind of believe that they're doing something. Oh angry, I still feel that way. I haven't changed. Sometimes it's like you're talking to a brick wall. And again, where I only have laymen terms, you know, and you hate it when, oh, what type of headache is that? Well it's right here and it hurts! You know. I can't say that it's a frontal, you know, and you mean the part of the brain that hitting stuff like that, you know. Sort of thing. Yeah if you could use those words. If you could use the right words and talk on their level, 'cause you are talking to a nurse or a doctor. It seems like you'd be.

(Cloris)

Anger may stem out of the loss of control felt by the individual. At the same time anger may be targeted at those perceived to hold the balance of power and control over the sufferer's fate, namely the physicians, bureaucrats and institutions. Within health care the sick person struggles for autonomy and agency, for validation and acceptance by a social institution – medicine. There exists a contest between authoritative knowledge-seekers and providers; between medical authority who believes that they are entitled to manage and prioritize the health needs of those marginalized individuals whom they believe incapable of making

decisions; and last, between those who feel trivialized, intimidated, devalued and silenced (Pauly-Morgan, 1998).

When ill, an assumption exists that you may rely upon your doctor for your health needs, guidance and treatment. In investing faith and trust in health care professionals an exchange occurs wherein one relinquishes some degree of autonomy permitting oneself to become dependent upon another, exposing one's body, feelings, emotions and innermost thoughts and secrets to another. "In the relationship between carer and cared-for, there is a continual tension on the part of the cared-for between wanting and appreciating care and resenting it" (Lupton, 1997: 105).

Foucault (1986) talks about practices of the self within the medical encounter. The doctor-client relationship becomes a pivotal site for the power play between those who are perceived to know and those who seek to know. As the patient, a struggle to challenge this power may occur in an effort to maintain some autonomy over self. At a more unconscious level, the patient may "behave in assertive or hostile ways because of their dependence on doctors, splitting their fears and anxieties about their pain or illness and projecting them onto the doctor" (Lupton, 1997: 106). No reason exists to believe that this unconscious acting out may not be projected to bureaucrats and institutions of control such as hospitals, other places of employment and the government.

Inherent within the social relationships we have with others lies an emotional investment. This component is not static but fraught with irrationality, ambivalence and conflict partly due to the level of risk involved—exposing one's innermost thoughts and feelings to another. The emotional investment leaves one open to embarrassment, humiliation,



vulnerability and anxiety. "To trust the other is also to gamble upon the capability of the individual actually to be able to act with integrity" (Giddens, 1992: 138). If the relationship fails to meet this expectation then a sense of betrayal and anger may emerge.

But what might happen when the individual refuses or does not have the resources to move beyond anger? Research in the field of psychoneuroimmunology has documented associated adverse effects that subjective events, such as stressors, have on the relationship between the mind and the body (Ader, Felton, Cohen, 1991; Lloyd, 1990; Friedman, Klein and Friedman, 1996; Cassel, 1990; Kiecolt-Glaser and Glaser, 1991, Dossey, 1996; Goodkin, Fletcher and Cohen, 1995). In studying the interaction between the brain, behavior, endocrine and immune systems an understanding of how "'real' organic diseases are linked to changes in one's belief about oneself and one's relationship to others" (Ornstein and Swencionis, 1990: 10) emerges. Stress may impact adversely on the body just as an organic dysfunction may.

There is significant data available to show that psychological stress (anger included) can produce physiological changes that result in suppressed immune systems and an increased risk of disease, including coronary heart disease. "We do now have a strong suggestion that positive emotion, positive feelings and states of expectancy, can work to not only enhance our health but eliminate disease, sometimes counter to all odds" (Sobel, 1990: 63). Conversely, through no stretch of the imagination, negative stressors may alter human resistance and susceptibility, increase risk factors for certain diseases and inhibit a return to a state of health and well-being (Friedman, Klein and Friedman, 1996). Thus anger, as felt and expressed by these participants, if perpetuated, may play a significant role in maintaining a disease state and interfering with their return to health.

### 3.5 Self-awareness

Beliefs, attitudes, and values structure how we perceive ourselves and the world within which we interact. If an individual believes that they have little or no control over their illness, maintain poor coping behaviors, see their self as the perennial victim continually externalizing their problems and placing blame on others, they are more likely to have a poorer outcome than those whose beliefs, attitudes and values alter, even in the face of significant challenges such as those experienced by environmentally sensitive individuals.

In an attempt to understand how the individual perceives the self when ill various theories have been proposed. One such theory that has been developed is labeling theory. It has been recently applied to chronicity by introducing the notion of 'self-labeling' (Nijhof, 1992). Rather than the sufferer remaining the passive actor in the sick role, dependent upon others to care and cure, and establishing their identity from this vantage point, self-labeling recognizes the ill as actively accounting for their behavior. This process of accounting provides a mechanism for the label to be accepted as legitimate and applicable to the individual.

In such an activated labeling theory, chronic illness is not (only) conceived of as the result of the labeling practices of others or of the secondary reactions to it, but (also) as the result of self-labeling practices in which the individual strives for the social status of a person who is chronically ill and successfully accounts for it

(Nijhof, 1992: 9-10)

In other words, the individual will label themselves based upon the embodied experience of body self, body social and body politic. Experience comes to define who there are and where they will be situated in the illness trajectory. Individuals may perceive themselves as disabled,

chronically ill or otherwise compromised in an effort to legitimate the experience particularly when the medical community at large refuses to acknowledge their illness narrative.

