THE EXPERIENCE OF ECOLOGICAL ILLNESS

ECOLOGICAL ILLNESS:
THE EXPERIENCE OF CONTROVERSIAL HEALTH PROBLEMS

By

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A Thesis
Submitted to the School of Graduate Studies
in Partial Fulfilment of the Requirements
for the Degree
Master of Arts

McMaster University

MASTER OF ARTS
(Sociology)

McMASTER UNIVERSITY
Hamilton, Ontario

TITLE: Ecological Illness: The Experience of Controversial Health Problems

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NUMBER OF PAGES: ix, 187

ABSTRACT

This research is based on semi-structured interviews with thirty-two people who understand themselves to be suffering from health problems called ecological illness, or environmental hypersensitivity. The research examines the experience of ecological illness.

Given that the medical status of ecological illness is controversial, and that troubles considered to be ecological illness are typically vague and non-specific, the study focuses on meanings and interpretive frameworks that are applied in the definition of such troubles; by those affected, by significant others, and by physicians. The analysis examines the nature and course over time of definitions of trouble-related identity and the social psychological and practical consequences of such definitions for respondents' illness experience. Because respondents largely define their troubles as physical health problems, a central issue in the analysis is the medical and social legitimation of illness claims.

The research found that, in the course of seeking medical treatment and legitimation for their problems, people's experiences of trouble were typically discredited. They were long unable to resolve conflicts between a self-identity as sick and others' assessments of them as "not sick" or psychologically troubled. While the eventual diagnosis of hypersensitivity was a profound relief to people in many respects, it was often not recognized and accepted by others as a basis for informal or "official" sick role considerations. Because of scepticism toward the concept of multiple sensitivities, many people continued to feel stigmatized by their problems. The study illustrates the impact and significance of controversies within medicine for the experience of certain kinds of health problems.

ACKNOWLEDGEMENTS

I wish to thank all who contributed to the preparation of this thesis. Thank you, first, to my supervisor, Dr. Ralph Matthews for his assistance in planning the research, his helpful comments on the writing, and, not least, his patience. I also wish to thank the other members of my committee, Dr. William Shaffir and Dr. Susan French, for their helpful comments and encouragement.

I am indebted also to all those who so openly shared with me their very personal experiences of coping with challenging illness problems; and to members of the Allergy and Environmental Health Association of Canada (formerly Human Ecology Foundation of Canada) who assisted me in locating volunteers.

Thank you also to my family for their support, encouragement and assistance.

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INTRODUCTION

Research in the sociology of illness is usually constructed on the basis of highly conventional, well-established categories of disease; medical diagnostic categories such as diabetes, epilepsy, rheumatoid arthritis, heart disease or cancer. This is true not only of older studies which have tended to be formulated in terms of quasi-medical questions such as etiology, utilization of services or compliance with treatment, but also of most recent work concerned with the subjective experience of sufferers and the social organization of their worlds. That medical diagnostic categories are relied upon in many sociological studies is not surprising, since sufferers themselves, following medical diagnosis, frequently come to rely upon such categories in making sense of and acting upon their experience. In varying ways, medical diagnoses provide conventional reference points, for doctors, for sufferers, and for sociologists analyzing their experience.

Because of frequent consensus among doctors, patients and others in the use of established medical diagnostic categories, their medical and social legitimacy seldom figures as a problematic in studies of illness experience. In other words, as much as they are used in analyses, they nevertheless rarely become significant analytic foci themselves.

In recent years, however, a number of less well established, highly controversial diagnostic categories have been developed within medicine (Berger, 1988). In contrast to established categories such as diabetes or epilepsy, diagnoses such as hypoglycemia, candida albicans, chronic fatigue syndrome, or environmental hypersensitivity are seen by many doctors to be either completely bogus or faddishly over-diagnosed. However, a minority of other doctors champion these new diagnostic categories. For example, an American doctor in this latter group has recently published a book addressed to lay readers in which he discusses a number of such controversial diagnoses under the title, <u>What Your Doctor Didn't Learn in Medical School</u> (Berger, 1988). Given this lack of medical consensus, the question arises as to whether the contested legitimacy of such categories has important implications for the illness experience of people who use them to organize their troubles.

Thèse

The present study addresses this question, focusing on the illness and help-seeking experience of people who have come to make sense of various troubles in terms of one of these controversial diagnoses: environmental hypersensitivity or ecological illness. Broadly put, the study is concerned with definitional and interaction processes involved as people make sense of and live with various kinds of troubles--troubles that they, at some point, define and organize as adverse reactions to various foods, drugs and environmental substances. Before elaborating on objectives of the study, it may be useful to provide some background on the phenomenon of ecological illness and the medical specialty of clinical ecology.

Ecological Illness and Clinical Ecology

The terms "ecological illness" and "environmental hypersensitivity" refer to a great variety of sometimes mild, sometimes debilitating chronic illness problems that result from inability to tolerate various foods, drugs and environmental substances. Such health problems have also been popularly referred to as twentieth-century disease (Government of Ontario, 1985:14). The recognition, definition, diagnosis and treatment of these chronic medical conditions has been the concern of a medical specialty called clinical ecology.

Clinical ecologists claim that increasing numbers of people are being adversely affected by a great variety of common food, drug, chemical, and natural inhalant exposures. Such exposures include, among others, chemical pollutants such as formaldehyde in building materials and clothing, soft plastic odours from home furnishings, tobacco smoke, natural gas fumes from stoves and heating systems, perfumes, chlorine and fluoride in tap water, food additives, pesticides and herbicides. Almost any food is recognized as potentially problematic to some "exquisitely" sensitive people. The most commonly identified problem foods are such frequently eaten foods as milk, corn, wheat, egg, yeast, potato, and beef. Problematic natural inhalants (also the concern of allergists) include pollens, dusts, animal danders, and moulds (Bell, 1982:15-16).

In addition to various local physical symptoms that have been identified in traditional allergy medicine, clinical ecologists have emphasized the role played by food and environmental intolerance in psychiatric, central nervous system and psycho-physiologic problems. Signs and symptoms of environmentally-induced illness can, therefore, be behavioural or "psychological", as well as including reports of pain or other symptoms traditionally associated with conditions of physical illness (Bell, 1982:14). Clinical ecologists also emphasize that any number and variety of body organs or systems can be affected by various reactions. Environmental hypersensitivity has been identified by clinical ecologists as responsible for producing symptoms and syndromes involving the following body organs and systems:

> Nervous System: Migraine, tension headache, irritability, anxiety, depression, uncontrollable

> crying or giggling, fatigue, unusual sleepiness, inability to concentrate or think clearly, feeling of floating or as if "drunk", stammering.
>
> Gastrointestinal: pain, bloating, diarrhoea, constipation, nausea, vomiting, anorexia, food cravings, difficulty in swallowing.
>
> Respiratory: recurrent colds or bronchitis, asthma, pain and congestion, shortness of breath.
>
> Musculoskeletal: joint and muscle pains, backaches, weakness, generalized stiffness or spasticity.
>
> Genitourinary: premenstrual headaches and depression, vaginal infections, bladder infections, enuresis, frequency of urination, painful urination.
>
> Eyes, ears, nose and throat: sinus infections, chronic stuffiness, dizzy spells, earaches, deafness, watering of eyes, blurring of vision, sensitivity to light.
>
> Skin: eczema, dermatitis, hives, flushing, itching, burning, chronic acne. (Bell, 1982:16; Government of Ontario, 1985:15-16)

This listing of possible symptoms is not exhaustive, but indicates the range of many frequently reported symptoms that have been attributed by clinical ecologists to food and environmental sensitivities. According to them, people with environmental hypersensitivities usually have multiple symptoms involving many parts of their body, including the nervous system (Bell, 1982:15). Because of this, ecological illness has been referred to as "a great imitator", mimicking "...any disease from cardiac disease to migraine headaches, to mental disease." (Maclennan, 1986:31).

popular belief

When patients complaining of such symptoms are physically examined by a physician, however, they are commonly found to be free of any objective indications of pathology. Consequently, many are diagnosed as psychosomatic or hypochondriacal (Government of Ontario, 1985:18). However, whether or not objective evidence of disease is found by conventionally practising doctors, many people who suffer from environmental illnesses are either chronically or episodically debilitated by their symptoms. A few have been identified by clinical ecologists as "universal reactors", debilitated by sensitivity to almost all food, chemical and inhalant exposures (Levin and Zellerbach, 1983:78). These individuals have occasionally attracted sensational media attention, being described as victims of "twentieth-century disease".

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Treatment

Treatment by doctors taking an ecologic approach involves avoidance of problem substances and possibly symptom-neutralizing doses of dilute extracts of the most difficult to avoid substances. Treatment also typically includes a "rotary diet" (providing an interval of four or more days between exposures to safe foods); and any changes to the home environment necessary to make it an "ecologically-sound oasis" as free as possible of sources of poorly tolerated fumes, moulds or dusts (Bell, 1982:14).

As noted earlier, ecological illness and ecologic medicine are highly controversial in medicine. There is a relatively small number of physicians in Canada who acknowledge that claims of such broad spectrum and multi-symptomatic sensitivities are medically valid, and that such problems constitute genuine illness syndromes that must be diagnosed and treated as such. The number of physicians who actually diagnose and treat ecological illness is quite small indeed. In Ontario, the province with the greatest number of clinical ecologists, there are at present eight physicians practicing ecologic medicine. The majority of the profession of medicine either dispute and dismiss the existence of such health problems or are unaware of them (Government of Ontario, 1985). Clinical ecology has been attacked within the profession as "fringe" or "alternative" medicine, thus encouraging an association with health care philosophies and techniques originating outside of mainstream medicine.

Canada Stats

The origins of ecologic medicine, however, are clearly within modern medicine itself. Clinical ecology developed historically out of the fields of allergy and immunology. The term "allergy", coined by Clemens von Pirquet in 1906, originally had a very broad meaning: "...any individualized reaction to an environmental substance occurring in time." (Randolph and Moss, 1980:22). In addition to substances such as dust and pollens, some

✓ historical allergy

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physicians interested in allergy in the first half of this century also began to focus on the role of adverse food reactions in various types of diseases and "mental" problems (eg. Hare, 1905; Rowe, 1931; Rinkel et al, 1951). After 1925, however, most North American and European allergists agreed to restrict the definition of allergy to bodily mechanisms explicable solely in terms of immunologic theory of antibody-antigen reactions. As Randolph and Moss (1980:4-5) argue, this narrowing of definition to phenomena that were increasingly amenable to precise measurement, served to enhance the scientific status of the field of allergy. However, it also eliminated as valid subjects of inquiry, many previously acknowledged kinds of reaction in which antibody-antigen reactions could not be demonstrated. From this time on, the food allergists who continued to investigate these latter kinds of reactions comprised an unorthodox minority in the field. It is in their work that the broad approach of clinical ecology to food and environment-related illness has its roots.

In the 1950's, Randolph (1962), one of the unorthodox allergists, extended his clinical investigations further to include common, low-level chemical exposures found in everyday living and working environments. By including foods and chemicals along with the traditional natural inhalants in their investigations, Randolph and other unorthodox allergists were increasingly out of step with the majority in their field. In 1965, a separate medical organization, The Society for Clinical Ecology, was founded by Randolph and like-minded colleagues in the United States. Since that time, organizations of physicians practising or interested in clinical ecology have also been formed in England and Canada; the latter being the Canadian Society for Clinical Ecology and Environmental Medicine established in 1985. In both medicine and psychology, a diverse literature supportive of ecologic concepts and methods has also developed in recent years (eg. King, 1981; Finn & Cohen, 1978; Egger et al.,1983; Gerrard, 1978; Dickey, 1976; Miller, 1972; Rae et al., 1978; Rapp, 1978; Philpott & Kalita, 1980; Rippere & Adams, 1982; Randolph, 1962; Levin & Zellerbach, 1983). 1985

While clinical ecology has attracted interest among some doctors and researchers, it nevertheless continues to occupy a marginal position in medicine. Bell (1982:24) attributes this, in part, to the interdisciplinary nature of clinical ecology; there is no single established medical field within which its basic concepts could be accommodated, tested and elaborated. As noted above, ecologic medicine goes beyond the more narrowly defined boundaries of allergy with its focus upon central nervous system and psychiatric problems. It also differs from toxicology in its insistence that many common substances ordinarily considered non-toxic can be factors in illness.

There is emphasis on the "total load" of multiple, low-level exposures and the idea that, because of this, safe thresholds of single exposures can not be established (Bell, 1982:24).

Perhaps related to this lack of fit with an established field within medicine, clinical ecology has been sharply criticized, sometimes ridiculed, particularly by those in fields with related interests. The American Academy of Allergy and Immunology has published a position statement on clinical ecology in which the notion of complex, multi-system disorders due to multiple sensitivities is dismissed as "unproven". ① Ecologic theories and claims generally are referred to as "dogma" (Executive Committee of the American Academy of Allergy and Immunology, 1986). Diagnostic techniques often used by clinical ecologists (provocation/neutralization and serial endpoint titration) are similarly rejected as "unproven". ② Ecologic treatment techniques are criticized as time-consuming, expensive, and restrictive. ③ The position statement also suggests that patients with multiple symptoms who do not fit a disease category and who fail to improve with conventional therapy are often appropriately labeled psychosomatic. Its authors suggest that such patients seek out clinical ecologists because they have trouble accepting and managing the concept of psychosomatic illness.

In Canada, the Allergy and Clinical Immunology subsection of the Ontario Medical Association has similarly taken a position that ecologic theory, tests and treatments are "unproven" (Government of Ontario, 1985:262). In addition, a number of critical articles have been published by two Toronto psychiatrists (Stewart & Raskin, 1985 and 1986; Stewart, 1987a and 1987b). They argue that cases of "20th century disease" often really involve well established psychiatric disorders that are "somatized", or physically expressed. Stewart and Raskin (1985) interviewed eighteen patients who claimed to be suffering from complex hypersensitivity-related problems. Using what they considered to be "strict diagnostic criteria", they judged that: "Clinically, 7 of the patients exhibited somatoform disorders, 10 suffered from a psychosis or an affective or anxiety disorder, and 1 had a personality disorder" (Stewart & Raskin, 1985). Stewart (1987b:54) further concluded that, "...20th Century Disease was not a new illness caused by reactions to a toxic-filled environment, but rather a trendy new diagnosis for a heterogeneous group of syndromes, many of which have been known to physicians for over 3,000 years." Stewart also suggested that ecologic treatment programs could be harmful in that, "...they impose isolation, reinforce invalidism, cause nutritional compromise, and prevent patients from obtaining treatments proven to be effective" (Stewart, 1987a:409).

The above examples indicate the kind of disparaging statements that have been directed at clinical ecology by its medical and psychiatric critics. The literature contains many other articles that are similarly critical of ecologic concepts and techniques (eg. Terr, 1986; Brodsky, 1983; American Academy of Allergy, 1981; California Medical Association, 1986; Lehman, 1980). The notion of complex hypersensitivity problems is clearly not merely something that doctors "didn't learn in medical school", as put by Berger (1988). It is an illness concept that many simply reject.

The Experience of Ecological Illness

Clearly, the phenomenon of ecological illness is a battleground of medical, psychological and moral meanings. Given the controversy and the fact that relatively few doctors support the diagnosis and treatment of ecological illness, the illness and help-seeking experience of people claiming to suffer such health problems might be expected to vary considerably from that of people who receive and accept more conventional diagnoses. Given the diversity of "troubles" typically experienced, and the fact that "environmental hypersensitivity" is not a medically popular diagnosis, the interpretation and management of troubles is likely to be highly problematic. Conflicts between self-identity and social identity relative to troubles experienced are likely to produce conflict and confusion with respect to how self and others respond to troubles. Insofar as the negotiation of some variant of a sick role depends upon some degree of consensus on an illness identity, then ambiguity or conflict becomes a central social psychological issue. Whereas a medical diagnosis might normally be expected to clarify and resolve the definition of an individual's health identity, controversial diagnoses such as "environmental hypersensitivity" are less likely than conventional, established diagnoses to be considered credible. Those who adopt such an interpretation, therefore, are likely to face ongoing challenges to their assumption of some type of sick role.

To summarize, this study examines the illness and help-seeking experience of individuals who have come to define certain troubles as due to environmental hypersensitivity. The specific foci of the study are experiences of trouble, related interpretations, and interactions involved in the shaping and re-shaping of trouble-related identity and roles. Also of interest are practical implications for the management of troubles resulting from the relative ambiguity, consensus or conflict involved in negotiations of trouble-related identity.

Organization of Chapters

The above outlined issues in the experience of ecological illness are examined in the proceeding chapters as follows. Chapter One discusses some concepts from symbolic interactionism and phenomenological sociology which inform the analysis. These include the concepts of identity, role, the social construction of meanings on the basis of typifications, and interpretive frameworks. The chapter also reviews relevant theoretical and research literature in the sociology of health and illness. This discussion focuses on the social construction of illness as a special form of deviance. Through a review of pertinent literature, it considers the distinctive meanings and social consequences of the identification of physical and psychological problems. The chapter also discusses the personal and social significance of medical diagnosis and the problems of informally and medically legitimating illness claims. The chapter ends with a review of a British survey of people with ecological illness.

Chapter Two examines the research design and methods used. It discusses the gathering of background information, the recruitment of interview participants, and the construction and use of an interview schedule. Also discussed are "roads not taken" in the design and execution of the research. The chapter ends with a summary of social characteristics of the people who participated in the study.

Chapters Three, Four, and Five contain the analysis of people's experience of ecological illness. Chapter Three examines respondents' experience and interpretations of troubles prior to the diagnosis of hypersensitivity. In describing their help-seeking efforts, the chapter also examines the definitions and interpretive procedures of physicians and family members. It analyzes the personal and social impact of both troubles themselves and the inability of many respondents to negotiate an illness identity and role.

The adoption of a hypersensitivity definition of problems is discussed in Chapter Four. This chapter discusses referral to an ecologically-oriented physician, the process of ecologic diagnosis as experienced by respondents, and the cognitive and emotional impact of the hypersensitivity definition of problems.

Chapter Five focuses on people's experience of managing and living with hypersensitivity. This chapter first examines the extent to which the hypersensitivity diagnosis was recognized and accepted by others as a basis for either informal or "official" sick role considerations. The discussion then turns to personal and social consequences of managing sensitivities: the social management of hypersensitivity as an abiding aspect of self; and the way in which some respondents experienced ecological illness as a stigmatizing illness.