In the social construction of illness we are principally concerned with the illness experience, the lay interpretation of this experience, the interactions encountered in the experience and the social norms that underscore illness behavior and the knowledge regarding health and illness. In framing illness the sufferer takes into account all of these elements in the process of definition-making. Rather than a given bio-medical fact, as we are often taught to accept, we have a set of “understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience and power relations that are constantly in flux” (Brown, 1995: 37). Self-awareness acknowledges these underlying concepts as capable of shaping the body self in the determination of knowledge and action related to the embodied experience and the conceptualization of health and illness. It determines who we are in relation to others at an individual and social level.

The recognition and evaluation of the symptom experience falls under the influence of culture and society. The cumulative effects of this influence impacts on the individual's subsequent evaluation of their health status and health seeking behavior. Physical sensations and mood changes are labeled as ‘symptoms’ by the lay sufferer. In turn, the identity of the individual shifts to that of the sick. Their cognitive processes, illness vocabulary, and phenomenological world interact to illuminate this ongoing process. Identification of self is often interpreted within existing modern medical and scientific paradigms of disease and illness (Angel and Thoits, 1987). But what happens when self-awareness or the self-identity of the sick role conflicts with existing models and definitions of illness and disease?

For those suffering from environmental sensitivities the desire to legitimate the illness experience by defining themselves as ill, victims of disease and justified in their behavior proves paradoxical. They experience symptoms deviant from the norm indicating that they should seek assistance for the problem but the problem cannot be identified within given bio-medical models. For all intents and purposes their identity of self should place them within the sick role. Unfortunately, for those whose self-awareness and self-identity continue to struggle within the bio-medical paradigm, resolution will be unsuccessful. Only those who shift their paradigm outside of the bio-medical model will acceptance, legitimation and a move towards health and well-being occur. For those who fail, the never-ending circle of victim and sufferer becomes their destiny.

Well I struggled daily not to become EI [environmental illness]. I mean it's so hard to fall into that trap because everything I knew I'd be affected by it somehow. Everything you do, everything you eat, everywhere you go. I mean when I first got sick, the first time, I maybe should explain this. When I first got sick and went off in '92, first of all you don't expect, I mean, I went back to work full time in the month of May. So I thought being home for three months was gonna cure me. I was gonna be better. Just need a little bit of fresh air and need some time off. Get rested because I was having some fatigue. But when I went back to work in May and I only lasted a month and then I was off for two years.

(Cloris)

Cloris goes on to explain how she now sees herself drawing upon the bio-medical model to partially rationalize the experience. At the same time, it becomes apparent that a shift in her cognitive thinking about the illness has changed. This may be due to the realization that what she experiences cannot be altered by following given social and medical definitions relating to illness behavior and health seeking patterns. In fact, since her illness falls outside the given parameters for disease to continue to maintain a belief in that paradigm would likely perpetuate

conflict, frustration and ill health.

Oh I might still call myself sick. I would not, in any circumstance, at one point it comes to government institutions, I would never consider myself disabled. I think I told you that before. Some people call themselves, they have a disability [she was referring to other individuals at Camp Hill with ES]. I do not have a disability. A disability is someone with a cane, can't walk, missing body parts and stuff like that. Or handicapped. Like to me being handicapped and being disabled are the same thing. Yes there's things that I cannot do, but in fact does not in any way make me handicapped...I have an illness but I am not ill.

(Cloris)

Cloris was answering the question about how she saw herself. She went on to talk about being sick as a day when she is unwell. Early on she had perceived herself as sick and struggled to place herself within the existing bio-medical parameters. She did have an illness as a direct result of experiencing symptoms that were outside of the norm yet the transition occurred to incorporate a more holistic picture. In this way she was able to accept the sick role and move on. She was no longer the illness.

Philip spoke of the experience as a challenge that enhanced their way of life.

It's been, at times, incredible growth of life in a lot of ways. I mean knowledge, about different areas, total career change for me and personal transformation. I mean I feel I'm, I feel now, I mean my whole approach to this is that it's been a positive experience. I feel I've come out of it a bit more whole, more whole than I was. Much better understood, and a much better sense of what I need to do with my life, and what I, what my values are. I do see myself as having a certain challenge, which I, the challenge is the changer. And I mean it's, I'm still restricted and I don't feel any restriction for instance in my lifestyle at all, my hobbies. I don't feel restricted professionally. I feel all that was fulfilling and happy results. One of the things that I still am restricted is what I do with certain goals.

(Philip)

Diane and Alexis talk about coming to terms with who they are, of learning to accept things as they are and of making changes. They have let go of the need to return to that pre-

symptomatic state. Life becomes a journey forward not backward for them.

Only the last year have I actually, mentally got it in my head that, that part of my life doesn't exist anymore. It's been a long time to change attitudes that I wasn't going back and doing the same career and it wasn't because I couldn't do it. I think, at some point, mentally it's because physically, I think, that I'm going to have to change my outlook. I'm not saying this illness has changed me for good. [goes on to talk about a change in values] I'm more content now. Um, I'm not as, like I'm not as much of a perfectionist like I used to be. And I've learned to enjoy life. If you have the energy that day or you are having a good day then I will enjoy life. I will enjoy things that are going to um, make me happy or things that I've wanted to do that I had put off because I was having a bad day. But that means leaving the dishes and I leave the dishes and go do it.

(Diane)

Okay, um, I, throughout the duration of dealing with environmental sensitivities when I finally got over the stages of denial and anger, grief and loss and all those sort of things, I finally said, 'okay this has happened. There is nothing I can do about it to change it, so deal with it!' And I was very, very fortunate to have the support system that I have. My family, my husband, friends, um, I've learned who my friends are and who I can count on. I think because of that. And I think because I then decided that, okay, what is it that I can do to understand what is going on with my body and how to cope with it and deal with it, um and I was very fortunate.

(Alexis)

In contrast, the following individuals continue to adhere to the bio-medical definition of health and illness. Their present and future expectations reflect the dichotomy of the mind/body split, of external rather than internal forces impacting upon their health, and the desire to return to their pre-morbid state of well-being.

But sometimes I worry about the, you know, my future. Whether I will ever be able to work again. You know, sometimes I, like when I'm feeling good, I'm really positive and I believe it will happen someday and uh, but then when I have all those bad days, you still, you wonder is it ever going to happen? You still, it is such a slow process. It's like so many years, you keep hoping that it will go away but it never does.

(Phyllis)

Just the main thing that um, bothers me right now is the uncertainty of the illness. Just how much will I get better or if I'm going to get better or just what sort of course that may take. Just not knowing and everybody is learning, um, like me. Like you and me have learned like everyday so it's not only a learning process for people that are ill but it's still a learning process for the people in the field that know the most about this illness up to this point. There is still a lot left to learn so, you know. I'm not going to be the first one to rush to any judgement until I know I'm getting the best treatment that is available, and um, maybe some people aren't as fortunate and uh, I'll just tell them that maybe down the road uh, things can only get better. I hope. [do you feel you have a future?] That I, I can't, I can't, I can't answer that. I don't know. I'd like to think that I do but I sometimes really wonder.

(John)

Another word that comes to mind is difficult [describing the illness experience]. Frustrating is another one. For example, – and I would like to marry and live in the same house but it is too difficult because – has so many scented friends, family and clients. It is unrealistic to try to get all these people scent free. And I need a place where scented people don't come. If we had lots of money we could live in a duplex—one side for the 'normal' scented people and one side for me. We will just have to wait until –'s girls have grown up and he is able to semi-retire.

(Greta)

I'm limited. Um, I don't really see it as an illness although sometimes I am quite ill. I guess I see an illness as something that comes, is treated and is gone. Um, whereas I really feel that this is really chronic and I think that certain aspects of it will stay with me for the rest of my life. Um, but I can see progress and I'm certainly better than I was when I first became ill. Since I first went off work. But you get so that you don't necessarily feel ill. There is a difference. I think, but then maybe there isn't. I don't see myself as being ill. That's not how I think of myself. Certainly limited and disabled somewhat right now. Then again, the disabled part, I don't see as continuing the same manner through the rest of my life.

(Patricia)

For these individuals a considerable amount of energy has been invested in the pursuit of legitimization of the illness experience. To shift this belief system would negate everything that has preceded this point in time. It challenges their identity of self and compromises the illness behavior in which they have engaged for an extended period of time. Further, one

senses an underlying fear of the future and what it has in store for them. Far simpler would be to ascribe to the belief that you are ill and that at some point technological intervention will result in a return to the pre-morbid state.

### **3.6 Discussion**

What allows one individual to rise above adversity and another to become lost in the illness experience or negative life event? Existing theories of bio-medicine and epidemiology are insufficient to answer such a loaded question. Focusing on cause and effect, pathophysiological, and biological data provide valuable but limited information in understanding resiliency. Answers are to be found in the personal experiences of those confronted with the illness experience. Listening to the illness narratives of sufferers provides insight into a poorly understood and stigmatizing disease. It was a powerful and at times saddening experience for me, as an anthropologist, to hear the suffering of these people, to put a face to an illness that medicine would be happier to ignore or dehumanize.

Resilience is the personal perceptions and response to stressful life events which, in turn, shapes the survival, recovery and rehabilitative process. "The experience of adversity and the drive to rise above it are themes that characterize the human condition" (Fine, 1991:493). Inner strength, what we refer to as the cognitive and affective processes of the individual, hold the potential to transform a most difficult event into a life-affirming, positive experience. This inner being interacts with the surrounding world, inventing and re-inventing the necessary coping skills and behaviors requisite to survival. For those who are successful a return to work and/or an improved quality of life resonates from their stories. For others this sense of resilience appears lacking.



In the course of interviewing people with environmental sensitivities, from Camp Hill, I asked them to choose a word that would best describe the experience for them. Answers ranged from terrifying to enlightening. Following are some excerpts from the interviews:

Terrified! Just don't know what was going on. What the, what your chemicals are going to do to me, inside. Cancer, scared of cancer. Everybody's scared of cancer.

(Lewis)

Well, it's debilitating. [pause] Well, I don't know if this is the right way but this is how I look at it. Like if you had cancer or something you either die or go into remission and you seem to recover quicker. With this illness there is, everything is so slow.

(Phyllis)

Criminal. Because, I think a lot of things happened that just kind of joined up. Kind of tumbled along uh, the way the building was made, the way the building was maintained, um, the additives they kept putting in the system. The way it was covered up and people weren't warned what was happening. And the way we were treated. I think it's criminal.

(Patricia)

Very unpredictable. Well, because you could have a good day and then you feel very good but then that's so short lived. That, uh, the bad days far outweigh the good days, that's why. It's unpredictable you know.