Chapter 1

THEORETICAL ORIENTATION AND RELEVANT LITERATURE

General Theoretical Orientation

The present examination of ecological illness experience is focused primarily upon interpretations of troubles, actions and interactions that are involved as people make sense of and cope with experienced difficulties. Given this concern with meanings and how they inform experience and interaction, the theoretical orientations drawn upon in the analysis are symbolic interactionism (Blumer, 1969; Mead, 1934) and phenomenological sociology (Schutz, 1967; Berger and Luckmann,1967).

Symbolic interactionism posits that reality, insofar as it is meaningful, is a product of human interpretive activity.[1] The social world is seen as a complex of meanings created by people in the course of interaction; meanings which, in turn, structure action and interaction. A fundamental assumption is that actions are

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[1] In addition to references cited, the discussion below draws in a general way on Stryker (1980), Hewitt (1976), and McCall and Simmons (1966).

formed on the basis of the meanings which various aspects of the physical and social world have for an actor. Meaningfully constituted "objects" (Mead, 1934) include anything to which someone might direct his/her attention: physical objects, ideas, events, situations, other people and their behaviour, or oneself. It is through processes of interpretation and definition in the context of interaction that such objects are identified, named or classified in various ways. Such classifications specify meanings of objects and thereby imply expectations regarding behaviour in relation to them.

In the context of particular interactive situations, individuals are placed or situated as social objects, both by others and by themselves. Such placements constitute identities (Stone, 1962). Expectations and beliefs with respect to behaviour appropriate to specific identities constitute roles. To varying degrees, depending on the specific situation and roles involved, roles are negotiated in the process of ongoing interaction. For Mead, communication and joint action depends fundamentally on the ability of individuals to take the roles of others. On the basis of such "role-taking" one is able to formulate actions and responses that may be understood and thereby "fit" with those of others.

Role-taking is also the basis upon which individuals situate or identify themselves. In Mead's formulation of self as a reflexive process, role-taking is the means by which an individual constitutes him/herself as a social object among others; as a "me".

For the purposes of the present study of illness experience, it is important to note some similarities and differences between self-identity and identity as a placement of self by others. In both cases, the process of identification involves attention to appearance, discourse and behaviour (Stone, 1962). A distinguishing feature of self-definition, however, is the additional incorporation of bodily sensations and emotional feelings--internal aspects of experience that are not directly available to others. The significance of this for the present study is that such sensations and feelings can become the basis of self-definition that may be at odds with placements made by others. People who claim significant illness problems which are not apparent to others by way of external signs might be expected to have difficulty in negotiating a health identity and role expectations that are consistent with their internally experienced capacities.

While internal bodily sensations are, in a sense, private, the meanings that a person uses to make sense of them are necessarily fashioned from knowledge that is socially available in his/her culture. Cultural knowledge provides notions of how to identify various internal sensations and of how to assess their significance and importance for everyday life. In this sense, it can be said that, insofar as they are meaningful, even the least shared, most private kinds of experience such as physical pleasure and pain are socially constructed.

The notion of reality being socially constructed on the basis of meanings is also central to the phenomenological perspective. In interpreting and ordering internal and other aspects of reality, individuals draw upon what Schutz (1967) termed their available "stock of knowledge". This consists of specific meanings and general schemes of interpretation or "meaning-contexts" that have been acquired during early socialization and subsequent personal experience. An individual's stock of knowledge contains "typifications" with which self, others, objects, events and situations are ordered and thereby made meaningful.

In many routine unproblematic situations involving familiar people, activities and purposes, typifications based on past experience can be almost unconsciously relied upon as guides for action; social order and the reality of everyday life are taken- for-granted. One taken-for-granted aspect of peoples' everyday life experience is a certain habitual capacity for mental and physical functioning in various roles and situations. Under habitual circumstances, usual bodily sensations and details of mental-emotional functioning are given little conscious attention; attention is focused more on the outside world and external events (Lindesmith et al., 1975:208; Idler, 1979:726). Habitual sensations and capacities constitute what Alonzo (1979) has characterized as "background bodily expectancies". However, if such expectancies are repeatedly violated by experiences of trouble, then the taken-for-grantedness of habitual functioning can be expected to give way to some sense of a problem.

As Emerson and Messinger (1977) have observed, many troubles appear vague at first. It is as steps are taken to remedy or manage them that they become progressively clarified and specified. The individual so affected may be variously identified or labelled and responded to by self and others, depending upon the imputed meaning of his/her experience and behaviour. The meaning imputed, however, will vary not only according to the experience and behaviour itself, but also according to available and accepted modes of interpretation. Various "troubleshooters" (Emerson and Messinger, 1977), both among intimates and officials (e.g. doctors, psychiatrists, social workers and others), may offer or promote definitions fashioned from diverse and competing interpretive frameworks.

Goffman (1974:22) has distinguished two broad classes of frameworks in western society that inform understandings of occurrences: natural and social. In his words:

> Natural frameworks identify occurrences seen as undirected, unoriented, unanimated, unguided, "purely physical"....It is seen that no willful agency causally and intentionally interferes, that no actor continuously guides the outcome....no negative or positive sanctions are involved.

Biomedical science and medical diagnoses of troubles that are considered to be physical illness clearly incorporate natural frameworks; trouble is defined as non-wilful. In contrast, trouble that is defined in terms of social frameworks involves questions of agency and responsibility:

> Social frameworks...provide background understanding for events that incorporate the will, aim, and controlling effort of an intelligence, a live agency, the chief one being the human being....What it does can be described as "guided doings". These doings subject the doer to "standards", to social appraisal of his action....

Because of the involvement of standards and normative judgements, definitions of trouble in terms of social frameworks carry potential moral and social consequences that differ markedly from those associated with natural frameworks. Definitions of trouble that imply intentions, personal control or other aspects of agency suggest deviance that is, in some measure, wilful. They raise questions of responsibility and blame, or at least of personal and social competence.

Depending upon the number and types of trouble-related definitions relative to an identified problem, particularly whether natural or social interpretive frameworks are employed, individuals may experience widely varying trouble-related "careers". Originally employed with reference to occupations and work by Hughes, the concept of career was subsequently broadened by Goffman (1958) in his discussion of the experience of mental illness. Also, Becker (1963) and others taking an interactionist-labelling approach used the concept of career in sequential analyses of identity and role changes involved in other forms of deviance and social reaction. Roth (1963:94-5) proposed the utility of the notion of career with respect to any course of life events characterized by "definable stages or signposts along the way and (having) a more or less definite and recognizable end-point or goal". The concept of "subjective career" (Stebbins 1970:34) refers to, "...the actor's recognition and interpretation of past and future events associated with a particular identity, and especially his interpretation of important contingencies as they were or will be encountered." This notion of subjective career is distinguished from the "individual objective" sense of the term, which refers to the actual progression of an individual through a series of stages.

With respect to people experiencing ecological illness, their subjective careers are clearly illness careers. Since consolidating an interpretation of their difficulties as ecological illness, a diversity of problematic experiences have come to be interpreted by them as illness-related. As noted in the Introduction, however, ecological illness is not a widely sanctioned diagnosis. That is, ecological illness has limited currency as a medical diagnosis, and there are relatively few physicians who practise or endorse ecologic medicine. The definition of certain kinds of problematic experience as symptoms of environmental-food problems, and the medical and self-labelling of an individual as ecologically ill, is expected, typically, to involve a lengthy and less-than-straightforward process of interpreting and responding to troubles. In cases where definition and remedy are particularly fraught with ambiguity or conflict, "troubles" may shift through a variety of frameworks and definitions, both over time and according to various troubleshooting agents consulted at any given time.

In examining ecological illness careers, the present analysis is concerned with the kinds of interpretive frameworks employed by those with problems, by intimate others and by official troubleshooters at various points in the process of defining troubles and taking remedial action. It also concerns the consequences of eventually adopting an illness definition of troubles that has limited legitimacy among those exercising official authority in the social construction of illness--physicians. The study examines consequences of consensus, conflict or ambiguity with respect to various kinds of definition--consequences for both identity and the practicalities of managing troubles in everyday situations. The discussion turns now to theory and literature in the sociology of health and illness that is relevant to this type of analysis.

Theoretical Perspectives and Relevant Literature in the Sociology of Health and Illness

Parsons' Sick Role and Illness as Deviance

In order to understand the assignment of various illness or other deviant meanings and identities, it is necessary to understand various criteria and typifications which generally serve as cognitive resources in distinguishing illness from other kinds of experience and behaviour in modern western society. In this regard, Parsons' concept of "the sick role" is particularly relevant (1951:428-479). Parsons' formulation of criteria and expectations of "the sick role" was the first sociological conceptualization of the social, as distinct from biological, meaning of illness. Premised on a functional analysis of illness as a type of social deviance threatening system integration, the concept of the sick role was intended to differentiate illness as a form of deviance that is distinct in important respects from other types, such as crime. According to Parsons, illness is generally distinguished by the assumption that the sick person is not responsible for his/her deviance. Thus, illness is considered a "condition" that "happens to" an individual rather than something he/she does. In Goffman's terms, natural rather than social frameworks apply. The distinction of illness as non-wilful deviance accounts for the distinctive nature of medicine as an agency of social control. Rather than punishment, medicine employs specialized, technical knowledge toward the end of therapeutic treatment. The sick role is a similarly distinct set of institutionalized expectations and obligations which are associated with an individual who is defined as sick. Briefly summarized, according to Parsons, the sick person:

> 1. Is defined as not responsible for his condition and, therefore, cannot be expected to "pull himself together" by an act of decision or will.
>
> 2. Is entitled to some exemption from normal role responsibilities, dependent on the nature and severity of the illness; such exemption requires legitimation by others, often including a physician.
>
> 3. Should see his condition as undesirable and, therefore, want to get well as quickly as possible.
>
> 4. Should seek technically competent help (usually a physician) and cooperate in the process of trying to get well.

According to Parsons' formulation, the "privileges and exemptions" of a sick role are conditional upon agreement by others that the person has a condition that "cannot be helped" by him/her, and that the nature and severity of the condition legitimately merit certain allowances. Regarding these conditions, "...the physician often serves as court of appeal as well as a direct legitimatizing agent." (Parsons, 1951:436).

Parsons' sick role concept expresses the "institutionalized expectation" that defines illness as non-wilful deviance. However, Parsons (1951:430-31) also noted that, "...motivational factors accessible to analysis in action terms are involved in the etiology of many illnesses,..." and that: "Illness may be treated as one mode of response to social pressures, among other things, as one way of evading social responsibilities." It is in connection with this perspective on illness as, in some sense, motivated (whether consciously or unconsciously), that Parsons emphasized the significance of both the sick role and that of the physician as mechanisms of social control. As Parsons (1951:477) put it:

> The sick role is, as we have seen, in these terms a mechanism which in the first instance channels deviance so that the two most dangerous potentialities, namely, group formation and successful establishment of the claim to legitimacy, are avoided. The sick are tied up, not with other deviants to form a "sub-culture" of the sick, but each with a group of non-

> sick, his personal circle and, above all, physicians....
> Furthermore, to be sick is by definition to be in an undesirable state, so that it simply does not "make sense" to assert a claim that the way to deal with the frustrating aspects of the social system is "for everybody to get sick."

In sum, while Parsons' sick role formulation took account of a general definition of illness as non-wilful, his deviance perspective emphasizes the importance of the social control functions of medicine in preventing "illness" as a widespread mode of evading frustration and responsibility.

As Twaddle (1979:55) has suggested, Parsons' sick role formulation can be seen as a proposed description of central tendencies with respect to expectations of sick people in modern western societies. It is an ideal type model of illness-related expectations. A number of empirical studies have been directed at assessing the extent to which Parsons' sick role expectations are adopted by different sub-societal groups. For example, Segall (1976) compared Anglo-Saxon Protestant and Jewish housewives' perceptions of the sick role. Although the Anglo-Saxon Protestants' perceptions conformed more closely to Parsons' ideal typical formulation, differences between the groups were not statistically significant. In a study of people recently discharged from hospital, Arluke, Kennedy and Kessler (1979) found variations in consensus on the four aspects of the sick role according to income, family size and age. Variations were small, however, and it was concluded that, with respect to their data, Parsons' model was a fairly accurate depiction of major patterns of sick role expectation.

In contrast to studies of expectations, studies of "illness behaviour" (Mechanic, 1978) have found large variations in actions which individuals take relative to experience of symptoms. Noting that delay in professional help-seeking has been found to be common, Zola (1973) suggested that action taken to see a physician will depend crucially upon the redefinition of commonly experienced or longstanding "symptoms" as abnormal. Zola proposed further that such an assessment may be prompted by various "social triggers": 1. the occurrence of interpersonal crisis; 2. perceived interference of symptoms with social or personal relations; 3. pressure from friends or relatives; 4. perceived interference of symptoms with vocational or physical activity; 5. a kind of temporalizing of symptom experience. This last "trigger" refers to decisions made to monitor symptoms for a decided period of time, seeking help if they are still present at the end of the period. The assessment of some aspect of an individual's experience as possibly or definitely a significant problem, then, depends on a process of interpretation in the context of contingencies of everyday life.

The Social Construction of Illness and the Labelling Perspective

The process of interpretation involved in the definition of illness or other types of irregularities is emphasized by Freidson (1970) in his elaboration on Parsons' sick role concept. In common with Parsons, Freidson sets his discussion of illness within a social deviance perspective. However, Freidson's discussion draws additionally on Berger and Luckmann's (1967) sociology of knowledge and the societal reaction or labelling perspective developed by Lemert (1951), Kitsuse (1962), Becker (1963) and others. Freidson has formulated a thoroughly constructionist conception of illness, asserting that "as a kind of social deviance, the etiology of illness is not biological but social, stemming from current social conceptions of what disease is..." (Freidson, 1970:223). Specific possibilities of illness, in other words, are socially constructed. In connection with this, Freidson notes that, while professional medicine and medical diagnoses are not uncommonly regarded as products of objective, scientific knowledge, they are, nonetheless, social products. With its monopoly on official authority with respect to illness, the profession of medicine not only has a legitimating role, as Parsons noted, but actually, "...creates the social possibilities for acting sick." (Freidson, 1970:206). Therefore, while there do exist distinctive lay theories and beliefs (Armstrong, 1983:97-9) which influence lay imputation and response to illness, it is currently accepted medical interpretations which provide for officially sanctioned illness designations and sick roles.

Following Becker (1963) and others in the labelling tradition, Freidson argues that the sociological task with respect to various kinds of deviance is to explain their perception and designation as deviance. Emphasis is placed upon the analysis of norms guiding the identification of various types of deviance. It is the imputation of certain meanings to physical attributes or specific acts that leads to definite ways of responding to individuals to whom they apply.

With respect to illness as a particular type of deviance, Freidson observes, with Parsons, that "illness" implies the perception of deviance that is unmotivated. An individual identified as sick is not considered responsible for his/her deviance, and therefore his/her behaviour is conditionally legitimated. The adoption of a specific sick role, however, will depend upon the degree of exemption from normal obligations; this, in turn, is a consequence of the imputed seriousness of the deviance. Therefore, in the case of imputed illness, as with other types of deviance, the strength of reaction to the deviance (according to the seriousness imputed to it) determines whether or not an individual will be assigned (by self and/or others) to a special role. Put in terms of social reaction theory as formulated by Lemert (1951, 1972), initially noticed signs or symptoms of illness constitute primary deviance--merely symptomatic behaviour that, as yet at least, has no social psychological significance as a particular illness identity or role. Secondary deviance may develop as others respond to the symptomatic behaviour, casting the individual into some type of sick role. Being regarded as sick, the individual's self-identity and actions tend to become organized around his/her social identity and role of being sick. These actions constitute secondary deviance.

Freidson elaborates further on Parsons' analysis by incorporating the concept of "legitimacy" (Freidson, 1970:239). He contends that along with varying degrees of imputed seriousness, an illness may be considered "conditionally legitimate", as in cases of illness considered to be temporary (the type most closely modeled by Parsons' sick role); "unconditionally legitimate", as in cases considered to be chronic or incurable; or "illegitimate", as in cases of imputed illness that is stigmatizing. Various combinations of imputed degree of seriousness of the illness and status with respect to legitimacy constitute a taxonomy of sociological types of illness. Each type of illness implies different consequences for identity and response from others.

Freidson's discussion is useful for its elaboration of sociological types of illness. Although Parsons also stipulated that "the nature and severity" of illness would affect the extent of exemption from normal role obligations, Freidson has emphasized that types of illness and their varying degrees of seriousness are matters of social construction and situational interpretation. And, rather than _the_ sick role, the imputation of illness may lead to only slight qualifications of normal roles, either temporarily or permanently. Or, it may lead to varying degrees of temporary or permanent suspensions of normal roles, with varying degrees of impact upon self and social identity.

Empirical studies of sick role expectations and behaviour relative to different types of illness have indicated the kind of variability in role expectations that Freidson elaborated. Thus, illness interpreted as minor is not expected to involve recourse to a sick role (Levine and Kozloff, 1978). Gordon (1966) surveyed sick role expectations of a sample of 1,000 people and concluded that in cases where the prognosis is believed to be certain and not serious, expectations encourage normal activity and involvement as much as possible. Gordon termed such expectations an "impaired role". Because chronic illness and disabilities are defined as permanent, such imputed conditions do not entail expectations of motivation to return to "normalcy". In such cases, various degrees and types of role exemptions may be expected depending on imputed capacities (Kassebaum & Baumann, 1965).

Other studies have shown that while certain kinds of deviance may be defined or labelled as "illness" by medicine, they may, nevertheless, be perceived to involve motivation and, therefore, responsibility. With regard to alcoholism, Chalfont and Kurtz (1971) found that few of the social workers they studied saw alcoholics as "legitimately sick" due to their feeling that alcoholism involves some degree of responsibility. Similarly, while it may be accepted that venereal diseases and AIDS are indeed legitimate illnesses, individuals considered to be sick with such diseases may, nevertheless, be seen to have had some responsibility in becoming sick (even though their responsibility for getting well may be largely regarded as a matter of cooperation with medical treatment).

With regard to "mental illness", assumptions and role expectations in modern western society generally differ markedly from those associated with illnesses defined as physical. Blackwell (1967) studied expectations for entering a sick role for physical and psychiatric dysfunctions. It was found that, while Parsons' sick role expectations were agreed to apply to conditions clearly defined as physical illness, the extent of agreement about admission to the sick role (as formulated by Parsons) decreases the more that the condition is perceived to involve social and psychological aspects. Sobel and Ingalls (1964) studied various sick role expectations as seen by psychiatrists, psychiatric patients, physicians, surgeons and medical and surgical patients. Their findings suggested that, when a condition is seen as having psychological aspects, questions are raised regarding responsibility; for both developing the problem and coping with it.