(John)

For Lewis, Phyllis, Patricia and John, all of whom have been unable to return to work, the choice of words indicates a sense of powerless, of helplessness and of hopelessness. They are the victims and are unable to change or to alter the course of the illness or their destiny. Fear underscores the experience inhibiting the ability to triumph over adversity. I feel a profound sense of sadness in re-reading the transcripts and listening to the tapes of these participants, sadness over the lack of confidence that life is worth living in spite of illness, in spite of life's challenges. I wonder if there is something that we, as health professional's and

the health care system, could do to alter a belief system that appears mired in futility?

Lewis, Phyllis, Patricia and John (of which one is a nurse and the others are kitchen and housekeeping staff) have been unable to make the transition back to work and, for them, life revolves around the illness and all the accompanying negative experiences. Considerable energy continues to be placed in having their symptoms affirmed and their disability recognized. When asked about the future answers often suggested little hope, no bright spot and uncertainty. It was painful to think about the future. In a previous quote, Greta (who also has been unable to return to work as a physician) preferred to remain in the present rather than face the future or reflect on the past in an effort to diminish the pain.

In contrast, the individuals who had been able to return to work (all were nursing and medical staff), or had remained working throughout the experience, saw it as an opportunity to grow and learn from the illness.

A condition. No I think it's permanent. I think it's manageable. I just don't think the management has, and I do believe that it is a positive thing. If I can get, If I can figure out, why...

(Sylvia)

Enlightening or awakening. Because I had [unable to make out] incredible education. It's been, at times, incredible growth of life in a lot of ways. I mean knowledge about different areas, total career change for me and personal transformation. I mean I feel that I'm, I feel now, I mean my whole approach to this is that it's been a positive experience.

(Philip)

Um, enlightening. Because I've grown tremendously. I always believe, I have a strong faith and I always believe that things happen for a reason. And I think once you can get through the, once you can muddle through the horrifying experience, those feelings of it being such a desperate situation, once you muddle through that and start to see and understand what is going on and then figure out why it's happening.

(Alexis)

Insidious. Because it gets [pause] nothing ever happened in a way, there was never [unclear] in your head, right? There was never something that you could point to and say “ah ha, look at that!”. All these little things. And there were those little [unclear] on your dignity in ways that you weren’t aware of because everyday there was some other little new things going on. And then, until you finally step back and said, “look this is not me. I am not a person who lies about, who doesn’t have energy, who can’t think properly. I am a very different person.”

(David)

For Sylvia, Philip, Alexis and David, there exists a powerful interaction among their inner psychological life, their relationship to the world around them, and their ability to cope and change as required. They have taken the illness experience and transformed themselves to incorporate this experience as part of their life, as a means of growing and learning from it. Rather than the experience becoming their life, they still remain in control. The illness represents but one facet of their lives, rather than the meaning of their life. “Successful coping promotes a sense of self-efficacy, which in turn, inspires more efforts at mastering difficult situations [Moos and Schaefer, 1984: 6]” (Fine, 1991: 494).

By efforts to understand and find meaning in the illness experience, attempting to deal with the reality and consequences of the illness and managing the feelings that emerge from such an experience, individuals are able to move along the health-illness continuum towards a better quality of life and a sense of well-being. In recognizing that some events are beyond our control and adopting new coping skills to accommodate such an experience increase the likelihood of a positive outcome. On the other hand, when an individual continues to utilize coping skills, to rely on modern medical models, and maintain the anger that arises from an experience beyond their control, the outcome is less likely to see an improved quality of life and a sense of well-being. In fact, the individual will continue to be the victim, to blame others

and their surrounding environment, to see themselves as disabled, and life as depressing with little hope for the future.

Part of the task of returning to health and well-being entails the altering of one's identity. A shift must occur to transform the individual from the sick role to an active, participating and contributing member of society regardless of the limitations that persist. Feelings of fear, vulnerability, loss, powerlessness and anger must be dealt with. This requires a change in the beliefs, values and attitudes of the individual. Persistence, flexibility and the ability to draw upon good psychosocial capacities and social support are instrumental in this change.

## **Chapter Four**

### **Implications for Research, Health Policy and Health Education**

Both men and women with MCS are at risk for verbal and other kinds of abuse as a result of having a little understood health problem. Both fail to fulfill expectations of others in terms of quantity and types of activities in which they are able to engage. Both defy gender role expectations: women in their inability to engage in the types of nurturing behaviors we have come to expect from women, and men for their 'weakness' embodied in their reactions to chemicals and their difficulties regarding financial provision.

(Gibson, Cheavens, Warren, 1998: 103)

The severely mentally ill face many roadblocks, not the least of which is discrimination by the government and by insurance companies. The inadequate coverage allowed the severely mentally ill by the insurance industry, Medicare and Medicaid is often as little as one fifth or less the coverage allowed other serious illnesses. This inequity not only contributes to the terrible stigma of mental illness, but also greatly increases patient suffering and results in needless fatalities—suicides that could have been prevented by properly reimbursed treatment. As the federal government prepares for the essential health care cost reform, it is imperative that policy leaders, physicians, and mental health care advocates demand equal treatment under the law for severely mentally ill. The Equitable Care for Severe Mental Illnesses Act of 1992 can provide a model for such action.

(Senator Pete V. Domenici, 1993: 5)

Research into environmental sensitivities, from an epidemiological and science based perspective, has increased over the last five years. Just searching the literature has shown a wealth of journal articles whose mandate attempts to establish a definitive link between chemical and environmental triggers and organ or system dysfunction. Efforts to prove cause and effect, to establish an appropriate definition within medicine, or to disprove its existence as a 'real' disease encourage frequent debates, some quite heated. In spite of the interest manifested by the scientific and medical community, in this poorly understood and accepted illness, little has been researched within the paradigm of the social sciences.

The tendency within research, particularly public health research, has been to rely on empirical quantifiable data while dismissing anthropological, philosophical and historical disciplines as too 'soft' and impractical. Little value has been afforded to the more humanistic, critical, theoretical and interpretative approaches of these branches of the social sciences. Part of this may be due to public health research and health promotion's close ties with bio-medicine. At the same time, it might serve us well to direct more energy into critiquing the accepted ideologies underlying health promotion and medical practice in an endeavor to capture the true essence of a variety of stigmatizing illnesses and diseases (Lupton, 1995; Sherwin 1992 & 1998; Corin, 1994).

In an attempt to understand this illness I have had to draw on research that has been conducted on mental health issues. I am not stating that I believe environmental sensitivities to be psychiatric in nature rather the similarities that arise regarding the impact and implications of environmental sensitivities on the individual correlate closely with those of mental illness. In fact, the marginalization of people with environmental sensitivities is no different than that of people with depression, schizophrenia, or other psychiatric disorders. This patient population experiences stigmatization, isolation, impoverishment, and abuse. Their response to the illness very often results in feelings of guilt, self-blame, inadequacy, poor self-esteem and self-worth, anger, and powerlessness. These outcomes are similar to those experienced by individuals with mental illness.

In previous chapters I have discussed how the incorporation of both qualitative and quantitative methodologies would provide for a greater level of knowledge and understanding around mental illness. Such is the case with environmental sensitivities. By seeking to

understand the meaning attached to the experience, socioeconomic data, and implications of socio-cultural norms and values a more holistic picture of the illness beyond that of cause and effort emerges.

Medicine is becoming a major institution of social control... It is becoming the new repository of truth, the place where absolute and often final judgements are made by supposedly morally neutral and objective experts. And these judgements are made, not in the name of virtue or legitimacy, but in the name of health. Moreover, this is not occurring through the political power physicians hold or can influence, but is largely insidious and often undramatic phenomenon accomplished by 'medicalizing' much of daily living, by making medicine and the labels 'healthy' and 'ill' relevant to an ever increasing part of human existence.

(Zola, 1972: 487)

What emerges from the medicalization process, wherein individual and group problems, conditions or choices are viewed in medical terms, is a sense of legitimacy for medicine rather than for the individual and their experience. If it cannot be explained or researched within medical concepts, theories and discourses then little credibility and value is placed on the experience. In short, to be successfully medicalized the event, problem or choice must meet three criteria:

- the domain, process, or topic must be definable and defined in medical terms, that is be assimilable and assimilated to dominant medical paradigms, theories, research, and methodologies and must be seen as only (or most) appropriately described through dominant medical discourse.
- medical authorities exercising the highest level of control over medical knowledge and treatments are seen as the only (or the most) legitimate authorities having appropriate authoritative knowledge and control over the means and personnel to apply that knowledge to the medically defined 'problem'.
- there must, ultimately, be widespread individual and group acceptance of the dominant conceptualizations of medicalization and active participation in its diverse, interrelated macro- and micro-institutions.

(Pauly-Morgan, 1998: 84-85)

We, as a society, have accepted the ideology that medicine legitimizes the illness

experience through acknowledgment of the symptomatology as 'real.' To enter the sick role our experience must be validated, diagnosed, treatment rendered and care and cure arrived at. When this fails to happen, the individual continues to seek out medical authority figures to validate the experience becoming further ensnared in the medical process. Even research must conform to this dogma. To be legitimate and scientific is to be quantifiable, verifiable and objectifiable. A somewhat illusive aspect of the social sciences.

Recent proponents of health education and research are encouraging the empowerment of the average individual to look beyond the medical paradigm to the hidden socio-economic and socio-cultural reasons for ill-health (Lupton, 1995). In so doing the sick and the well are encouraged to move beyond the authoritative voice of medicine by initiating autonomy and authority in the individual and group voice.

One avenue that would encourage the voices of the silent to be heard is through the ethnography. Ethnographic approaches to health research describe cultural models of health and illness providing a framework for understanding individual and group level knowledge and beliefs about health risk, transmission and behavior. They identify key social contexts within which beliefs and values are turned into action and establish the intervening conditions that protect or prevent change. Furthermore, they provide the framework for the role of decision-making process and identify conditions that are necessary to maintain behavioral change. Finally, ethnographic studies are able to identify the symbolic and communication patterns of a culture as they relate to health.

By incorporating the qualitative social sciences approach into epidemiological studies through techniques such as illness narratives we may:



- enhance the understanding of the diversity and local knowledge and its relationship to health and illness.
- avoid the inherent problem of category 'fallacy' when we try to universalize the individual qualities to the group.
- increase our understanding of the meaning of health and illness for a population, such as those with environmental sensitivities, which would assist in the implementation of more effective health policy.
- and finally, we would acquire a greater understanding of the disease causality and the fact that it extends beyond the pathophysiological (Corin, 1994; Pauly-Morgan, 1998; Lupton, 1995).

In summation, a more global understanding of their social determinants of health and illness and the characteristics of the group/community/population that mitigate it may lead to policies that:

- target interactive interventions which involve the group/community/population as an active rather than passive partner in health<sup>21</sup>.
- are more realistic, achievable and effective rather than implementing numerous policies for specific groups alone<sup>22</sup>.