In a discussion of differing social implications of "mental" and "non-mental" illness labels, Fabrega and Manning (1972) have suggested that mental illness is generally seen essentially as a problem of the self. In cases of imputed physical illness, however, illness is objectified and separated from self. It is merely "the body" as an objectified entity that is flawed, not the individual him/herself as a socially competent person. Concomitant with perception of physical illness as "not self" is the perceived inapplicability of notions of motivation, intention and responsibility. Bury (1982) has argued similarly that it is this distancing of disease from the self, provided for in the objectifying concepts and diagnostic categories of medical science, that gives legitimacy to illness as deviance and to clinical interventions intended as treatment.

Clearly, whether an individual is identified as physically sick, disabled, mentally ill, psychologically or socially troubled, or in some other way deviant is crucial to whether or not, or to what degree, he/she may be seen by self or others to be responsible for "the problem". Conversely, the interpretation of responsibility may also sometimes be crucial to what kind of identity is assigned. And, depending on what kind of identification is made, an individual may seek treatment (with or without stigmatization), be punished or ignored. In other words, the type of problem-related career that is experienced by an individual will vary markedly according to the specific identity imputed relative to perceptions and definitions of the problem.

The Experience of Illness

Influenced by Lemert's concept of the secondary deviance process, labelling studies have tended to focus on social reaction and ways in which constructions and judgements of deviant behaviour, particularly those of official agents of social control, serve to create and consolidate deviant identities and roles. As discussed above, Freidson's application of a labelling-constructionist perspective to illness resulted in a thoroughly sociological analysis of illness as a social rather than biomedical phenomenon. As noted by Petrunik

(1983) and Warren and Johnson (1972), however, the labelling perspective has resulted in greater attention being given to social reaction and the passage from a "normal" to "deviant" status than to the subjective experience of being deviant at any given point. When subjective experience has been a focus, it has tended, following Goffman's Stigma (1963), to be concerned primarily with symbolic implications for identity; the concern of individuals with labelling and others' reactions.

However, other studies, focused on the subjective experience of non-willful forms of deviance, have shown that individuals with various conditions, including those that are stigmatizing, are not concerned only or even primarily with negative impact on identity. Thus, information management by epileptics is geared not only to fear of stigma but to practicalities of maintaining social roles (Schneider and Conrad, 1980, 1983); and by the deaf, to indicating or even exaggerating their deafness to others in order to clearly define realistic expectations (Higgins, 1980). A number of other studies of the experience of illness have also focused on the social impact of the "primary" differentiating condition itself, and the practical and social psychological challenges involved in living with illness (e.g. Roth and Conrad, 1987; Strauss, 1975; Schneider and Conrad, 1983; Locker, 1983; Kotaraba, 1983; Charmaz, 1983; Bury, 1982).

With respect to medical diagnosis specifically, the labelling perspective has tended to emphasize identity-tainting implications of medical labels (Freidson, 1965; Waxler, 1981). This emphasis is illuminating, particularly with respect to many types of chronic illness where distinctions between the disease or disorder and self become blurred (Schneider and Conrad, 1983:147). Even with conditions that are not stigmatizing in an obvious way, the normal competent self is tainted to some degree simply by virtue of the permanency of an undesirable health status.

Labelling studies, however, have tended to give less attention to other important dimensions of medical diagnosis. For example, they focus little on the fact that those experiencing puzzling and bothersome chronic troubles want and search for diagnosis (Hilbert, 1984). Obviously people seek diagnosis in the hope of treatment, but there are also other concerns involved. A disease category enables one to give a creditable account of troubles to others. This can be important both symbolically and practically. Except in cases of highly stigmatizing diagnoses such as AIDS, a legitimated illness account of trouble may be less morally discrediting than negative qualities that might otherwise be imputed. And regarding practical needs, a diagnostic label may be important to negotiating adjustments of others' expectations and to obtaining their cooperation in remedial measures. An official illness label may also be important for purposes of obtaining financial compensation for work loss or other kinds of supportive resources felt needed in treatment or management. Finally, as Hilbert (1984:368) has put it in his discussion of chronic pain sufferers, "...a diagnosis provides a sense that one is living in an orderly world, that one's condition can be located in medical indices and in libraries, that others share the condition and, especially, that one is sane." In other words, diagnosis confirms that one's sensations are documented and are, therefore, of the order of reality. Whatever is wrong, at least one is "experiencing reality correctly", and, therefore, there is nothing "_really_ wrong" (Hilbert, 1984:368-70).

Considering these aspects of medical labelling, from the standpoint of the experience of illness an official sick label may be considered, at least in some respects, as much a resource as a social catalyst in spoiling identity.

Legitimating Illness

When troubles are informally understood and legitimated as illness by self and others, there may be no necessity, cognitively and socially at least, for an official medical diagnosis. In some such instances, external signs of physical change or incapacity may be seen by self and others as clear indications that an illness problem of some kind exists. While negotiation between self and others over the specific nature and severity of the problem may occur, the preliminary definition of "some kind of sickness" is relatively straightforward. For others, however, no such clear external signs may be present. If the individual him/herself, nevertheless, comes sooner or later to interpret the troubles as illness, then the social legitimation of difficulties as illness may involve a challenging process of negotiation with physicians.

Telles and Pollack (1981) have discussed the problem of legitimation of illness when "feelings" are the grounds for illness claims. As they note, feeling states and changes in them subjectively define health and illness and are employed as criteria for defining experience throughout episodes of illness. Lay negotiations of the meaning of reported problematic feelings may be concerned with whether external signs related to feelings can help to make sense of them. Assessments might be made of whether the feelings are insignificant "normal aches and pains" or whether they are unusual enough that expert help should be consulted. Toleration of some level of distress without seeking a sick role is usually expected. Therefore, the frequency of illness claims from an individual may influence whether or not he/she may be labelled a malingerer or hypochondriac by others.

If an individual, independently or with the concurrence of others, does consult a physician, "...the feeling must be stated in a way which suggests the existence of a known syndrome.... If patients' presentations are too vague to fit into some medically recognizable pattern...their presence in the office will not long be tolerated." (Telles & Pollack, 1981:248-50).

With respect to conventionally recognized chronic illnesses, a number of studies have noted that initially noticed changes in feeling states or capacities may be intermittent and unpronounced. Because of this they are often interpreted by self, others and physicians as minor and inconsequential. Alternatively, circumstances may be found to "normalize" their occurrence. With regard to epilepsy (Schneider & Conrad, 1983), arthritis (Locker, 1983), and multiple sclerosis (Stewart & Sullivan, 1982), it has also been noted that people with vague complaints or complaints that cannot be corroborated with diagnostic tests are not uncommonly diagnosed initially as having emotional or psychological problems. Regarding their study of the pre-diagnostic experience of multiple sclerosis patients, Stewart and Sullivan (1982:1403) concluded that, "The physician's ultimate legitimation of the patient's claim to the sick role was in part dependent on the patient's ability to negotiate effectively." Stewart and Sullivan's study also showed that when persistent attempts on the part of their interviewees to achieve medical diagnoses failed, in most cases they felt that relatives and friends viewed them as hypochondriacs or malingerers. As symptoms became increasingly serious from their own point of view, they felt pushed toward an effort to adopt a sick role. However, because of the diagnostic uncertainties and the refusals of physicians, relatives and friends to legitimize the adoption of a sick role, "...they found themselves in an ambiguous and uncertain limbo." When diagnosis was ultimately achieved, many experienced relief and received greater support from family, friends and physicians.

Another example of medical legitimation and explanation being difficult to obtain is the controversial illness, hypoglycemia. As discussed by Singer et al. (1984, 1987) and Hunt (1985), people with vague and diverse troubles that they eventually come to define as hypoglycemia typically have great difficulty in having their experience credited by doctors. Many respondents interviewed by Singer et al. (1987) reported that their experience of symptoms was discounted by physicians. When objective, technological tests failed to reveal any conventionally established syndrome, their symptoms were commonly diagnosed as psychogenic. As Hunt (1985:1292) has observed, the consequence of this is that: "Patients' experiences are denied authenticity. Patients given a psychogenic diagnosis for their symptoms are thus forced to either redefine their bodily experiences as unreal, or to reject the diagnosis." It is expected that this scenario of conflicting self and social health identities will also be found to characterize the pre-diagnostic experience of many claiming to suffer from problems due to hypersensitivities.

The Experience of Ecological Illness

It would appear that the only existing work which gives attention to the experience of ecological illness is that of Rippere (1983). A summary of her findings indicates a number of notable aspects of peoples' experience.

Obtaining a sample through self-help organizations concerned with allergies in England, Rippere conducted a survey of eighty-five people (twenty male and sixty-five female). She queried people regarding onset of their difficulties, precipitants of symptoms, types of symptoms, help-seeking experience, self-help measures, limitations on everyday activities and social reactions. Of those surveyed, 90% reported some family history of allergies.[2] An unspecified number reported multiple times and circumstances of onsets of difficulties, indicating an episodic, life-long illness experience. Onsets of difficulties at birth or in infancy were reported by 27% of respondents; 47% reported onsets in childhood or adolescence. In adulthood, 16% reported gradual onset; 18%, onset after acute stress; 20%, onset "out of the blue"; and 11%, unspecified circumstances. Onset of difficulties after pregnancy was reported by 11% of females.

With regard to precipitants, 86% reported sensitivity to more than one type of precipitant, i.e. foods, chemicals, or natural inhalants. Reaction problems with foods were reported by 96%; with chemicals, 78%; with pollens, 13%; and with dusts, 12%.

Rippere also categorized types of symptoms reported. The five most frequently reported types of symptoms were: migraine and headache (55%), respiratory (53%), abdominal (52%), skin (48%), energy loss/general fatigue (36%). Although these types of symptoms were most frequently reported, if all categories of symptoms affecting "the nervous system, psychological functioning and behaviour" are taken together, they comprise 40% of

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[2] Of the percentages given below, some are quoted from Rippere (1983) and some were calculated on the basis of figures provided in her report.

reported symptoms (Rippere, 1983:75). It is not entirely clear which categories Rippere grouped together to produce this last figure, but the following categories of reported symptoms would be examples of some of them: 55% of respondents reported migraine or headaches; 32%, mental dullness and confusion; 26%, aggression and irritability; 23%, "malaise"; 21%, "clouded consciousness"; 14%, anxiety; 11%, tension.

Although figures are not given, Rippere reports that in many cases respondents had consulted with more than one physician. The data that she does present show that: 87% of respondents had seen a "GP"; 26% had hospital investigations; 25% had seen clinical ecologists; 19% had seen conventional allergists; 15%, an unspecified type of physician; 9% had seen a psychiatrist; and 7% had consulted a dermatologist. A number of other specialists also had been consulted by smaller numbers of people.

In her discussion of help-seeking, Rippere cites a number of examples illustrating dissatisfaction with contacts with conventionally practising physicians. Such dissatisfaction concerned perceived trivializations or dismissals of reported symptoms ("it's nothing to be concerned with" or "it's all in your mind" or "just your nerves"). Symptom-suppressive drug treatment following only routine tests was also a source of frustration in consulting conventional physicians (Rippere, 1983:121-27).

Regarding evaluations of benefit from various types of treatments, not all respondents gave evaluations of all treatments experienced. The figures, therefore, represent an undetermined selection of evaluations. This noted, Rippere reported that of those treatments given evaluations approximately 24% of conventional medical treatments were considered to have been of "moderate or great" benefit; of "alternative" treatments, 25%; of clinical ecologic treatments, 54%; of self-help activities, 78%. This last category included activities such as self-monitored diets, avoidance of precipitants, food testing, self-prescribed remedies and vitamins, self-help groups, reading and other types of information-seeking.

Of the self-help activities reported, reading and participation in self-help groups were two of the three activities reported to be of most help (the third was food elimination dieting). According to respondents' reports, such activities were considered sources of useful information and support. As a result of reading books or other material about clinical ecology, many reportedly first found an interpretation of their previously intractable problems that, in principle, made them appear soluble. By means of self-testing outlined in such books, many self-diagnosed specific sensitivities. Through self-help groups, many respondents also gained information and advice. This included lay referrals to clinical ecologists and access to books and articles about hypersensitivity. Many also reported that support and encouragement in dealing with their problems was gained from participation in self-help groups.

Experiences of limitations reported by respondents concerned debilitating effects of unavoidable or unpredictable reactions to precipitants and also the necessity of avoiding or adapting to activities or places that would precipitate symptoms. Such activities and places often included social occasions involving eating or drinking, problematic work environments or activities, and home environments. These limitations resulted in the loss of pleasurable activities, social life, and what might once have been the taken-for-granted freedom of eating, drinking and circulation without a lot of forethought and planning. Some respondents also reported loss of normal capacity for work or leisure activities due to symptoms, or inability to continue work at all due to problems with the work environment (Rippere, 1983: 145-159).

Regarding social reactions, Rippere also asked her respondents how they experienced others' perceptions and reactions to them and their problems. Social reactions reported ranged from acceptance of their experience as an illness problem, to ridicule and applications of discrediting labels. Some thought that media publicity of recent years had begun to bring increasingly accepting reactions from others. However, almost all respondents reported being subject to discrediting social reactions of some kind. Commonly, with both physicians and others, hypersensitivity difficulties seemed to respondents to be seen by others as unduly exaggerated or "all in the mind"; in short, as evidence of a psychological or "attitude" problem rather than distress from physical illness. Respondents reported being accused of "just craving attention", or "wanting to be sick". Others reported that their experience of difficulty was often dismissed as "nerves", anxiety, or psychosomatic, particularly by doctors who could find no positive laboratory test results that were consistent with reported difficulties. Labels applied to individuals included, among others, finicky, neurotic, fussy, overprotective, hypochondriacal, obsessive, anxious, and anti-social. Because many such discrediting social reactions were experienced in relation to strategies to manage symptoms (such as inquiring in advance regarding ingredients in foods, physical environments, or bringing one's own food to an occasion), many respondents reported frequently being faced with choices between ridicule (or at least being seen as socially awkward), and risk of exposure to symptoms. In summary, most respondents commonly experienced social situations and contacts in which others reacted to them not as "sick", but rather as fitting some other more discrediting typification of deviance.

Rippere's study offers useful glimpses of some salient aspects of hypersensitive people's experience of illness. Her respondents' reports of difficulties in obtaining social validation from doctors and others for what they experienced as a "legitimate illness" are particularly relevant to the interest here in definitions of health identity. Because of such difficulties, reading and contacts in self-help groups became important means of locating "medical problem" definitions felt to be consistent with their experience, and which recommended specific problem-solving measures; or specific doctors (usually clinical ecologists) who could be relied upon to provide such definitions and therapeutic recommendations. A number of Rippere's respondents felt the need for others to grant understandings or concessions associated with a sick role, but were frustrated by discrepant perceptions and definitions of health identity.

Rippere's analysis usefully discusses the issue of various meanings attached to the behaviour and reported experience of her respondents. Largely not analyzed in her survey, however, is the nature and course over time of cognitive and interaction processes in which various definitions of trouble-related identity are formed and applied by various parties. In examining these processes in this study, an attempt is made to identify varying trouble-related career patterns, some of the variations in troubles and interpretive processes that underlie such patterns, and some of their consequences for living with and managing ecological illness.

Chapter 2

RESEARCH METHODS

Recruiting Volunteers for Interviews

This study is concerned with an "insider" perspective (Schneider and Conrad, 1983) on illness: the experience of people in making sense of and living with troubles that they have come to define as being due to environmental sensitivity or ecological illness. With the interest being in sufferers' perceptions, feelings and interpretations, the primary research strategy used was in-depth interviewing. The analysis that follows this chapter is based on interviews with thirty-two people who claim to suffer effects of environmental hypersensitivity.

Contacts with people with ecological illness were made through the Human Ecology Foundation of Canada (HEF), a clinical ecologist's office and "snowballing". The HEF is an information-sharing and support organization concerned with environmental illness. The organization has a number of branches in Ontario and a few in other parts of Canada. Since my interest was specifically in people who have adopted the broad ecological illness definition, as opposed to allergy, the HEF seemed an appropriate place to recruit some of the participants. Early in the project, before interviewing, I contacted the national president of the organization regarding contacting its members. She was receptive to the idea of the study, but told me that the membership list for the organization is kept confidential. It was then decided with her that I would contact branch presidents in Toronto and Kitchener-Waterloo regarding an appeal for volunteers through their local newsletters. I followed up on this and my requests for participants were eventually published in the two newsletters (see Appendix A). In response to these newsletter appeals, seventeen people contacted me.

Early in the project, before doing interviews, I also attended an annual gathering of the Waterloo-Wellington branch of the HEF. I counted about seventy people there, about 75% of them being women. The gathering consisted of a vegetarian cooking presentation and exhibits of local businesses promoting products such as organic food, air and water purifiers, and cotton clothing. In addition to providing an opportunity to hear various peoples' conversations about sensitivity-related interests, the gathering gave me an opportunity to personally appeal for participation in the research. Along with chatting to a few people individually, by arrangement with the branch president, I addressed the room with my request for participants. When the gathering was over, twelve people had volunteered to participate.

Assuming that members of HEF might tend to be a rather select group of "veterans" with similar interests and concerns, it was thought that attempts should also be made to recruit others who had not yet consolidated their problems as hypersensitivity. However, if one were to simply advertise for people with multiple unidentified puzzling problems, there would be no reliable way of knowing in what ways, if any, respondents' problems might be comparable to "ecological illness" or whether the respondents might eventually define them this way. Necessarily, therefore, a defining criterion for participants in the study was that they already see their problems as related to hypersensitivity.

Nonetheless, an effort was made, to recruit participants who were not "veterans" and who were not members of HEF. In order to recruit some people who were closer to just beginning to consider a hypersensitivity explanation for their problems, I contacted two clinical ecologists. I intended to ask their permission to leave the written appeals for volunteers in their waiting rooms. In a brief meeting with one of them, after I explained the nature of the study, including my interest in talking with new or recently taken patients, I asked to leave the appeals. The doctor suggested, however, that I should be talking with experienced patients who had more knowledge of managing the problem. He subsequently refused permission to leave the appeals for volunteers. In contrast, the other clinical ecologist seemed quite interested and had no hesitation in having me leave the request sheets. He also went further by referring me to the woman he employs to counsel new patients. She also showed interest and suggested that she could personally tell new patients about the study. In checking back with her a couple of weeks later, the forty sheets I had left had been taken and she had photocopied more. Despite this seeming success, however, only two people who had picked them up ultimately contacted me; and unfortunately neither of them were people just beginning to understand problems as hypersensitivity.

Through referrals from one person to another or "snowballing", another eighteen potential participants were also found. Nine of these referrals were people who had had little contact with HEF, and were among those interviewed.

Decisions about which of all of the potential respondents would be interviewed depended on availability and where they were located; (in response to the newsletter appeals, I received responses from northern Ontario and Hawaii, among other places). In four cases, people to whom I had been referred or who had themselves volunteered, ultimately declined to see me, saying that they were not well enough.

The total number interviewed was thirty-nine: seven in preliminary interviews and thirty-two in the more focused interviews that are analyzed here. As has been described, the composition of the sample was determined by self-selection, snowballing and availability. It is limited, therefore, in that there is no way of knowing to what extent the people interviewed are representative of people with ecological illness generally. However, while it might be of interest to attempt generalizations regarding the relative frequency of various types of people with ecological illness, the primary purpose of this study was to develop some initial understanding of the kinds of trouble-related experiences that a number of them have had. The study is guided generally by an interest in understanding what it is like for people to make sense of and live with medically controversial illness problems. The following section describes the interviewing efforts that were made toward this end.

Background Orientation and Preliminary Interviews

Before beginning the seven preliminary interviews, I had already become familiar with some of the medical and popular literature on ecological illness, and had also read the report of an Ontario Ministry of Health "Committee on

Environmental Hypersensitivity". I had also become familiar with some of the issues involved through attending both the Waterloo-Wellington HEF gathering referred to above, and a public meeting of the Ontario Public Health Association in Toronto. This latter meeting was focused on controversy over the medical status of such health problems. It included presentations by a woman from HEF, three doctors, and the provincial court judge who headed the government committee on hypersensitivity. In addition to these sources of background information, I was personally familiar with health problems that my sister had experienced a few years ago following her second pregnancy; she eventually came to believe that the immediate cause of these problems was sensitivity to a number of foods and chemicals.

On the basis of all of these sources of background information, I was aware as I began the interviews that a number of people experiencing complex sensitivity problems had long histories of medical and/or psychological help-seeking before discovering and adopting a sensitivity definition. It seemed that many were concerned, and others very angry and bitter, that the problems of people with ecological illness are often misunderstood or unrecognized--both by medicine and people generally. With these impressions in mind, I began the preliminary interviews wanting to know just what some people's trouble-related experiences had been.

The discussion of respondents' experience typically began with my explaining that I was interested in hearing their story of sensitivity-related problems and their efforts to deal with them. I explained that I understood that such health problems were not always well known or accepted by doctors, and that, therefore, I was interested to know what it was like to have health problems that were often not recognized as medically legitimate. I often made a point of adding also that I had a few allergies myself, and that my sister had had more complex sensitivity problems. By sharing a little of my sister's experience, I was able to communicate that I already understood something of the challenges involved in dealing with complex sensitivity problems. Particularly with respondents who seemed a little wary at first, this seemed to help in establishing rapport and trust that I would not be negatively passing judgement on their experiences.

In discussing respondents' experience, I usually first asked what kinds of sensitivity problems they were currently managing. I usually then asked them to recount their past experience beginning with first experiences of trouble. The people spoken to in these preliminary conversations typically reported a great number and diversity of troubles. At different points, their troubles may have been variously interpreted by themselves and others as physical illness, effects of stress, mental illness, "normal aches and pains", or as imaginary. Efforts to make sense of and obtain help in dealing with troubles typically lasted a number of years. Also, typically, these efforts were characterized by ambiguity and often conflict over whether significant problems existed, and if so, what kinds of problems they were. With the adoption of a hypersensitivity diagnosis this ambiguity and conflict over trouble-related identity was not always resolved. In sum, what seemed to be clear from these preliminary conversations was that the interpretation and definition of troubles and trouble-related identity were frequently highly problematic.

The Interview Schedule and Further Interviews

On the basis of the preliminary interviews, a structured schedule of questions was constructed for use in further interviews (see Appendix C). The intent was to provide for a more focused and systematic inquiry in which the same questions would be asked of all respondents. In addition to sections of questions concerned with social-demographic characteristics and general health background, the schedule consisted of questions regarding three distinguishable phases of trouble-related experience:

1. Troubles, interpretations and help-seeking prior to diagnosis of hypersensitivity
2. Finding and adopting a hypersensitivity diagnosis
3. Managing and living with ecological illness.

The division of the interview schedule into these three sections corresponds closely with the organization of the analysis in Chapters Three, Four, and Five. In the first of these sections, questions concern the history of what are eventually defined as hypersensitivity problems--the way(s) in which they may previously have been perceived and interpreted by self, intimate others, doctors, psychiatrists or others. The first section also contains questions to do with how troubles may have been explained or concealed in various situations, and with others' reactions and attitudes toward self; with the possible impact of troubles on relationships, social activities or work roles; with their possible impact on other valued activities or ambitions; and the impact of both troubles and help-seeking efforts on the respondent's view of him/herself. The second section deals with the definition of troubles as hypersensitivity problems--how this definition was adopted, its cognitive and emotional significance for self, and the responses of others to this definition of problems. In the third section, questions deal with the extent of continuing impact of both troubles and management upon relationships, work and other activities; with the extent to which the hypersensitivity definition of troubles is recognized and accepted by others--both informally among significant others, and formally by officials of various kinds; and with how troubles may now be explained or concealed in various situations.

Like the preliminary interviews, interviews done using the interview schedule usually lasted between two and four hours. The character of my conversations with respondents, however, had changed considerably. The schedule was designed to chronologically trace respondents' trouble-related experience, as had been done in the loosely structured preliminary conversations. I found, however, that in attempting to keep the conversation "on track" with the schedule, I was frequently distracting myself from valuable comments the respondent was making about areas that came later in the schedule, or that, perhaps, were not sufficiently anticipated in the schedule. While I was sometimes able to guide the focus without disrupting respondents' spontaneity and an easy flow in the conversation, beyond a certain point such efforts threatened to make the interchange rather hesitating and stilted; and also threatened a loss of information that might not be recalled in the same way later. Respondents' spontaneous associations of thoughts and feelings as they recalled their experience frequently led them to quickly jump from the past to the present and from one aspect of things to another. When respondents began to strike off in a direction that was not to the point of the present area of questioning, but highly relevant nonetheless, I increasingly felt that it was important to go with them and probe further rather than attempting to control too much. Consequently, after about ten interviews using the schedule, I decided to begin using it more as a guide. In doing so, care was still taken to cover the applicable areas of the interview schedule, but not necessarily in the same order or with precisely the same wording of questions. This approach allowed for the flexibility necessary to adapt to individual respondents' experiences and the individual ways in which they might recall it.

In addition to talking about their experience of ecological illness, at the end of the interviews respondents were asked to complete three written scales designed to assess levels of self-esteem, depression and social support. The scales used were the Centre for Epidemiologic Studies Depression Scale or CES-D; Rosenberg's Self-Esteem scale; and the Interpersonal Support Evaluation List (ISEL). In the planning of the research, it was decided to include these scales as a means of more objectively assessing these aspects of people's experience. Because of the length of the interviews and the limited stamina of some of the respondents, these were often left behind along with a mailing envelope. In a number of cases, however, after conversations that involved respondents telling me of how they had become bitter in response to their troubles being interpreted in psychological terms, these questionnaires were looked upon with suspicion. Items on the scales frequently referred to what, for the respondents, were symptoms of their physical illness problems rather than psychological indicators. A number, therefore, expressed reluctance to complete them, feeling that their answers would be misconstrued.

For somewhat related reasons, I also developed some reservations regarding the value of responses on these scales. At the core of the present study is the issue of how the reality of trouble can be variously socially constructed. The meanings of troubles studied here are very much "up for grabs". The question arises, then, as to whether the scales can properly be considered "objective" measures, since the scales themselves represent particular constructions of "self-esteem" and "depression". As I doubted the utility of the scales, I grew less inclined to incorporate them in the analysis. When ultimately eleven respondents failed to return them by mail, I did not pursue them, deciding not to use the scales.

Other Methodological Issues

As discussed above, although observation at a couple of gatherings served to indicate some issues in people's experience of ecological illness, the primary research strategy of this study was interviewing. Being interested in subjective experience ranging over a long period of time and numerous everyday life situations, it was necessary to rely on what people would say about their experience. Relying on what people say, however, particularly about events, perceptions, thoughts and feelings in the past, has a number of limitations. Recall is inevitably selective and coloured by retrospective interpretation. As Becker and Geer (1972) have argued, as perspectives on events and experience change over time, so do perceptions and memories. Because of this, a longitudinal study involving a number of interviews with the same respondents over a period of months or years might have been preferable to reliance on one-time retrospective accounts. As discussed earlier, however, because of the need to recruit respondents who are comparable with respect to having already defined troubles as ecological illness, even talking to people earlier in the process would not have eliminated the need for retrospective accounts of prior experience. Another way of obtaining information on earlier experience is the use of diaries or other written records. When arranging interview times in this study, I told respondents of my interest in their past experience and asked if they might have any written records that might help refresh their memories. Many did, and some were willing to give me photocopied material regarding doctors seen, correspondence, etc. While such records do not substitute for speaking with people earlier in the process, they were often useful nonetheless. While there are problems associated with reliance on retrospective accounts, the in-depth interviews for this study provided much detailed information on people's experience of ecological illness. On balance, the in-depth interview is an appropriate method by which to talk to a number of people in a relatively short period of time.

In order to further enrich the information obtained, a number of conversations with each respondent would have been valuable. With some respondents particularly, building rapport and trust through a few meetings might have encouraged both better recall and greater freedom to talk. In the time available, however, this would have meant a smaller sample.

The data would also have been enriched by hearing from spouses or others intimately involved with the respondent. For a short period of time in five of the interviews, others did contribute to the interview with the respondent. Their input in these cases was often useful in that they were directly expressing interpretations and reactions that would otherwise only have been interpreted and relayed by the respondent.

The example of one of these interviews, however, makes clear that systematic interviewing of intimate others would have necessitated additional, separate interviews. In this case, the husband of a woman to whom I was talking was busy doing something in an adjacent room. He occasionally added a word or two as he overheard the conversation, and then eventually sat down to join in fully. After a few minutes, he then left to go to a store. My impression from his conversation was that he was well acquainted with his wife's problems and that he seemed quite supportive of the various things she was doing to deal with them. However, a short time after he left his wife intimated that she could now tell me how things really were from her point of view. She proceeded to tell me at length that her husband actually thought that the ecologic diagnosis and management of her problems was "nuts" and that this difference between them was bringing them close to separating. A while later when the husband returned, she promptly stopped talking about this. Clearly it had been important in this woman's case that she had an opportunity to talk to me without her husband present. A fully joint interview would have prevented her from fully sharing her experience.

Enriching the study through systematic interviewing of spouses or others would have required additional separate interviews and would have limited the sample size. However, in some cases an interest in talking separately with intimate others might have been threatening to respondents themselves. For many of those interviewed, their trouble-related experience was a highly sensitive matter, particularly in connection with other family members. While the interviews often seemed to be enjoyed by respondents as an opportunity to talk freely to someone interested in their experience, the involvement of others in some cases would likely have discouraged openness or perhaps any participation at all. In sum, then, while interviews occasionally benefited from others' comments, no systematic effort was made to include others' perspectives in the study.

This last point touches also on ethical issues of consent and confidentially. In arranging interviews, respondents were assured of anonymity and confidentiality. At the beginning of interviews, this was repeated in the course of asking them to sign a written consent to participate in the study (see Appendix B). While most participants in the study were content with this, in one case a respondent telephoned me a few days after the interview to ask that I not use the material from the interview. He wanted to be absolutely certain that the circumstances of his story would not indicate his identity to people where he worked. I tried once again to assure confidentiality and that I would not be reporting details that would reveal his identity, but he was firm in withdrawing from the study. As a consequence, this respondent's interview is not among the thirty-two interviews analyzed in this study. Bearing in mind this type of concern, in the discussion that follows care is taken not to include certain kinds of circumstantial information that might indicate the identity of respondents. Also, while detailed examples are used to support the analysis, entire individual case histories are not recounted in detail.

As noted earlier, the analysis is based on interviews with a sample of thirty-two people with ecological illness. Before moving to the analysis, the next section describes some social characteristics of the sample of people interviewed.

The Sample (see also Table 1)

Of the 32 people whose experiences are examined here, 28, or 87.5%, were women. Although there do not seem to be any figures from epidemiological studies of ecological illness to which this high proportion of women can be compared, it is consistent with clinical observations of doctors treating hypersensitivity

TABLE 1: Social Characteristics of the Sample

	Number (total 32)	%	Women	Men
AGE:				
20-29	2	6	2	--
30-39	10	31	9	1
40-49	9	28	8	1
50-59	8	25	7	1
60-69	1	3	1	--
over 70	2	6	1	1
MARITAL STATUS:				
Married/Permanent Relationship	23	72	20	3
Separated/Divorced	2	6	2	--
Single	7	22	6	1
EDUCATION:				
Some Secondary	3	9	3	--
Secondary Graduate	2	6	2	--
Some Post-Secondary/in progress	5	16	4	1
Post-Secondary Diploma/Certificate	8	25	7	1
Bachelor's Degree	11	34	9	2
Post-Graduate Degree	3	9	3	--
OCCUPATION:				
Clerical/Service/Technical	8	25	6	2
Professional	12	38	11	1
Homemaker	6	19	6	--
Full-Time Student	3	9	3	--
Retired	2	6	1	1
No Occupation	1	3	1	--
*INCOME:				
Less than 5,000	2	6	2	--
5,000-9,999	1	3	1	--
10,000-19,999	3	9	3	--
20,000-29,000	5	16	3	2
30,000-39,000	4	13	3	1
40,000-49,000	7	22	7	--
50,000-59,000	7	22	6	1
60,000-69,000	1	3	1	--
70,000 or more	2	6	2	--

*In the twenty-three cases of those who are married, income levels represent combined incomes of husband and wife.

Table 1 continued...

TABLE 1 (continued): Social Characteristics of the Sample

	Number (total 32)	%	Women	Men
RELIGION:				
Protestant	13	41	11	2
Roman Catholic	6	19	5	1
Other Christian	5	16	4	1
Jewish	2	6	2	--
Eastern Religions	1	3	1	--
No Religious Affiliation	5	16	5	--
ETHNICITY:				
English/Scottish/Irish	20	63	17	3
French	4	13	4	--
German	5	16	4	1
Italian	2	6	2	--
Finnish	1	3	1	--

(Randolph, 1979; Berger, 1988) and with proportions of patient submissions to the Ontario Ministry of Health "Committee on Environmental Hypersensitivity Disorders" (Government of Ontario, 1985:125).[1]

Among the 28 women, 20 were married and the rest were separated, divorced or single. Of the 4 men, 3 were married and 1 was single. Respondents ranged in age from 26 to 80 years, with 19 (59%) being between 30 and 50 years old; the average age was 45 years. With respect to education, all except 3 had completed high school; 27 (84%) had attended or completed some form of post-secondary education; 11 (34%) had completed a Bachelor's degree; and 3 (9%) had a graduate degree. The number of respondents in professional occupations was 12 (38%) and in technical, clerical or service occupations, 8 (25%); 6 (22%) were full-time homemakers; 3 were full-time students, 2 were retired, and 1 had not developed any occupation due to her illness problems. In connection with respondents' occupations, 9 (28%) were unable to work because of illness problems at the time that I talked with them. With respect to religious affiliation, 13 (41%) were Protestant, 6 (19%) Roman Catholic, and 2 (6%) Jewish; 5 had no religious

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[1] Randolph (1979), among other physicians, suggests that menstrual, menopausal and pregnancy-related hormonal changes can contribute to lowered resistance to exposures. Berger (1988) suggests that women are more vulnerable because of the greater complexity of their endocrine systems generally.

affiliation, and the rest were mostly other Christian denominations. The ethnic background of 20 (63%) of the respondents was either English, Scottish or Irish; there were also 5 of German background, 4 French, 2 Italian, and 1 of Finnish background.

To summarize, those interviewed were mostly married, well-educated, middle-aged women of English-speaking background. While most were active in full or part time employment or as homemakers, just under a third of those interviewed were not working due to their sensitivity-related problems.

Chapter 3

BEFORE THE DIAGNOSIS OF HYPERSENSITIVITY

This chapter, along with chapters five and six, discusses respondents' experiences of making sense of and coping with 'troubles' considered to be ecological illness. The present chapter begins by examining peoples' experiences of trouble prior to defining these troubles as sensitivity-related: the various kinds of difficulty experienced, efforts to make sense of and cope with troubles, and the kinds of interpretations made by self, significant others, and various physicians from whom help was sought. Of particular interest are the perceptions, interpretive work and knowledge which form various parties' interpretations of trouble and trouble-related identity; and the consequences for respondents' trouble-related experience of various kinds of definition and definitional ambiguity or conflict.

Overview of Troubles and Help-Seeking

For those interviewed, making sense of various troubles was typically a long, often preoccupying, process. The period between first experiencing troubles that were later interpreted ecologically and eventually consolidating such an interpretation ranged from one to twenty-five years; the mean length of this period was nine and one-half years. During this period, for varying lengths of time, all respondents became debilitated enough that they felt themselves unable to function normally in their usual work roles or other activities. For many, this meant a disturbing deterioration in usual capacities. However, eleven of the thirty-two people interviewed had become more seriously disabled during this period, unable to work or attend school for a number of months or years. In efforts to understand and cope with problems, respondents typically consulted doctors, psychiatrists and, in a few cases, other health care practitioners. The number of doctors or others seen prior to consolidating an ecological understanding of troubles ranged from one to more than twenty, with twenty-one respondents (nearly two-thirds) having seen five or more. Generally then, those interviewed experienced problems for which they sought help for many years, from a number of doctors and others.