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<sup>21</sup>

Listening to the group is more likely to be productive and provide more information to address the issues and concerns of a people than to continue to work solely with the individual at an individual level. The latter continues to be reductionist and limiting in scope.

<sup>22</sup>

Very often characteristics of groups and health concerns overlap. By limiting policies to specific groups stigmatization and ostracization may inadvertently occur. In looking for similarities people do not feel so 'different' and are more likely to work towards a positive

- respect the cultural diversity making policies more acceptable.
- are built on community strengths.
- result in behavioral change through the understanding of diversity.
- take into account the tolerances and intolerance of the problem within a given group/community/population<sup>23</sup>.
- focus on 'target conditions' instead of 'at risk groups'<sup>24</sup>.

"Voices bespeak the conditions of embodiment that most of us would rather forget our own vulnerability to" (Frank, 1995: 25). One of the most difficult duties as human beings is to listen to the voices of those who suffer. These voices may send mixed messages, painful messages we would rather ignore or discount. The importance lies in the ability of the listener, the health professional, to hear and acknowledge the message the ill are trying to convey.

The very framework of the illness narrative helps us to recognize what basic life concerns are being addressed, what changes are required, our perceptions, as listeners about the relationships of the body to the world, as well as that of the sick person. It is unconscionable to stand by mutely and fail to acknowledge the illness narrative. That action

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resolution or improved quality of life. At the same time, similarities provide a framework for policies that are more cost effective and less redundant by addressing specific groups alone.

<sup>23</sup>

It is far easier to educate groups if one first understands where the group is coming from and the boundaries within which the group operates.

<sup>24</sup>

When an emphasis is placed on the risk group as opposed to the target condition the grounds are laid for misperceptions, stereotyping and stigmatizing behavior.

only serves to perpetuate the stigmatizing effect of disability and illness. “Nobody wants an anonymous illness” (Frank, 1995: 117). The illness narrative represents a form of reflexive monitoring whereby the teller and the listener label a symptom or series of symptoms, provide legitimation, a reference point, a sense of social understanding and concreteness to that which originated as an abstract entity.

People talk about their health to provide information, not just about their physiological self, but also about their social self. Our conceptions of health are shaped by personal experience, cultural ideology, biomedical constructs and environmental cues. By offering comments about health people are “making claims about themselves as worthy individuals, as more or less ‘fit’ participants in the activities of the social world” (Radley and Billig, 1996: 220). Accounts of health and illness are more than mere reflections of one’s physiological state. They articulate the individual’s situation in the world vis-a-vis the illness experience (Radley and Billig, 1996).

Perceiving illness as a *real* entity involves both personal images and social norms in constant interplay. What the individual states about their illness reflects not only the individual’s perspectives of the issues but the way society constructs these issues. Illness narratives provide more than a description of ideas people share about health and illness; it also provides a glimpse into how a “social object takes shape for members of our society, and of grasping its implications for the relationship of the individual to society” (Radley and Billig, 1996: 223). We do not have, merely, individual attitudes, but general beliefs and shared theories that we have internalized as part of our social learning.

The central fact of illness implies that the “world [may be] made meaningful only

through culturally situated social interaction” (Pirie, 1988: 631). Emphasis is placed upon the subjective experience from a culturally bound perspective. To look at illness as distinct from the socio-cultural denies the experience, ignores the social implications within the illness experience, and diminishes the mitigating or exacerbating effects of these factors on disease etiology. Rather than placing our energies on understanding more about less, as modern epidemiology appears to be doing, we should reintroduce the population perspective, socio-cultural warts and all into the framework of etiology and trajectory of illness. Only then will we truly come to understand disease, its cause, and ultimately its effect on the human body and the society within which this body resides.

## **Conclusion**

Working as a health professional at the Nova Scotia Environmental Health Centre over the past four years I found my curiosity piqued by the stories I would hear over and over again. The injustices, it seemed, for individuals with environmental sensitivities was all too common. The staff who worked at Camp Hill between 1987 and 1993 know first hand the experiences that arise from having this illness. These individuals, perhaps, are best thought of as the canaries in the mines. Their experiences, as they struggled to bring attention and credibility to a health crisis situation, seemingly went ignored by the medical community. Attention has been garnered, over the years, in the media. More often it was voyeuristic and sensationalistic rather than productive and educational. The most important arena, the medical community, has consistently chosen to ignore, like the ostrich with its head in the sand, in the vain hope that the problem will go away if one ignores it long enough.

As a result I felt that by exploring issues around the Camp Hill experience a greater insight into environmental sensitivities could be achieved. More importantly, as an anthropologist, I wanted to give a voice to those most often silenced by authority. By providing an opportunity for people with environmental sensitivities to speak out, without fear of recrimination or judgement, wonderful pathographies have come to light affording greater insight into this poorly understood illness.

In deciding to undertake an exploration of the Camp Hill crisis, I never dreamed that it would affect me so profoundly. Originally I felt that by exploring an issue of critical importance for our patient population I would gain greater insight and knowledge into the problem and how best to work with them. I walked away with far more than knowledge. In

fact, as the old saying goes, 'walk a mile in my shoes.' Unless one has had the experience, the ability to 'feel' what the individual with environmental sensitivities has gone through is almost impossible.