Consistent with discussions of ecological illness in the medical and popular literature (eg. Rippere, 1983; Bell, 1982; Levin and Zellerbach, 1983; Randolph and Moss, 1980), respondents typically reported having experienced a great number and variety of troubles. All but two respondents had a number of difficulties that seemed to affect them mentally or emotionally in addition to problems experienced primarily as physical. One woman, a nurse, described the development of the following combination of problems:

> At first I was getting really bad headaches and tension in my neck; and joint pains in my legs. I also had heart palpitations fairly frequently. Around that same time, I was also getting more and more tense and irritable, and feeling really hostile with everybody--absolutely no patience with anything or anybody it seemed. Later on, after a couple more years, I was getting more and more fretful and anxious a lot of the time; and I was having trouble thinking straight and remembering things at work. These things really started to bother me.
> (Interview #6)

The great diversity of complaints reported here was typical of all those interviewed. The difficulty with thinking clearly was one of the most frequently reported by respondents. As with the woman above, one of the men interviewed stressed that such troubles were among the most difficult to handle:

> Part of this sort of tired hung-over feeling I always had was that I just wasn't sharp. I was starting to make mistakes at work and, otherwise, I was too slow at getting things done. This got to be a real problem--you're not with it, but don't really know why. How do you explain that to the supervisor? (Interview #21)

As is illustrated by the man and woman just quoted, the troubles people experienced were frequently vague and not localised in one specific body area. Even the "strictly physical" complaints of one of the two people who reported no mental-emotional kinds of troubles were diverse and, in some respects, vague: "feeling tired all the time,... feeling really weak,... diarrhoea,... stomach bloating,... losing about twenty-five pounds in six weeks." (Interview #2).

In some cases, at least some troubles later associated with ecological illness were seen previously as definite, obviously medical problems of some kind, and were readily identified as such and dealt with in some way by doctors. One woman, for example, had a long history of multiple problems: chronic kidney infections, polyps in her nose and on her vocal chords, cysts in her breasts and arthritis in her legs. Over the years, these problems were all dealt with individually in medically conventional ways by specialists concerned with each type of problem or body area. Many others also had one or a few complaints that were obvious and medically identifiable in some way; for example, obvious infections or symptoms associated with common allergy.

More often, however, respondents' complaints were vague and more resistant to straightforward medical diagnosis. The most frequently reported kinds of trouble were: fatigue or weakness, mental dullness, depression, memory problems, mood swings, gastro-intestinal problems, and muscle and joint pains (see Table 2). While some reported difficulties that are commonly associated with

Table 2: Troubles reported by 25% or more of the sample

Troubles	Number Reporting	Percentage Reporting*
1. Fatigue/Weakness	28	88
2. Difficulty Thinking Clearly/ Mental Dullness	24	75
3. Depression	20	63
4. Memory Problems	18	56
5. Moodiness/Mood Swings	16	50
6. Gastrointestinal Problems	16	50
7. Muscle/Joint Aches or Pain	15	47
8. Irritability/Aggressiveness	13	41
9. Uncontrollable Crying	12	38
10. Anxiety/Panic	12	38
11. Chest Pain/Congestion	11	34
12. Headache/Migraine	10	31
13. Skin/Hair Problems	9	28
14. Dizziness/Fainting	9	28
15. Coordination Problems	8	25
16. Nervousness/Shakiness	8	25

*Rounded to nearest 1.0%

allergy such as hay fever or eczema, it is possible that these types of allergy symptoms were generally under-reported due to the greater salience in peoples' experience of other more disturbing troubles. The number of troubles reported by individual respondents ranged from three to seventeen. The average was nine different types of difficulty that were later associated with hypersensitivity.[1] Taken together, those interviewed reported thirty-two different kinds of troubles.

Noticing Something Wrong

During the typically lengthy period prior to ecological diagnosis, almost all of those interviewed became either constantly or intermittently preoccupied with determining the nature and causes of their problems and with finding ways of resolving or managing them. Initially, however, a number of respondents did not readily interpret changes in feeling states or capacities as particularly problematic. For some, especially early in the experience of troubles, difficulties occurred sporadically and did not significantly interfere with important routines or activities. This, combined with the diversity and frequently vague character of troubles inclined them to view their difficulties initially as

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[1] Because respondents' reports of troubles were based on memory rather than checking off a list, it is probable that troubles were under-reported rather than over-reported.

fleeting or minor. In addition, however, the recognition of an as yet unexplained problem can be felt as a threat. That which does not fit with everyday classifications of experience constitutes an anomaly which threatens order (Scott, 1972; Berger and Luckmann, 1967) and which calls for the creation of novel responses. Thus, rather than recognize an anomaly or problem, people may be more inclined to neutralize troubles as insignificant or interpret difficulties as normal-under-the-circumstances (Schneider and Conrad, 1983:56-59). Some of those interviewed initially normalized their experience by drawing upon common, routinely employed explanations for feeling somewhat below par: not eating well enough; temporarily over-stressed; or not sleeping enough. Such normalizing explanations allowed for a stance of "nothing unusual is happening" (Emerson, 1970), and, for awhile at least, eliminated any need to markedly disrupt usual routines. One of the men interviewed, a busy self-employed contractor, remembered his early experience this way:

> At first I was just going from the dinner table to the rug in the living room and conking out. I'd just fall dead asleep for the rest of the evening until my wife would wake me up to go to bed. It was odd in a way, but I thought I was just working too hard and was overtired. I figured I was just run down a bit and didn't get too concerned about it. (Interview #2)

Others similarly normalized their troubles at first. A woman who noticed herself feeling constantly fatigued decided initially that it must be due to having given birth a few months before and then having an active baby to care for. She was supported in this view of the situation by her husband and family doctor. Only as the fatigue seemed to be very prolonged did she gradually begin to see her situation as a distinct problem requiring greater attention. While the difficulties experienced by these respondents were clearly deviations from the "background bodily expectancies" (Alonzo, 1979) of their usual selves, there were situational circumstances that, for awhile at least, seemed to explain them as normal under the circumstances. A clear sense of something unusual happening, something wrong, arose only as such explanations no longer seemed adequate.

There were other respondents also who, for longer periods, accepted various troubles as essentially normal. However, rather than seeing departures from a normal well self as normal-under-the-circumstances, five women interviewed had viewed difficulties eventually associated with ecological illness as simply part of their normal experience of self. During childhood, these women grew up learning to accept certain uncomfortable feeling states and reduced capacities as "normal for them". One of these women remembered the following:

> When I was quite a young kid in school, I was almost always tired and felt I couldn't hope to keep up with other kids, or even just get through days at school. I

> remember actually dreaming dreams where I would wish that I could just sleep in because it seemed impossible to get up....And I very often had funny little mood changes where I would just find myself feeling very strange and sad and far away from people; but I'd have no idea why--nothing I was particularly sad about.... It was like that ever since I could remember...so I just thought, I feel kind of funny, but that's just how I am.
> (Interview #17)

As a child, another of these women learned to incorporate certain discomforts as usual background expectations through being discouraged from complaining:

> Well, when I was really small, I was acutely sensitive to smells. I would smell certain things and feel sick but nobody else would smell it. Like, being in the car, I felt weak and nauseous smelling the car and the exhaust, even on short trips. It happened really often with other smells too--with things cooking sometimes. My parents ridiculed me though because they said they smelled nothing. So I just would shut up about it.... From when I was about eight years old, I've always tried to numb myself to things I felt and just ignore them. (Interview #13)

Another woman said that at some point during her teen years she became markedly withdrawn, introverted and depressed. She had difficulty concentrating, could not finish things at school and her grades fell dramatically. She said that she was not particularly alarmed, however, as she interpreted her experience this way:

> I always did well in school, and was a pretty conscientious, cooperative kid. I never did anything wild or crazy much.... When this happened, I actually felt that this was probably my way of rebelling as a teenager, even though it wasn't acting out

> or anything. I was pretty self--conscious at the time, like a lot of teenagers I guess, and I remember thinking that maybe I was just an introverted person after all....At the time, I didn't think there was anything particularly wrong with me, even though I didn't like how I felt a lot of the time. (Interview #22)

The recognition of something wrong, unusual or abnormal depends partly on having a well-formed sense of how things could or should be otherwise. As a teenager who felt her self to be in transition, this woman had no such firm self-expectations. As she became depressed and her previously highly valued school performance fell off, she was not alarmed. She simply called into question what had previously been usual for her and looked more or less positively upon the changes as a normally rebellious phase of growing up.

For all of these women who initially accepted troubles, a clear sense of problems needing remedy was "triggered" (Zola, 1973) only later as it became more difficult to manage and contain troubles in valued roles and situations (Alonzo, 1979). The woman just discussed, for example, went to university with the goal of going on to medical school. As the depression, inability to concentrate and memory problems continued she was unable to handle her first year courses. At this point she became quite concerned about what she now clearly defined as a problem.

In contrast to those who initially normalized changes, for other respondents, even initially, there was a more definite sense that something was wrong. Changes in feeling states or capacities interfered with an established, taken-for-granted normal experience of self; or were so disruptive of important activities or roles that ignoring or just accepting them was not possible.

Initial Self-Interpretations of Troubles

Whether the sense of something wrong developed quickly or gradually, respondents' efforts to deal with their troubles typically involved a lengthy process of self-assessment and help-seeking in an attempt to understand and remedy problems. Quite early in this process, five of the thirty-two people interviewed thought of their problems as being primarily psychological. Two of these people were women who had had long childhood histories of both medical and psychiatric diagnoses. Both of them had spent time in psychiatric hospitals, one of them having been hospitalized five times by age twenty-eight. This latter woman said that she had grown up thinking of herself as "a bit crazy" (Interview #18), while the other woman had always thought of herself as having "problems with nerves" (Interview #5). Another respondent, the woman previously quoted who had once thought of herself as a rebellious teenager, subsequently interpreted problems with depression and concentration as family-related psychological problems that she needed to resolve. And one of the men interviewed similarly saw troubles with mood swings, feelings of anxiety and paranoia as psychologically rooted problems. The fifth person who saw her problems this way, a woman, had a chronic problem with severe depression.

Others interviewed said that they initially felt that their difficulties must be caused by health problems of some kind. For most of these people, the phenomenal quality of many troubles was primarily physical: disturbing changes in bodily appearance or feeling states such as sudden weight loss, pain or fatigue; and either episodic or chronic decreases in physical capacity for usual activities. Like the five people referred to above, many also had mental-emotional troubles. Unlike those above, however, for varying reasons they felt that such troubles must also be related in some way to health problems. For sixteen of these people, those troubles that had a mental or emotional quality either accompanied and seemed to be associated with physical troubles, emerged only later in conjunction with worsening physical problems, or developed with the use of prescribed drugs. One woman, a librarian, described her experience this way:

> In 1974, I started having sneezing bouts that went on for hours, and congestion in my sinus and nose. It got worse when I handled the really old books in the library

> basement....Eventually I saw an allergist who tested and said I had the usual allergies like dust, grass, moulds and things like that. He prescribed an antihistamine, Eltor. For two years I took this regularly and it helped the congestion and sneezing...but the side effects were pretty bad and seemed to get worse. I'd be sort of hyperactive, dizzy and irritable and had palpitations. At this same time I lost a lot of weight, and had swollen ankles and legs. Then, when I was appointed to the art department in the basement of the library, I got a lot worse....This was what I had really wanted to do, but there were more and more days when I felt depressed and irritable and the sneezing attacks got worse. Then when the maintenance people changed the floor wax they were using, my lungs felt like they were burning, and I'd get confused and lose track of what I was doing; I couldn't think straight and couldn't do my job.
>
> (Interview #1)

This woman's account conveys the way in which, for many respondents, mental-emotional troubles were clustered together with what were felt to be primarily physical problems.

For five other respondents this was not the case, but mental-emotional kinds of trouble were nonetheless not felt to stem from psychological problems of self. The experience of such troubles seems to have been akin to that of stutterers as analyzed by Petrunik and Shearing (1984; 1983). As with stuttering for stutterers, the phenomenal quality of disturbing mental-emotional changes for these people was such that they seemed to be "the work of an alien inner force...which takes control" (Petrunik and Shearing, 1983:127). In other words, such troubles seemed to be "happening to" respondents rather than being states which they could expect themselves to control. As the following words of two of the women indicate, the disturbing mental-emotional changes seemed to be products of influences that took over self but that were not of self:

> I was having great mood swings with really extreme flare-ups of anger, or other times I'd just be crying very easily. It was out of all proportion to anything, but I just felt that way. Often too, I couldn't organize my thoughts--couldn't think clearly. I started feeling like my personality was changing, that I was cracking up....But these really extreme spells would last a day or so and then I'd be myself again. Then I'd know that this really wasn't like me....It was sort of Jekyll and Hyde...I knew there had to be a cause for it. Interview #27)

> ...these crying spells seemed to go on forever and I couldn't stop. But I wouldn't even know why I was crying, like it wasn't really even me crying. It was like it just built up inside and then I was in tears. (Interview #28)

The belief of three other women that various mental-emotional troubles were "not me" seems to have had less to do with the pattern of their experience than with their concluding that such troubles made no sense for them and their life situations. As one of these women put it:

> It seemed like I'd changed. More and more of the time I was feeling really sensitive and fragile, kind of weepy and with a lot of depressive thoughts....But then sometimes I'd just think, "This doesn't add up. I enjoy my job, I have good friends--there's no reason for this."...I felt like

> there must be something that they couldn't pick up on their tests. (Interview #17)

Despite the ambiguity of certain of their troubles, these women defined them generally as physical health problems. As is discussed further below, a number of respondents who initially interpreted their troubles this way later doubted and struggled with themselves as to whether certain of their problems were, indeed, of the body and not the self; with whether they were not weak-willed, imagining things or had serious psychological problems. For some, such doubts arose with the later emergence of more engulfing, more incapacitating mental-emotional kinds of trouble; for others, with the influence of family members or doctors not supporting an illness interpretation, or simply lack of success in finding a fitting medical diagnosis and remedy. To begin with, however, most people sought remedies for what they defined as essentially health problems.

In efforts to cope with their problems, both initially and at other times while help-seeking, a number of respondents experimented on their own with diet changes, exercise or methods of reducing stress. A few people found that some of these efforts helped them to some degree. However, as various troubles persisted and typically worsened, they sought outside help. As adults, three respondents first saw a chiropractor or naturopath and one first sought psychological help. The remaining twenty-eight people, however, sought help from doctors.

Seeking Medical Help: The Quest for Legitimation and Treatment

Generally speaking, people can be seen to be motivated by two major concerns as they seek help from doctors. First and most obvious, they seek a solution to their problems. They hope that a diagnosis will lead to effective treatment. A second major concern is that a private subjective experience of discomfort and trouble be socially validated and be made comprehensible in some way, both for self and others. Medical categorization and naming locates a person's experience as a particular instance of a generally recognized, known phenomenon. Thus, however private the experience, it is socially objectified and, therefore, not simply "all in my head". By thus typifying troubles, diagnoses similarly make clear to others that the individual has a recognizable and, therefore, genuine medical problem. Particularly when peoples' troubles do not have obvious external signs (Telles and Pollack, 1981), a medical diagnosis can serve to legitimate claims of trouble and thereby aid the development of consensus in redefining an individual's health identity. As Twaddle and Hessler (1987:130) have observed, "...to have a disease is not sufficient to be treated as sick. A person can be sick on his own authority for only a limited period of time...". Some type of consensus that an individual is, indeed, sick in some way is thus a necessary basis for assuming some variation of a sick role: modifying usual role expectations and obtaining others' understanding and cooperation in remedial efforts.

As mentioned at the beginning of this chapter, people seeking help for what they eventually felt were ecological illness problems typically consulted many doctors in search of a diagnosis consistent with their experiences of trouble. For most, the negotiation of a consensus on the nature and seriousness of their complaints was difficult and frustrating. At some point or other in their contacts with doctors, seventeen of those interviewed had certain of their complaints diagnosed in terms of one or more established medical diagnostic categories. Thus, just more than half of those interviewed had a few of their concerns legitimated as illness. Complaints that were taken account of in such medical diagnoses typically had signs that were either visibly obvious or detectable in diagnostic tests. The most frequently made diagnoses were common allergies, various infections, and arthritis. As treatments were tried, however, these people typically came to feel that such diagnoses dealt with only some of their complaints, or did not adequately explain the severity or chronicity of various problems. In their dealings with doctors, most of these people, and others who obtained no diagnoses, felt that many of their concerns were either ignored, not taken seriously or wrongly considered psychological problems. They were frustrated in their efforts to gain medical support for definitions of themselves as sick. For example, one woman who had seen a number of doctors was concerned that physicians did not take her complaints seriously when diagnostic tests were negative:

> The most frustrating part of all this was that so many doctors I saw didn't take things seriously and really look into it...always being told there's nothing seriously wrong when an x-ray showed nothing, but then meanwhile I'm having trouble walking. A couple gave me prescriptions for painkillers, but those really made my head spin, and I still had no idea why I had this pain. They'd just keep saying that there was really nothing to worry about. And one just said I should expect some stiffness at my age (50's).
> (Interview #9)

As in this woman's case, one of the ways in which physicians defined peoples' complaints as medically insignificant was similar to the way in which some respondents had initially dismissed them; through normalizing them--defining them as "nothing unusual under the circumstances". And, once again, as with the woman just quoted, physicians quite commonly dismissed any need for concern by referring to people's age. Another woman in her forties was also reminded by her physician that she was getting older when she consulted him about swelling in her ankles and chronic headaches. To two other women who had concerns with memory problems, fainting spells and "spacey" feelings, it was suggested that their discomforts were not unusual during menopause. An eighty year old man similarly had difficulty being taken seriously when tests failed to reveal any basis for dizzy spells and hallucinations. Bitter about this he remarked: "This bright young geriatrist reasoned that if she told me I was okay, that would suffice." (Interview #29).

In other instances of physicians not acknowledging and supporting an illness identity, it was suggested that people were hypochondriacs or, more mildly, that they were simply worrying too much about themselves. A woman who had consulted an infectious diseases specialist about recurring flu-like symptoms, balance and memory problems remembered being told: "I suspect you're paying too much attention to your bodily functions. Perhaps you should get busier with things and don't think so much about your body." (Interview #17). Another woman who was having problems with abdominal pains, indigestion, night sweats and light-headedness was found to be normal after tests by an internist. She recounted that, "When he was finished telling me that all the tests were negative, he said very sarcastically that I just needed to get hold of myself and quit worrying about my health." (Interview #4). Two other respondents said that they had been told directly that troubles were "probably all in your head." (Interviews #21 & #22).

At some point in their contacts with doctors, eighteen people were given the opinion that they had psychological problems. The problems of five of these people were predominantly mental-emotional kinds of troubles that are quite commonly assumed to have a psychological or stress-related aetiology: depression, anxiety, crying easily, mood swings, and sleep problems. However, not all of these people themselves endorsed this interpretation. One woman, a nurse, gave the following account of seeking help for extreme anxiety, and of her own efforts to understand it:

> I woke up one day in complete panic seized by anxiety. I was totally mystified by it, but I couldn't do anything to talk myself out of it, had no control over myself. I tried a bath to relax--but nothing...Next day, things were no better. I was beside myself...(the doctor) had me go to the hospital....As a nurse I had never seen this happen to somebody, but I knew this wasn't just stress or something and felt there had to be some cause for it. At first, I thought I'd see the doctor and get things sorted out....I wondered about some drugs a doctor had given me before for feeling fatigued. After a month on them, I'd just finished them two days before...and before that I'd been taking antibiotics almost continually for a few months for ear infections that wouldn't go away...but I didn't really know.
> At the hospital though, things didn't sort out quickly and I was moved to the psychiatric section and was there for four months....I had drugs and shock treatments, and then had psychotherapy...sometimes with my family there also....I didn't really

> feel this had much to do with my family, but I thought maybe they knew best....A year later I was in the hospital again for two months....This time the anxieties were diagnosed as phobias...but what they said didn't make any sense to me and I began to get more sceptical about their approach and what they could do for me. These drugs and shock treatments and psychotherapy weren't helping. (Interview #20)

A few years later, this woman had two more month-long hospital stays before eventually spending six months in a provincial psychiatric hospital. In addition to the phobia diagnosis, she was diagnosed as having a schizoid personality at one time, and at another, passive-aggressive anxiety. About her hospital experience she also stated:

> They always said I wasn't trying--well, I knew I was trying. But I identified more with the staff than with patients there. I came from a good home and family that was loving and supportive--the whole thing didn't make sense. So I gave up any hope that these problems would be really understood. (Interview #20)

Two other women had also spent time in psychiatric hospitals. Both of these women had seen a multitude of doctors, including psychiatrists, since they were children. One of these women had a particularly extensive psychiatric history marked by many diagnoses: childhood arm and leg pains were diagnosed as psychosomatic (attention-getting to avoid school), adolescent dysfunction syndrome, manic depression, reactive depression, schizophrenia, and multiple personality. Given their long histories of problems with anxiety and other difficulties, both of these women had grown up regarding their problems as primarily psychological.

Thirteen other respondents who were given psychological diagnoses, however, had been seeking help for what they felt to be primarily physical illness problems. As they first consulted a doctor and examination and test results failed to account for a number of their complaints, some were told initially that there seemed to be nothing medically wrong. Others' complaints were either normalized or discredited as imaginary as was discussed above. Having received such responses, but concerned nonetheless, respondents frequently made repeat visits or "shopped" other doctors for an interpretation more compatible with their own sense of their problems. In other cases, general practitioners referred difficult to diagnose complaints to various specialists. Whether as a result of referrals or medical "shopping", some respondents accumulated a great number of medical opinions, including psychiatric diagnoses. One woman, a high school teacher, gave the following account of some of her help-seeking efforts and the diversity of often conflicting medical opinions she was given:

> I think it was the spring of 1980, I began having ear infection after ear infection. The doctor gave me decongestants and antibiotics off and on for a few months. Then he referred me to an allergist, but the skin tests were negative for anything he tested--no allergies....But I kept having congestion and coughing problems

> after that...in the 84'-85' school year, I began feeling very slowed down and lethargic, really fatigued all the time. The doctor I saw ran a bunch of tests, but couldn't find anything wrong. Through that winter, though, things got worse...the fatigue and coughing got worse...my ears felt swollen underneath, I was losing weight and I had swelling in my legs...and regularly had diarrhoea and was often feeling sort of spaced out and disoriented. I was going back to the doctor about every two weeks but he kept saying there was nothing wrong and not to worry so much about my health. At some point, he got impatient and sort of said, or at least implied, that I was just imagining things. I just told him I knew that something wasn't right. Eventually, he came out and said that he thought I should see a psychiatrist....I felt, "I'm not nuts", but at this point I just went along and said okay....Then after meeting with the psychiatrist three times, he wrote to the GP that I should see a neurologist and an allergist...he thought I wasn't well, but that I didn't need psychiatric help....So I saw a neurologist,...he ordered an EEG, which turned out negative. So then he very condescendingly told me I was neurotic....Then I saw an Ear, Nose and Throat guy, and he at least took seriously that I was sick. He said he thought I had allergy of some kind. So I saw another allergist, but of course the skin tests were negative again. By this time I'd been off sick a lot and wondered if I could continue working much longer....The whole thing was pretty scary. (Interview #14)

In this woman's case, assessments that her complaints were psychogenic appear to have been made primarily as a result of physicians being unable to establish any medical explanation for them. A similar pattern also occurred in the experience of twelve other respondents. One of the men interviewed, for example, experienced disabling pain in his back, neck and head. Over the course of a couple of years he consulted two orthopedic specialists, a neurologist, and a psychiatrist. The doctors consulted could find no physical basis for his pain and concluded that the man's pain was psychologically based. Another of the men interviewed, accustomed to being active with swimming and jogging, found his exercise stamina deteriorating. He began feeling chronically fatigued, as if "hung over", and shaky much of the time. After seeing a general physician and an internist whose test results were negative, it was suggested that he should see a psychiatrist. A woman who was troubled by chronic diarrhoea and abdominal pains was similarly found to be physically normal after numerous tests and an examination by an internist. As her problems continued and she continued to raise concerns with her general practitioner, it was suggested that she had emotional problems and should see a psychiatrist.

In all of these cases, a psychological interpretation seems to have been made virtually by default--since no medically known basis for complaints was found then the problem must have been psychogenic. Alternatively, the fact that some people continued to press their concerns after being assured of nothing wrong might also have encouraged some physicians to view them as abnormally anxious about their health.

As is evident in the foregoing accounts, people typically had much difficulty in either having certain troubles taken seriously or in having them medically defined in a way that was consistent with their own sense of having illness problems of some kind. As a consequence, in addition to seeing doctors, most respondents also attempted to diagnose themselves. Whether tentatively or confidently, twenty-six people made various self-diagnoses; most on the basis of health-related reading or television programs, and a few others primarily by examining their "ups and downs" for patterns or other clues. In many cases, people first learned of particular diagnostic ideas or books in conversations with friends or acquaintances. Eleven people came upon material about food and chemical sensitivity in books or television and considered that this might be their problem. Through examining and reflecting on their difficulties, five others arrived at more limited ideas about certain foods or certain chemicals causing or exacerbating their problems. Other diagnoses that people commonly considered included hypoglycemia, pre-menstrual syndrome, and candida albicans (intestinal yeast overgrowth). As with self-diagnostic attempts of people found to have multiple sclerosis (Stewart and Sullivan, 1982), respondents were essentially trying to find clues that could help a doctor arrive at a diagnosis. As they shared their ideas with doctors, however, some felt that they were not taken seriously and received little response. One woman, for example, raised with her doctor the possibility of chemical sensitivity after identifying with symptoms mentioned by a clinical ecologist on television:

> When I mentioned it, she (the doctor) just looked at me a little puzzled, but didn't say anything about it. She didn't want to discuss it. She just said she thought I should see an internist. (Interview #20)

In other instances, people felt ridiculed by doctors for suggesting diagnoses that are medically controversial. Following are the accounts of three respondents:

> I read a book called the Yeast Connection and found that a lot of the different symptoms that they had in there fit with what was happening to me--the fatigue, the emotional swings and depression and other things....So I showed the book to my GP, and he just said right away, "That's garbage. All of those symptoms could just be menopause." So after that, I didn't pursue it. (Interview #25)

> I'd been reading about hypoglycemia and there were a lot of similarities with what I'd been going through....I found another GP, a woman, who I thought might be more sympathetic...and I asked her about hypoglycemia, but she just dismissed it...said it wasn't a real diagnosis and wouldn't consider it....Then later on I saw an internist and asked if he would order a blood sugar test for hypoglycemia. This one told me that hypoglycemia was a fabrication of Ladies Home Journal...was pretty scathing, and told me I was suffering from depression.
> (Interview #13)

> I'd been to one (an allergist) before and tested negative on the skin tests for the usual things, so I told this one that I had noticed feeling worse, quite nauseous, around paint fumes or fresh glues, and so I wondered about things like that. He didn't say much, and just went ahead with the normal allergy skin tests. They were negative like before so he said I had no allergies. So I asked again about the paint and things. This time he got kind of hostile and pooh-pooed it. He very condescendingly gave me a lecture about basic facts of allergy and said that chemical sensitivities were impossible. He said he thought that people who claim to have chemical sensitivities really have emotional problems. (Interview #14)

The hostile, somewhat aggressive response of doctors in these instances was likely due not only to the controversial nature of diagnoses suggested, but also to the fact that patients were assuming a very active role in their own diagnosis. Patients perceived to be taking too active a role in diagnosis violate a fundamental normative expectation among physicians: that they alone have the expertise to diagnose illness (Stewart and Sullivan, 1982). However mildly, such initiatives by patients threaten medical authority. They might, therefore, be expected to elicit the kinds of hostile responses received by some respondents; even though respondents' intent had been to help their doctors to help them.

To summarize to this point, while some people had certain problems medically diagnosed and some appreciated doctors' efforts to help them, most respondents more frequently felt frustrated and discredited by doctors' inclinations to dismiss, trivialize or psychologize their experiences of trouble. As people encountered difficulty in negotiating a medical definition of their situation that was consonant with their own, they typically made repeat visits to their doctor to try again, sought help from other doctors, and attempted to diagnose themselves. The frustration of many respondents was well summarized by one woman in these words:

> After being told by seven doctors that there was nothing wrong with me, that it was all in my head, I remember thinking, "If this next doctor tells me I'm going to die, it would be a relief just to know that someone believes me that something is really wrong." (Interview #23)

It is probably fair to say that, among physicians it is an item of accepted wisdom that people who persistently visit doctors' offices in spite of negative findings, and who also attempt to diagnose themselves by keenly reading medical self-help books, are indeed likely to be hypochondriacs. However, people's medical shopping and self-diagnostic attempts might also be partly explained by characteristics of diagnostic practice and modern medical knowledge. Balint (1972) has observed that medical diagnosis is not so much a matter of simple identification of disease as it is a process of negotiation between doctor and patient. In the interaction between doctor and patient, illness is taken from an "unorganized" phase of often unfocused complaints to an ordered one entailing a prescribed course of action. Balint's analysis thus suggests that health status or identity is socially constructed or reconstructed by doctor and patient together. However, while diagnosis may be a negotiation as Balint suggests, it is the physician as the authoritative consultant who ultimately determines its course and outcome. To make a diagnosis, the physician typically gives attention to and selects only a subset of symptoms that make it possible to match the patient's problem to a particular known syndrome (Mishler, 1981:8). In so doing, the possible significance of other complaints, some of which may be equally or more troubling, may be ignored, minimized or explained away. Certain concerns are left inadequately addressed and the individual is thus prompted to make a return visit or to look for answers elsewhere.

In addition, though, judgements regarding what is medically significant in an individual's complaints are crucially guided by perceived signs, whether directly observable or as detected in diagnostic tests. As Twaddle and Hessler (1987:127) have noted, reported symptoms that are not corroborated by such signs are seldom taken in themselves to be definitive of an individual's health status. The distinction between symptoms and signs corresponds to what Sullivan (1986) has termed an "epistomological dualism" in modern medicine, an opposition between subjective awareness and direct observation. With the increased use of autopsy in the late eighteenth and early nineteenth centuries, the visibility of an anatomical lesion became a new standard of truth in medicine (Sullivan, 1986; Foucault, 1973). With this ascendancy of visual inspection in determining pathology, the patient's subjective account of distress was increasingly deemed unreliable and therefore less important to diagnosis. Thus, reported symptoms are considered a "softer" form of evidence for something wrong than are observable signs. As Kirmayer (1988:61) has nicely put it:

> The disease revealed by physical examination and technical instruments is at once more real and more important than the patient's subjective distress. The rational order of medicine eclipses the bodily-felt reality of the patient.

As evidenced by the accounts quoted above, as respondents sought help for a variety of distressing "symptoms", usually only those that correlated with perceived or tested signs were credited. From the viewpoint of physicians, without such signs there was no "real" medical problem. Therefore, the person's suffering must have been an exaggerated complaint about a minor discomfort, simply imagined, or in some other way psychogenic. In Kirmayer's (1988:61) characterization of the situation: "If biology provides no rationale for suffering then medicine can wash its hands of the patient who must be responsible for (his or) her own recalcitrant problem."

If not always helpful to patients, the use of psychogenesis as a default diagnosis is attractive to physicians and serves medicine well. As discussed in Chapter One, psychological or psychosomatic definitions of health identity raise questions of responsibility and competence both in developing and coping with problems. With a psychogenic diagnosis, a physician effectively shifts responsibility for whatever is unexplained and uncontrollable to the patient. By so doing, the physician's authority (and that of medicine generally) is maintained intact even as he/she is unable to help. For individuals whose problems seem to be essentially happening to them, however, the notion of responsibility associated with psychogenic diagnoses is confusing and discrediting.

Family Members' Responses

For seventeen of those interviewed, the distress resulting from medical help-seeking efforts was mitigated to some degree by recognition and support from families. While certain troubles with clear signs were frequently given some degree of acknowledgement by doctors, in the course of everyday intimate contact, their chronicity or severity were sometimes more clearly apparent to family members. Similarly, in cases in which a medical examination and diagnostic tests failed to indicate any medical abnormalities, sometimes family members themselves had noticed subtle signs which indicated to them that something was wrong: diminished energy level or decreasing interest in valued activities. Thus, six respondents with somewhat vague troubles such as neck pain, chronic digestive discomfort, lethargy, fatigue, anxiety and sleep problems were viewed by family members as having health problems, even as doctors could find nothing wrong. In one of these cases, a woman's husband insisted on such an interpretation as she began to doubt it at one point:

> In early 1983, I was feeling so tired that I completely gave up any social life....But after seeing all these doctors and hearing there's nothing wrong, I began to believe them.... I finally told my husband that I just gave up--that I must be crazy. Then he said, "No you're certainly not crazy"; and then he dialed another doctor that a friend told me about....He was sceptical about the doctors finding nothing wrong and then told me later that he was concerned I might have M.S. and that it just wasn't like me to be dragging around....He and my son were both very supportive and helped a lot when I was having trouble keeping up with things. (Interview #23)

Although the nature of troubles was ambiguous, the problems of this woman and others were informally, if not formally, legitimated as illness and sick role considerations made. One of the men reported that both he and his wife saw his troubles with fatigue and shakiness as some kind of physical health problem, and that she understood and accepted his not managing well. However, later in the interview his wife added the following:

> I mostly did think there was something wrong. He just seemed to have no energy much of the time--even when he wanted badly to do something he really likes to do. Except sometimes if I didn't think about it, I mean he didn't really look sick or anything, and sometimes I'd just be annoyed and think he was being lazy.
> (Interview #21)

For this man's wife, his failure to look sick brought occasional changes of attitude. According to fifteen other respondents, though, family members consistently saw them as "not sick", particularly as they failed to obtain any diagnosis of a medical disorder. The troubles with which these people were most concerned were typically either complaints with few, if any, obvious signs of illness, or mental-emotional troubles that appeared as such to others. Some people troubled primarily by being "always tired", or difficulty concentrating, reading or thinking clearly said that they were regarded by family members as "complainers" or as "not making an effort". Two women recalled the following:

> He (husband) knew I had migraines sometimes and he understood that. But if I mentioned the problems concentrating and reading, or being absent-minded and forgetful, or having numbness in my feet, he just felt I was complaining too much about nothing; that it was all in my head. (Interview #6)

> It was getting to the point where I was just barely managing my job which was only part-time anyway. I'd have no energy left for anything else but my husband was getting sick of always hearing me say, "I'm too tired" about doing anything. To him, there was no reason to be so tired all the time--particularly when I'd go to

> doctors and they'd find nothing. He'd just say I wasn't making an effort.
> (Interview #13)

The lack of a medical diagnosis mentioned by the second of these women was also felt by others to influence family members' interpretations of their complaints. Not being medically legitimated, concerns which were difficult to understand in any event, were thought to have no medical basis. Thus, in these cases, respondents' illness identities were not considered creditable and were not supported by family members.

In other cases, people whose problems included depression, irritability, anxiety, or mood swings, were given psychogenic diagnoses and were also seen by family members as having emotional problems. Two of the women who had spent periods of time in psychiatric hospitals had, at some point, been judged by psychiatric staff to be "not trying" enough to cope effectively with their problems; and their families viewed them similarly. Another woman said that her very obvious mood swings combined with persistent attempts to get help from doctors for these and other problems were worrying to both her and her husband. Because of differing interpretations, however, they worried about different things:

> Yes, he was concerned alright and felt that something was wrong. He could see how easily I'd break down crying at almost nothing. But he thought it was just me and that I had to get hold of myself. He was worried that I was going nuts. I told him

> I knew the ups and downs were somehow related to something--I thought maybe PMS then--and that I couldn't just get hold of myself. But he knew the doctors couldn't find anything and that one wanted to refer me to a psychiatrist. He felt that I was a hypochondriac, that I was just looking for a way to explain giving up doing things I didn't want to do. Both of us were fed up and feeling helpless about things, but he didn't understand how it was and there was a lot of tension. The whole situation was quite a strain on our marriage for awhile.
> (Interview #11)

This woman's comments indicate the way in which divergent definitions of troubles led, in some cases, to conflict and strains in family relationships. In addition to this woman, three others said that such conflict strained their marriages. In two other cases, distress created by problems combined with conflict were said to have led to a separation.

Self-Doubt and Limbo

Over time, the conflict between a self-identity as "sick" and identification by others as "not sick" or as psychologically troubled, prompted many respondents to question whether, indeed, they did have "real" health problems. As Berger and Luckmann (1967:150-60) have pointed out, a specific subjective reality or self-identification must be confirmed and supported by others if its plausibility is to be maintained. This is frequently accomplished in conversation, whereby the naming or classification of experience in language serves to objectify it--to give it a definite place in the order of reality. If a particular subjective reality is not interpreted and classified in a way that is supported by others, then its plausibility becomes problematic.

As the accounts above indicate, in negotiations of reality with respect to matters of health and illness, interpretations and classifications made by physicians often strongly influence, if not determine, lay interpretations. The profession of medicine officially legitimates illness. Importantly also, medicine "...creates the social possibilities of acting sick." (Freidson, 1970:206). If certain problematic experiences subjectively defined as illness defy interpretation in terms of available medical classifications, or if physicians and/or others simply interpret them as other than illness, then their plausibility as illness is, thereby, strongly challenged.

The difficulties which respondents had in legitimating what were experienced by them as serious illness problems constituted strong pressures on them to drop such definitions and attempt either to reinterpret or to ignore their problematic experiences. On the other hand, such problems were experienced by people as compelling intrusions on normal feeling states or capacities--intrusions which, they felt, they could neither ignore nor interpret as other than health problems. Thus, despite others' challenges to their self-definition as sick, including those of doctors, such ongoing experiences of difficulty asserted their own persistent plausibility as illness.