The illness narrative of environmental sensitivities needs to be told and retold. Unless we are willing to sit down, listen and learn this crisis will happen again and again. Regardless of the fact that medicine has yet to define environmental sensitivities, and even worse, exhibits an unwillingness to accept this as a disease phenomenon, environmental sensitivities exists. Sadly this reflection of our societal values, desires and norms indicates our need to place a far greater emphasis on efficiency, dehumanization, mechanization and technology through the use of more and more chemicals, machines and windowless worlds. Here we sit pious and somewhat sanctimonious in our belief that 'it won't happen to me', or, at least, 'not in our back yard.' Unfortunately it did happen and it is imperative that we do not ignore the voices and the stories they have to tell.

In a society obsessed with health we have a very poor grasp of this enigmatic state. Funny how when we no longer have it, we come to realize and understand health and grieve the loss. More profound when, through no fault of their own, grieving becomes inhibited by a medical system that does not acknowledge the problem. Individuals are left searching for validation to symptoms that fall outside socially and medically defined norms. Specialists are seen, visits to emergency departments occur, family members, friends and co-workers alienate the individual and all that emerges from this process are the words, 'it's all in your head.' In order to move forward along the health continuum requires validation and legitimization of the illness experience.

Further, stereotyping, stigmatizing behavior, and abusive accusations propel the individual away from help and support into isolation. In withdrawing, anger arises not just because of feelings of alienation and being different, but because of a system that betrayed them. They believed the system would be there to help them in time of need but it failed them and in essence, failed all of us. Anger attacks more than the psychological aspect of an individual, it effects the entire body, wearing it down little by little, until ill health and a negative attitude are all that remains.

For some, the recognition that health professionals and the health system are fallible, enabled them to draw upon an inner strength and emerge, as the phoenix from the ashes, with a new sense of awareness of who they were and a renewed purpose in life. As one of the participants stated, “things do happen for a reason”. In taking up the challenge and working with it within, and in spite of, limitations placed upon them they are able to achieve a positive outcome. For others, who are still confined to old, established belief systems of medicine as authority, knowledge and power, the inability to move reflects their powerlessness, sense of futility, and desire to return to a pre-morbid fantasy state of health. For them, health has become the utopian ideal, an unrealistic state impossible to achieve.

The ability to accept the fallibility of medicine, that it doesn't always have the answers to all the symptoms that individuals may suffer, will assist the individual from falling into the trap of legitimization of the illness experience. Some individuals become so entrapped that they move from one doctor to another, one specialist to another in a vain attempt to have their experience validated. We have become socialized in the belief that the bio-medical paradigm provides the only mechanism to supply the answers, the cure and the care. In order to

transcend the experience of environmental sensitivities we require a complementing of allopathic and alternative practices, beliefs and values. That, and an inner strength and resolve to rise above life's adversities. "Truly functioning coping behavior has been characterized as not only lessening the immediate impact of stress, but also as maintaining a sense of self-worth and unity with the past and an anticipated future [Dimsdale, 1974]" (Fine, 1991: 497). Inherent in this is the ability to change rather than remain static; to act as if one is influential rather than helpless through the use of imagination, knowledge, skill and choice (Fine, 1991); and to become an active rather than a passive player in the sick role. Only then will we see individuals emerge from the catastrophe of stigmatizing and devastating life experiences such as environmental sensitivities.

In order to address the inherent problems of an illness that has yet to be defined within scientific parameters we must transcend verifiable, quantifiable, objectifiable data as the prerequisite of knowledge and understanding and seek to incorporate a more humanistic, critical and interpretative approach. In so doing we will come to understand, to have empathy for a people who could just as easily be each and everyone of us. We are social beings not machines as medicine would have us believe. We communicate, act and interact in a manner that sets us apart from other sentient beings. We tell stories, interpret and attach meaning to our experiences, and in this way structure our lives. Narratives will never replace modern technology and all the advances that have allowed the human race to excel and survive. By incorporating the illness narrative we add the influence of the mind, emotion, and culture to bio-medicine making it more empathetic, holistic and better equipped to deal with the challenging new diseases as we enter the next millennium.



## **Appendix**

### **Faculty of Sociology and Social Anthropology Dalhousie University**

#### **Consent to be a Research Participant**

##### **Purpose**

There is very little published research studies concerning peoples' first hand experience with environmental sensitivities, particularly concerning how they define issues of health and illness. The purpose of this study is twofold. The first is to describe how individuals come to create a meaning for the environmental sensitivities illness experience. The second is to define wellness, from the perspective of people with environmental sensitivities since it is poorly understood by the majority of health providers. The study will be conducted by Brenda Sabo who is a Master of Anthropology student at Dalhousie University and a Nurse at the Nova Scotia Environmental Health Center. The researcher is interested in personal accounts concerning how the individual defines the illness, how they see their health, and lastly, their interactions with doctors and other health professionals within and without the Nova Scotia Environmental Health Center.

This study will involve individual interviews of people with environmental sensitivities and chart reviews where Brenda Sabo will be looking at symptoms reported and references to a return to health. I am participating in this study because I have experience with environmental sensitivities and because I was employed at Camp Hill Medical Center, at some time, between 1987 and 1993.

##### **Procedure**

If I agree to participate, the following procedures will occur:

I will be interviewed by Brenda Sabo at the Nova Scotia Environmental Health Center or if this is not convenient, I will be interviewed in a location that I choose. I will be interviewed for 60-120 minutes or I may break this interview up into two shorter sessions if I prefer. I will be asked about the illness, my support network whether it is family, friends or support groups, my feelings on traditional doctors and alternative practitioners and how I feel they may have helped or hindered my progress, and what I believe is health and wellness. Some background information may be required of me. The interview will be taped if I agree.