For most of those interviewed, this conflict between self-identification as sick and other kinds of social identity relative to troubles meant a continuing and long-unresolved process of inner turmoil and self-doubt. As with the diagnostic quest of people with multiple sclerosis interviewed by Stewart and Sullivan (1982), respondents found themselves in "an ambiguous and uncertain limbo." They felt both inwardly pushed to define troubles medically, and outwardly discouraged from doing so. Their situation also bears some resemblance to that of chronic pain sufferers described by Hilbert (1984:375) as "falling out of culture" as they were "unable to document their dominant life experience as typical or recognizable." As with chronic pain sufferers, with medical evidence saying there was nothing wrong respondents felt pushed "...to consider whether they were experiencing reality correctly". They questioned whether they were not imagining things or exaggerating the significance of difficulties; whether they were not weak-willed or just becoming lazy, or whether problems that they experienced as simply happening to them were not actually psychosomatic or psychological problems. In short, people felt set apart and stigmatized. If people's troubles, or claims of troubles, were not explicitly labelled "psychological" or "imaginary" by others, in the absence of an explanation for their troubles, they tended to apply pejorative labels to themselves (cf. Miall, 1986:279). Speaking of this self-doubt and self-labelling, two women said the following:

> Sometimes I just wondered if maybe I really was nuts after all--if maybe it was just in my head. After awhile with everybody saying you look fine, there's nothing wrong with you, you just think, "Alright, if I pretend it doesn't exist, maybe it won't exist." Sometimes I'd look in the mirror myself and think "Yeah--I don't really look unhealthy". But inside I'd feel so tired and spacey and couldn't think clearly. But I'd put on a happy face and try to act normal. For a long time I was going through different phases. Sometimes I'd just ignore it and deny it, but then I couldn't any more so I'd try again to see what was wrong. Then that would go nowhere....Sometimes I'd wonder what I'd done to cause these problems--maybe not handling stress very well. And then sometimes I'd think, maybe this is just my cross to endure in life--some kind of test, my fate. (Interview #3)

> I'd been through this round of referrals to specialists and they all found nothing. After one of them told me I just needed to get hold of myself, I sometimes wondered if I wasn't just making it up. For awhile then I thought maybe it was psychosomatic. But I was feeling really sick and like things were out of control. Anyway, I saw a psychoanalyst that a friend referred me to. That was useful in sorting through certain things, but the abdominal pain, dizziness, and sore throats were no better, so I still didn't know what to think.
> (Interview #4)

Like this woman last quoted, a number of others also struggled specifically with whether their problems were psychogenic. Having tried unsuccessfully to gain control of their problems through medicine, eight people also actively attempted in some way to resolve their problems psychologically. One of the men gave the following account of his efforts:

> I was getting very anxious about these spasms--not knowing the cause. I wasn't sleeping and was feeling out of control--felt like my life was falling apart. So I really tried to just lighten up and not be so tense. But I was grasping at straws. I tried some relaxation tapes, and I saw a psychologist a couple of times....I tried to psychoanalyze myself....Then I got more serious about it and saw a psychotherapist for over a year. That was somewhat useful--I learned quite a bit; but it was still missing the problem. I still had the spasms and the anxiety problems. (Interview #31)

Obviously, the ambiguity surrounding troubles meant that respondents had few, if any, firm guidelines in coping with them. Typically also, this lack of an adequate account for troubles created additional problems in everyday dealings with others. The effects of various troubles were such that people often felt compelled to excuse or explain their appearance, awkward behaviour or compromised performance (Scott and Lyman, 1968). For certain troubles, some people could rely on stock explanations such as allergies, colds or other infections. However, with other more nebulous problems such as chronic fatigue, mental dullness or anxiety, particularly in sustained involvement situations such as work or friendships, illness accounts of difficulty could not be given. Not knowing what was going on, respondents felt at a loss to provide a face-saving account, either to themselves or to others. Feelings of inadequacy or incompetence stemming from problems such as mental confusion, anxiety and deteriorated abilities were exacerbated as respondents felt helpless to say anything to prevent others from viewing them similarly. Once again, similar to chronic pain sufferers described by Hilbert (1984), they felt caught up in experiences that they could neither comprehend themselves nor share with others. They lacked a "vocabulary of trouble" with which to typify their experience for their own or others' understanding. As a couple of women said:

> People were looking at me rather oddly sometimes--it was obvious how spaced out I was...but I didn't talk about it. It's pretty hard to say anything about something you don't understand yourself. This really bothered me. Here you are, thirty years old, but always tired and dragging through things. You want to say something like, "Look, this isn't really me" but what's the point? There's nothing you can really say except that you're washed up and don't know why. (Interview #10)

> At work I was feeling really dumb and inept. My thinking would go--I wasn't sharp. It was difficult--I'd want to explain why I was having trouble coping, but couldn't really...with my symptoms I didn't really look sick...So I'd try to just go along as if nothing was wrong and

> put up a front. I was getting through my days for a while there, but I know people wondered about me. (Interview #25)

Because of both their troubles and their inability to account for them, many said that they often avoided seeing other people. Respondents with difficult to control emotional troubles were particularly concerned that they not be among others if they felt likely to appear out of control. However, they were not always successful in avoiding awkward situations. Two women remembered feeling forced to account for themselves in the following incidents:

> I was often feeling weepy--like I could break down in tears easily. So I wasn't going out so much...I wouldn't want to have to explain...One time I went to my daughter's school for a teacher interview. After five minutes in the school my eyes were watering, I was sneezing and then I was crying. I was very embarrassed so I said I had a cold--I had to say something.... If I was in one of these crying bouts at home and the phone rang, I'd say the same thing. (Interview #11)

> I could usually control the crying when I was at school (teaching). The weepy feeling was often there but I'd manage to hold it in and smile a lot; except for sometimes I would go to the washroom for a few minutes. There was one time though when I got really embarrassed. Some other teachers and myself took the kids for a nature walk through some woods. After about half an hour I just started crying and having trouble breathing. The others didn't know what was going on...I said I must be allergic to something. I didn't know what else to say. (Interview #28)

Another woman succinctly summarized the way in which she coped with others:

> I didn't really have any explanation why I felt so out of it...so I'd put on a front for other people...when I couldn't put on a front, I didn't see anyone...so I was pretty well keeping to myself I guess.
> (Interview #23)

With troubles that were threatening and isolating, the more so as they went unexplained, people typically felt increasingly desperate about their situations. As mentioned at the beginning of the chapter, while seeking a diagnosis and help, eleven of those interviewed became unable to work or attend school for a number of months or years. In three cases, cooperative doctors validated absences as either "general ill health" or "chronic infections". Thus, while still in the dark regarding aetiology and how to remedy problems, these people were able to assume "official" sick roles when they needed to do so. In three other cases, people had been given psychiatric diagnoses. The other five people, having no account of their problems, simply left jobs. Three of these people subsequently resumed working at less demanding jobs that they could handle while continuing to grapple with their problems. In other words, unable to manage their problems and perform adequately in their usual "well" roles, but also unable to assume a sick role, they adapted to lesser capacities by making "downward" adjustments in their well roles. Six people also said that they had felt forced to abandon or markedly alter career goals because of their problems. Feeling desperate about their situations, six respondents said that they had occasionally felt suicidal. In the absence of diagnosis and treatment, others said that with worsening troubles they became increasingly pessimistic and feared dying.

Summary

As evidenced by the discussion and accounts of respondents above, the process of identifying problems and seeking help prior to consolidating an ecological illness interpretation was lengthy and trying; characterized by ambiguity, conflict, losses and sometimes despair. People could neither ignore persistent troubles, nor succeed in clearly making sense of them. Along with the undermining impact of troubles themselves, people typically felt discredited by responses of physicians and others as they sought recognition and help. Such discrediting stood in the way of problem definitions, health identities and role expectations that were compatible with their troubles and with their desires to overcome them.

Chapter 4

THE DIAGNOSIS OF ENVIRONMENTAL HYPERSENSITIVITY

Although some respondents had previously identified certain foods or chemical exposures as problems, it was typically not until the discovery of an environmental hypersensitivity diagnosis that self-doubt and turmoil over the meaning of their experience was relieved. The present chapter discusses how people were led to see a doctor who diagnosed environmental sensitivities, their expectations as they made a first visit, and their response to the diagnosis.

Pathways to an Ecologically-Oriented Physician

In the course of coping with troubles while help-seeking or earlier in their lives, seventeen respondents had either been medically diagnosed as having common allergies, or had diagnosed themselves as sensitive to particular common allergens, foods, drugs or other chemicals. Over half of those interviewed, then, had at some point become personally familiar with the notion of hypersensitivity. Typically though, people had been aware of only one or a few specific troubles being related to a small number of excitants; such as seasonal congestion with pollens, or abdominal discomfort with a particular food. Neither they nor their doctors readily generalized such an interpretation to other substances or other problems that they were experiencing. As noted in the previous chapter, eleven people began to consider that many or all of their problems could be sensitivity-related only as they read books or saw television programs about food and environmental sensitivity. Typically, however, a firm consolidation of a food-environmental illness interpretation ultimately came with such a diagnosis being made by a physician. Of the thirty-two people interviewed, twenty-seven were first tested and diagnosed for sensitivity-related problems by a clinical ecologist, four by other nutrition-oriented physicians, and one by a general practitioner.

As pointed out in the introduction, clinical ecology is a highly controversial specialty within medicine. Official medical bodies have taken the position that its diagnostic and treatment methods are unproven. Allergists particularly have been aggressively opposed to the notion of broadening the concept of adverse reactions beyond that for which their testing methods are designed, namely IgE-mediated immune responses (Bell, 1982). As a consequence of ecologic medicine's controversial status, there are relatively few doctors who either practice ecologic medicine or who would be inclined to refer patients to the few that do. This situation was clearly reflected in the ways in which respondents first came to see doctors who diagnosed their problems as related to multiple sensitivities.

Only six of the thirty-two respondents were referred to clinical ecologists by other physicians. Three of these referrals were by general practitioners, and one other by a doctor working in a clinic specialized in the treatment of "Pre-Menstrual Syndrome". In another case, a referral was made by a Research Rheumatologist at a large city hospital. The one other doctor-originated referral was interesting for the way in which it clearly indicated the marginal medical status of clinical ecology. While in hospital, one of the women who had had multiple psychiatric diagnoses was quietly slipped a note by one of the doctors working the floor. The note included the name of the Human Ecology Foundation and a clinical ecologist.

In seven other cases, people took initiatives to find a clinical ecologist themselves after reading or seeing a television program about food and environmental sensitivity. One woman, for example, contacted a Hamilton television station to ask for further details about clinical ecologists practising in her region. Another woman who had seen a clinical ecologist from the United States on television wrote to this doctor for referral to a local doctor. And yet another woman successfully looked for a clinical ecologist in the yellow pages of the telephone book.

The most frequent sources of referral to an ecologically or nutrition-oriented physician, however, were relatives, friends, or acquaintances. As some people were referred to books describing sensitivity problems they were also given the name of a doctor who had been known to diagnose and treat such problems. Others were simply given a doctor's name or were told about related lay organizations, the Human Ecology Foundation and the Candida Information and Research Foundation. Altogether, sixteen people, or half of those interviewed, first saw a doctor who diagnosed multiple sensitivity problems as a result of some type of lay referral.

Scepticism and Hope

As some respondents first visited a clinical ecologist their hope for an explanation and resolution of problems was tempered by a measure of pessimism born of past discouragements. As one woman said, "There was a little feeling like this was one more doctor in a long line....So I mean, I was hopeful but I was also sceptical at first." (Interview #8). Some respondents were sceptical at first also because their troubles seemed quite different from symptoms that are usually associated with allergy. As one of the men said: "When my sister gave me the book about allergies I thought that allergies as a cause (for chronic neck and back pain) didn't seem plausible. I thought of allergies as sneezing and a runny nose--things like that." (Interview #31). In another couple of cases also, people were sceptical of a medical approach that they had never heard of before and that seemed to be little known generally.

In contrast, a number of others optimistically anticipated finding a long sought answer to the puzzle of their problems. Having previously come to understand some troubles as adverse reactions to particular foods, drugs or other substances, they now anticipated that some of their other problems might be similarly explained. One woman, for example explained:

> When this friend of mine told me about clinical ecology and the doctor in Toronto, I felt right away that it made sense. I had already found out that I reacted badly to some foods, so I was hopeful that he could help sort out if there were other things involved. (Interview #26)

Some people who thought that their problems resembled sensitivity problems described in books or television programs had already experimented on their own with dietary changes. For a few of these people, the results of these experiments gave them confidence that sensitivities constituted part, if not all, of their problems. Others who had simply identified with descriptions of such problems were similarly hopeful that they had found some important clues to their problems.

The Diagnosis: Validation and Relief

As they began seeing a doctor who diagnosed sensitivities, a few of those whose hopes for an answer were mixed with scepticism said that they did not immediately accept the diagnosis. One woman in particular said that after being given an ecological diagnosis it was a year before she accepted its validity. Generally, however, such slow acceptance of the diagnosis was unusual. As they began seeing a doctor who diagnosed sensitivities, most of those interviewed fairly quickly felt that they had finally found an explanation for their problems.

As their problems were diagnosed as sensitivity-related, or shortly thereafter, people described themselves in various ways as having been profoundly relieved and, in some cases, elated. A couple of those interviewed remembered their relief in these ways:

> I was elated...the first time that finally someone says "Yes, I believe you.", and to know that it's not just all in my head.... To be able to put a name to it, you can go back to people with an explanation instead of them just thinking you're a chronic complainer. (Interview #23)

> That night I was excited--very hopeful that I could work things out. It was such a relief just to have a medical name for it

> all...because I'd been afraid sometimes I was losing my mind. (Interview #25)

These statements explicitly indicate the importance and impact of finally obtaining a specific illness label and account for troubles experienced. No longer was the experience of trouble merely a private unspecified reality that was "all in my head" and therefore questionable. Troubles were now situated and objectified in language and medical knowledge. They could be regarded as typical of known, codified problems that are also experienced by others. Other respondents specifically mentioned their relief in feeling that their troubles were recognized and taken seriously by the doctor they saw:

> This was the first doctor I'd seen that seemed to recognize what I was talking about as genuine problems. He wasn't baffled or just dismissing things... the way that he took things seriously,...I felt relieved...and reassured that it wasn't just me. (Interview #16)

> Just the fact that he credited what I said was happening, that he seemed to recognize these things...I felt vindicated that things weren't just in my head. (Interview #15)

> I was delighted that finally someone recognized that I was ill and accepted what I said about getting sick with fumes. (Interview #10)

> When I told him some things that were happening, and then he kept asking for more details,...I was amazed that he wrote it all down, and asked about other things. He asked a lot of details about things and I went on and on--but he took it all seriously and said that he thought he might be able to help me. (Interview #28)

In addition to this last woman quoted, others also mentioned that they were surprised and impressed that the doctors they saw took extensive histories and asked in great detail about their problems. Typically they felt that their concerns were listened to more seriously than they had been with most other doctors. One reason for this may be that in making an initial evaluation, such physicians typically rely more heavily than others upon circumstantial details of symptoms. From both respondents' reports and other published descriptions of ecologic evaluation (Bell, 1982; Randolph and Moss, 1980; Government of Ontario, 1985), it would appear that in the initial interview, ecologically-oriented physicians typically obtain detailed histories and descriptions of complaints in order to identify clues to possible relationships between diet or environmental factors and troubles experienced. Consequently, extensive descriptions of how, when and where various troubles are experienced are frequently not only tolerated but encouraged. As indicated by the quotes above, for many respondents this interested, crediting response to their complaints rekindled or supported notions that they had "real" rather than imagined medical problems. What ultimately made a hypersensitivity diagnosis convincing to many people, however, was their experience with diagnostic testing.

Diagnostic tests used by clinical ecologists include generally used routine laboratory tests and other tests specifically designed to detect possible sensitivity problems. Three of these latter techniques that were referred to most frequently by respondents are called Serial Dilution Titration, Provocation-Neutralization, and "challenge" testing. According to Bell (1982:41-44), both of the first two of these techniques employ dilutions of extracts of substances being tested. Serial dilution titration testing for sensitivity to pollens, dusts and moulds involves evaluation of the skin's "whealing" or swelling response to shallow injections of varying dilutions of extracts. Not only sensitivity but also a treatment or "neutralizing" dilution is determined through evaluation of this whealing response. Provocation-Neutralization testing similarly employs serial dilutions but distinctly involves assessment of the ability of test doses to evoke symptoms rather than simply a whealing response. Test doses are introduced either under the skin by injection or as a drop under the tongue. This method is used not only with natural inhalants but also with foods, chemicals, drugs, hormones and other substances. As with serial dilution titration, the goal of the technique is to identify substances to which the individual is sensitive, and then to determine which dilutions effectively neutralize or relieve the reaction produced. In addition to these and other clinic or laboratory-based tests, people may also be advised to "challenge" test for particular food sensitivities at home. This involves avoiding a particular food for four or five days and then test-eating the food once again. Challenge testing by sniffing may also be recommended for testing tolerance of chemicals in a variety of materials.

As can be gleaned from this brief account, patients and their subjective experience are given a prominent role not only in the initial interview but also in diagnostic testing and determination of treatment. Both Provocation-Neutralization testing and challenge testing depend upon patients' own awareness and judgement of changes in physical and mental-emotional feeling states. As Bell (1982:40-41) has observed:

> CE (clinical ecology) is unusual in the medical world for its emphasis on the active part that patients must play in the successful evaluation and management of their own illnesses, using physicians mainly as guides.

For those interviewed it was precisely this involvement of their own awareness and judgement that sooner or later made an ecological diagnosis irresistibly convincing. In the course of provocative testing procedures, numerous long-familiar troubling sensations were systematically provoked and then often neutralized. That various familiar complaints could be thus deliberately produced by dilutions of foods and other everyday exposures was for many an amazing revelation. As a number of respondents recounted their experience with such testing, they seemed to re-live the eye-opening impact that it had upon them:

> It was incredible! It was so clear that right then and there different things they gave me reproduced things I'd been experiencing for years. And then they'd neutralize the reaction....Over the two days of testing I went through all the familiar symptoms: the muscle weakness in my arms, pain in my hands, creepy-crawly feelings in my skin, pain in my chest, feeling spacy and unable to read or think straight, feeling anxious, and feeling irritable. It was unbelievable. I felt, I'd finally found the answer to all that chaos. (Interview #25)

> The provocative testing was extremely revealing. I could tie in all these symptoms I'd been having to things they tested for. For me it was mainly foods and inhalants. They don't tell you during testing, but I found I was getting the headaches with moulds, fungus and yeasts. (And I'd never tested positive for these things in allergy testing before.) With weeds and ragweed I was getting the usual sneezing and stuffiness, but with grass I was feeling very slowed down and sleepy. With wheat I was groggy and spaced out and then almost in tears....I knew after the testing that I was on the right track. (Interview #26)

As these accounts suggest, the immediacy, clarity and familiarity of various sensations experienced during the testing made the identification of problem substances very convincing. Respondents were similarly convinced of problems with certain foods that they challenge-tested on their own at home.