I will not be identified by name in Ms Sabo's notes and may choose to use my own name or a pseudonym for the duration of the interview.

## **Risks and Benefits**

This study will involve a loss of privacy in that I am telling my personal story. However, my confidentiality will be protected as much as possible. My name or details that may identify me will not be used in any reports or presentations. The study findings will be reported in terms of issues that are common to most individuals who participate in the study. When the tape is transcribed, identifying information will be deleted and the tape will be kept in a locked filing cabinet, separate from the transcripts. The tape will be destroyed upon completion of the transcription. Transcripts will be identified by a code number and stored separately from the consent form until no longer required. No staff at the Nova Scotia Environmental Health Center will have access to my tapes or transcribed notes. I may request a copy of the transcription of the tape for myself should I wish.

Another potential risk is that discussion of my experience may stir up uncomfortable feelings. I can refuse to answer any question or ask to stop the interview at any time.

Participation in this study will not change or influence, in any way, my treatment at the Nova Scotia Environmental Health Center.

Upon completion of the project and submission of the thesis for publication the tapes will be destroyed.

## **Benefits**

I cannot expect direct benefits from participating in this study, although I might enjoy talking about my experiences and making suggestions for health providers. My participation may benefit other people with environmental sensitivities by helping health professionals who care for them better understand their needs in order to help them treat their patients more sensitively and effectively.

## **Financial considerations**

There will be no cost to me nor will I be reimbursed for participating in this study.

## **Questions**

Should I have questions or concerns about this study, I should first talk with Brenda Sabo (902) 860-0055. Should I prefer not to talk with her, I can call the Department of Sociology and Social Anthropology, Dalhousie University and ask to speak with her advisor, professor Marian Binkley, 9am-4pm Monday-Friday at (902) 494-6589/423-2448.

**Consent**

**My participation in this study is strictly voluntary.** I can choose not to participate. If I choose to participate, I can refuse to answer any question, stop the interview or withdraw from the study at any time without penalty or disruption of present or future treatment. My participation will not affect any current or future health or social services.

If I wish to participate, I should sign this form. I will be given a copy to keep.

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**Participant's signature**

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**Date**

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**Researcher's signature**

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**Date**

## Question Outline

### 1. Body self (lived experience)

- I would like you to take a few minutes to think back to what life was like before started to experience symptoms. Tell me a little bit about yourself, your likes, dislikes. (How would you describe yourself?)
- what did it mean to be healthy? (What did health mean?)
- how did you see your body?
- during this time, describe a typical good day. What word would you use to describe this day? Why?
- ...typical bad day. Word? Why?
- what were some of the things that made you happy? Anxious?
- shift to start of experiencing symptoms—how did this make you feel?
- did you start to see your body differently? In what way?
- what things make you anxious now? Happy?
- ...typical good day. Bad day.
- do you feel there is a difference between good day then and now? Explain. How does this make you feel?
- what do you believe is key to becoming well? Why?
- what does health mean to you now?

### 2. Body social

- how would you describe your experience (the development of the symptoms)? How did this affect your life?
- if you could pick a word to describe this experience what would it be?
- tell me why you feel this word best describe...
- do you feel there is a difference between this experience and other disease/illness? Explain
- tell me how you would describe an absence of the symptoms
- these words that you use, have you heard them before? Tell me where? Why do you like to use them? When did you first start to use them?
- have you or do you now belong to a support group?
- tell me about this experience; how did it make you feel? If not belong, why?

### 3. Body politic

- if you were to think about your experiences with health professionals, over the years, what were your expectations when you went to see ...before developed ES?
- why did you go to the doctor?
- tell me about these experiences
- what did you feel you needed to do when you went to see the health professional?
- now tell me about your experiences since you developed symptoms
- do you feel the experience has changed? Explain

- what are your expectations now when you see a health professional?
- what do you feel you need to do now?
- if the experience is negative, what do you feel would help to change the experience?
- do you see alternative health practitioners outside of the Nova Scotia Environmental Health Center ? If yes, tell me about the experience. How did this make you feel?

**Chronological Sequence of Events Pertaining to the Camp Hill Experience (Fox, Shires, Fox, and Reudy 1996; Taylor 1996)**

- 1987            kitchen staff begin reporting symptoms of indoor air quality problems (IAQ)
- 1987-89        approximately 127 of 160 kitchen workers report symptoms
- 1989 (late)    cases similar to those of kitchen staff now reported on second floor of the Veterans Memorial Building with increasing severity of symptoms
- 1991-93        more than 700 of 1250 staff report symptoms. Almost all of the symptoms were reported at the Camp Hill site but 17 cases were reported at the Halifax Infirmary which had been previously undergoing renovations and IAQ problems were identified.  
Over 300 workers were off work for periods ranging from 3 months to 3 years  
term 'environmental irritant syndrome' introduced
- 1996            Cullen report – Dr Mark Cullen, Professor of Medicine and Public Health and the Director of the Occupational/environmental Medicine Program, Yale University School of Medicine, New Haven Connecticut is interviewed by the members of the Environmental Hypersensitivity Committee, Department of Health, Province of Nova Scotia, November 22, 1996. He had been brought in as an expert witness in the field of environmental and occupational health to address the Camp Hill experience.
- 1997            *Report of the Advisory Committee on Environmental Hypersensitivity to the Deputy Minister of Health, Province of Nova Scotia*, June 24, 1997 comes out.
- 1998            current estimates from the Nova Scotia Environmental Health Center state that approximately 100 to 120 staff remain unable to return to work

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