New Attitudes to Familiar Problems

In addition to providing people with positive evidence of sensitivity problems, such testing and the diagnosis generally, had a profound impact on some respondents' perceptions and interpretation of their experience. As pointed out in the previous chapter, many of those for whom mental-emotional troubles were prominent had puzzled and struggled with the meaning of their problems. Particularly in the absence of a medical diagnosis, people questioned whether ongoing problems with anxiety or depression did not indicate deep-rooted psychological problems. For these people, provocation and challenge testing dramatically transformed threats to the integrity of self into situation-specific aberrations of their experience. Rather than being manifestations of a fundamentally disordered self, extreme and inscrutable mental-emotional states were now revealed to be biochemical, nervous system effects of adverse reactions. With the testing, then, respondents' interpretations of such troubles decidedly shifted from a social to a natural framework (Goffman, 1974). It now seemed clear that such problems had not been due to personal or moral failures of will or self-control but rather were simply happening to them. This change in how people viewed their problems constituted a fundamental questioning of usual, everyday assumptions about mental-emotional experience. Rather than associating mood changes or specific emotions with personality, relations with others or other such influences, it now became possible that mental-emotional changes were mere artifacts of what people had eaten, the soap they used, the clothes they wore, or the buildings in which they lived or worked. Those who talked about the impact of testing in this respect mentioned their sense of relief from self-blaming:

> With the testing I thought, "Wow!". All these things were happening with different things they gave me. I felt the depression, the weepy feeling in my chest. And a couple of times I couldn't hold it and was crying during the testing. Everything made sense right then--it was these reactions. I felt like this was the best thing that's happened to me--I felt lucky. It was a great relief knowing that it wasn't in my head. (Interview #28)

> It was obvious that these reactions were causing the anxiety, the pain and the fatigue. So it was proof that it wasn't just psychological, that I wasn't "nuts". I felt like a weight had lifted-I knew it wasn't self-induced. I could take that pressure off myself. (Interview #31)

> I could feel now that the depression was directly related to these foods and chemicals. Realizing that it wasn't psychological,...I felt relieved not to have to deal with a mental explanation for it. (Interview #19)

As is evident in these people's statements, a hypersensitivity interpretation of various mental-emotional troubles rendered them less a threat, less daunting. A similar kind of relief was also experienced by respondents who, having no medical diagnosis, had feared becoming permanently disabled or that they might have a difficult to diagnose, life-threatening illness. Understanding that various discomforts and losses of capacity were related to adverse reactions reduced their gravity:

> I was afraid I was losing my ability to do things--I'd thought sometimes that I must have something really serious and I was afraid sometimes that I was dying...but then feeling these problems come and go and change with the drops,...I knew it was these reactions and I was very relieved. I felt that now I had a handle on what was going on and could do something about it.
> (Interview #25)

> Before that I felt cornered without anything to go on and was getting worse. I was reluctant to accept that I would be disabled but that's how it was going. So when I began to see that by avoiding some of these things I could be better, it was a great lift. I felt much better about myself...I felt like finally I had some control of things. (Interview #9)

As these women also indicated, in addition to alleviating gloomy forebodings, the diagnosis also gave people a sense that they now had a better hold on dealing with their troubles. Learning that certain difficulties were brought on by particular exposures was practical information useful to managing problems. Others similarly said that with the diagnosis, they felt a new sense of control:

> I'd always felt if I could find the root cause, I could work things out. Knowing that it was a physical problem that I could control by diet, I thought, finally, I could do something about it.
> (Interview #22)

> I had been afraid of losing my job...so it was a great relief to find out something

> that I could do about it. Seeing how these reactions could affect you, I had some sense of control over things.
> (Interview #21)

The hypersensitivity diagnosis, then, was an answer to a number of longstanding uncertainties surrounding people's difficulties. Ill-defined troubles were now validated as genuine, known illness problems. As people settled upon this interpretation, they were typically relieved to have found a medical diagnosis that was both consistent with their many and varied troubles and that suggested means of managing them. After lengthy help-seeking efforts, much of their relief was also that they now had an explanation and a vocabulary with which to make sense of troubles. Moreover, the explanation and vocabulary were medical and emphasized impersonal physical factors. Although clinical ecologists espouse a "holistic" approach concerned with the "total load" of stressors in illness, in practice many are inclined to de-emphasize psychological or social aetiological factors and interventions in favour of food, chemical and other physical factors (Bell, 1982:55-56). While this type of modern, impersonal concept of organic disease has been criticized as reification (Taussig, 1980), it would appear from respondents' comments that they largely welcomed such a conceptualization of their problems. These findings accord with those of Stewart and Sullivan (1982) with respect to the diagnosis of multiple sclerosis and of Bury

(1982) with respect to rheumatoid arthritis. As Bury (1982:179) has observed:

> Medical conceptions of chronic organic disease and its causation are not regarded as illegitimate 'reifications' from a lay point of view. They provide an objective fixed point on a terrain of uncertainty.

As evidenced by respondents' comments here, the hypersensitivity diagnosis both resolved uncertainty and rendered troubles less a threat in some respects. Viewed as problems of the body rather than self, even mental-emotional problems could now be seen as less a threat to conceptions of self as socially competent and, above all, sane.

An Uncertain Outlook

As much as respondents were deeply relieved to obtain a hypersensitivity diagnosis most respondents soon realized that controlling their symptoms through diet and environmental avoidance could be a complicated, long term management challenge--one that would affect what they could eat and drink, and where and how they could circulate, work and live. Consequently, relief was soon followed by a new uneasiness. As Bury (1982:173) has noted with regard to chronic illness generally, "... a strict separation of disease and self...is precarious....(An) uneasy balance is struck between seeing the condition as an outside force and yet feeling its invasion of all aspects of life." Most respondents found that they were reacting badly to a great many foods, chemicals and inhalants and soon came to feel that their problems might not be easily and straightforwardly resolved. One of the men interviewed referred to the complexity of his problems and of measures taken to improve his health:

> It was a great relief to understand what was going on. But at first especially, the management problems were monumental. I found that almost anything I ate seemed to make me worse. And the effects of reactions would last for a couple days, so it was hard to identify which foods were really a problem and how to deal with it....It wasn't just a matter of the testing telling you what was a problem and then that's it. Because things would shift and change as I began avoiding things. Also, with the testing I was reacting to some degree with almost all foods and chemicals they tested....There were so few foods I could eat and so many things to be careful of. I had great problems finding a water that I could use....I replaced all my synthetic clothes and bought an air purifier. You did what you knew to do, but there was a feeling of helplessness to make quick improvements. It soon became obvious that there was no quick fix....You knew that this was something you could be coping with for a long time. It was kind of scary--I wondered sometimes, "Can I get better?" or "How much better can I get?" I wondered how long it might take to get things better under control so that I could live more normally. (Interview #31)

As is clear from this man's statement, while the hypersensitivity diagnosis resolved uncertainties regarding the identification of troubles, other questions took their place. Like the man just quoted, as other respondents took remedial measures, they also wondered about the dimensions of their sensitivity problems and possible implications for their lives:

> At first I thought, "Okay, a few months of being careful with things and getting this Candida problem under control, and then I'll be back to normal." But then after a few weeks I realized that things weren't improving all that fast--I realized that dealing with this was a long term commitment....I hated having to be so fussy about what I ate and always thinking about details with foods, cleaners, materials and things in my apartment; or where I could go without being worse,...sometimes I was scared that I might always be that restricted and that I might not be able to continue working....I wondered sometimes how much better I could get.
> (Interview #12)

Other respondents also began to feel that both their problems and the need to manage them would be ongoing. They were uncertain, however, as to how much they might improve and to what extent both symptoms and management would continue to intrude on valued activities, roles and relationships.

Summary

The diagnosis of multiple sensitivities brought people a profound sense of relief. Uncertainties regarding how to define and respond to their problems seemed largely resolved. Efforts to remedy and manage problems, to assume some variant of a sick role, were now guided and sanctioned by a medical diagnosis. For these who had previously wondered if they did not have deep-seated personal flaws of some kind, this unequivocal adoption of a medical interpretation prompted most to turn away from self-absorbing efforts to analyze personal inadequacies, and towards diet and environmental control measures. As people began such attempts to remedy their problems, however, they faced new uncertainties. They wondered to what extent remedial measures might restore their capacities for previous "well" roles, or whether they would have to come to terms with some type of ongoing "impaired" role (Gordon, 1966).

With this uncertain outlook, people typically became preoccupied with finding information and experimenting with diet and environmental changes. Important to their attempts to control symptoms, improve their health, and "normalize" (Strauss, 1975) their lives as much as possible, were the responses of family members and others. The next chapter turns to a discussion of people's experience with the management of sensitivity problems, including the extent to which others supported respondents' adoption of a hypersensitivity diagnosis and the remedial/management measures that they wished to take.

Chapter 5

LIVING WITH SENSITIVITIES

The environmental hypersensitivity diagnosis clearly defined respondents' troubles as health problems and brought with it a number of newly-defined treatment and management strategies. The present chapter discusses respondents' experience in living with and managing sensitivity problems. It first examines the extent to which the hypersensitivity diagnosis served to promote consensus among family members, employers and others that respondents' troubles were indeed health problems. As discussed in Chapter One, medical diagnoses are normally regarded as authoritative legitimation of illness claims and a foundation for negotiations of understandings, allowances and cooperation associated with some type of sick role (Parsons, 1951; Freidson, 1970; Telles and Pollack, 1981). In connection with this issue, the chapter discusses the extent to which respondents were able to negotiate cooperation and altered role expectations important to managing their health problems, both informally with family members and others in everyday social situations, and "officially" with employers, insurance companies or social assistance agencies. The chapter also examines other implications of having and managing sensitivity problems: the personal and social consequences of having to avoid or minimize problem exposures; and whether and in what way respondents may have experienced sensitivity problems as stigmatizing.

Negotiating an Informal Sick Role: Responses of Family Members to the Hypersensitivity Diagnosis

As respondents became convinced that their problems were sensitivity-related, they were typically concerned to have family members and others close to them understand and accept the diagnosis. Particularly in cases in which they felt viewed by others as simply not making an effort, too prone to complaining or as psychologically troubled, they wanted to change such discrediting perceptions. As they now wished to view their troubles as non-wilful, body-environmental problems rather than personal flaws of some kind, they were concerned to have others change identity-spoiling views of their problems to the less morally charged medical definition.

Along with concerns with repairing identity, however, people also had practical needs for cooperation and support with treatment/management measures. In addition to personal diet changes, remedial measures also typically included environmental changes that would have a significant impact on others. For example, several respondents said that because of sensitivity to petroleum products they found it necessary to convert from oil or gas heating to electric heating, or to add air cleaning equipment to their existing furnace. A number of people also said that they needed to buy water filtration equipment. For many, the concern with exposure to sources of chemical outgassing, dust and mould necessitated changes in carpeting, furnishings, clothing, and cleaning materials and practices. People's concerns also extended to their own and others' personal habits: smoking in the home; the use of certain soaps, shampoos, deodorants or perfumes; or the use of paints or glues. Given the disruptiveness and financial cost of efforts to reduce symptom-provoking exposures, it was particularly important that family members accept that the hypersensitivity diagnosis was valid and that such measures were necessary.

Fifteen respondents said that family members were quite readily accepting and supportive following the diagnosis. In most of these cases, family members had previously shared respondents' concerns that "something was wrong". In some cases, like respondents themselves, they were previously aware that the person had considerable allergy or other sensitivity problems, and they shared the hope of finding effective remedies. Thus, the diagnosis was plausible and they were willing to go to some lengths to cooperate in remedial measures. In the cases of another fifteen people, however, family members either continued to deny the existence of a problem or were sceptical of the hypersensitivity diagnosis. (In another two cases, respondents were living on their own with no family members nearby.) Some women whose husbands had not previously accepted that their wives had significant health problems said that their husbands also did not now accept the notion that their emotional "ups and downs" could be caused by sensitivities. One of these women felt that her husband's scepticism was largely due to the marginal medical status of clinical ecology:

> He found the whole thing way out, and questioned why we should believe someone who is so off the beaten track of conventional medicine. Just the name "clinical ecologist" threw him off. If it had been a regular allergist I'm sure he wouldn't have argued with it.
> (Interview #26)

This woman also said that her husband questioned the diagnosis particularly as he was irritated with her difficulty in eating out in restaurants or at social functions related to his work. He did not accept the necessity of allowing for food-related problems. Thus, in this situation, the disruptiveness of diet management measures combined with the questionable legitimacy of the hypersensitivity diagnosis to create conflict in the negotiation of "sick role" considerations. This lack of consensus regarding the validity of her troubles and of measures to manage them became an ongoing source of antagonism in her marriage. Another woman whose husband similarly did not see her as having significant health problems, also said that he was sceptical of the diagnosis and concerned with the disruptiveness and cost of management measures. She felt that her husband's refusal to agree to certain alterations in their home prevented improvement in her health. Their marriage had deteriorated to the point that she wanted to leave her husband:

> I can't get any cooperation. He says that Dr.___ is just a quack and that he's ruined our marriage; that all my attention goes to worrying about what I'm eating or wanting to make changes around here, and not to him; and also that the testing and those foods I get are a financial drain. He refuses to consider getting rid of the carpet or doing anything about the heating system. He says if this testing's not covered by OHIP or other health plans, then it must be quackery. The thing is, he still thinks I'm just exaggerating things, that it's in my head, and his family's the same. His mother thinks it's "nerves". Our marriage has gotten to the point that I've wanted to leave, but I feel trapped right now. I really don't feel well enough that I could go back working full time to support myself. (Interview #24)

In other cases also, family relationships were either strained or destroyed by conflict over the legitimacy of the hypersensitivity diagnosis and related treatment/management measures. One woman said that such conflict contributed to her being divorced. Another woman said that an aunt drew on her authority as a nurse to convince other extended family members that the diagnosis was nonsense. As a consequence, friction developed amongst several family members over the issue. In yet another case, a sceptical husband apparently asked the family's general practitioner for an opinion of clinical ecology and, specifically, the doctor who diagnosed his wife. After being advised that the clinical ecologist was a "quack", he became firmly opposed to her seeing the doctor any further. The woman said that because of her husband's hostility to the idea, she eventually began to conceal the fact that she was continuing to visit the doctor.

Some respondents attempted to counter others' scepticism by sharing information about clinical ecology and complex hypersensitivity problems. One woman, for example, said that at one point she very deliberately gathered her family together to explain the diagnosis, how her problems affected her, and the treatment/management measures she was taking. She described this attempt to influence her family's understanding this way:

> I had my parents, my brother and sister-in-law, my aunt and my cousin together and went through the whole thing...Well, the reaction was flat--no questions, no comments, nothing. So when I asked them if they now had a better understanding, they were evasive, but then eventually seemed to say that my being immersed in all this didn't seem like a very wholesome preoccupation. So in the end, instead of understanding what I was dealing with, my father and my brother and sister-in-law especially, felt even more that I was too preoccupied with my health. My brother particularly was agitated and hostile. At other times, whenever I said anything about

> it, he bristled. One time he told me, "You don't think well now, your judgement is off". (Interview #17)

These instances of respondents experiencing continued tension and conflict over the interpretation of their troubles, even after having them medically diagnosed, clearly indicate the limited social currency of environmental hypersensitivity as a legitimate illness. Rather than resolving definitional conflict and allowing for sick role considerations to be made, the hypersensitivity diagnosis and remedial measures associated with it became a new focus of conflict. Thus, despite obtaining a medical diagnosis, discrediting, identity-spoiling interpretations of complaints by family members continued to play a part in several people's experience of their problems. In some cases, family members gradually became more accepting of the hypersensitivity interpretation as respondents' troubles improved. It would seem that improvements made the diagnosis and remedial measures appear more credible. Also, however, for several respondents, improvements allowed an easing of stringent management measures that interfered with or prevented normal routines with others. Some people said that as their problems became less demanding of special accommodation or adjustment from others, then understanding and acceptance became less an issue.

Negotiating an "Official" Sick Role: Medical and Institutional Responses

The limited medical legitimacy of environmental hypersensitivity was also confronted by some respondents in the course of further contacts with doctors. In various ways, other doctors that people consulted following their diagnosis indicated that the sensitivity diagnosis had little credibility. For example, one woman who was seeing a gynecologist for a check-up said:

> During the interview, I mentioned that I'd been to Dr.__, and that I was getting treatment for Candida. She got very sarcastic and said, "Oh, and I suppose he's put you on a protein diet and given you lots of vitamins and whatnot." After that she was really irritated and seemed to want to be rid of me. (Interview #13)

Another woman who told her general practitioner of her success in finding an understanding of her problems remembered the following:

> I told him about the sensitivities with foods and chemicals and about treating the yeast problem and that I thought I finally had a better handle on what was going on. Then he said, "You're such an intelligent person, how can you believe that? You've got to accept that you're chronically depressed." I was annoyed so I asked when I ever came in looking depressed. Then he said, "Well, you haven't; but it's not normal for anyone to have so many symptoms." (Interview #17)

For several respondents, the marginal medical status of the diagnosis indicated by these accounts, did not only have consequences for the negotiation of informal sick role considerations. It also affected access to formal sick role considerations, such as financial benefits normally due individuals with chronic illness. Eight out of ten people whose doctors cited hypersensitivity problems as a basis for applications for disability benefits or income tax deductions, were refused benefits. Although a few of these people were ultimately granted certain benefits, it was only after a number of appeals or by obtaining another diagnosis that was considered acceptable. In attending medical assessments arranged by insurance companies or government assistance agencies, respondents typically felt that the hypersensitivity diagnosis they had previously obtained was given little serious consideration. It was often as a result of negative findings in such assessments that claims for disability benefits were either denied entirely or granted for a limited period only on a psychiatric basis. In one of these cases, a woman had left her job because of her problems before obtaining the hypersensitivity diagnosis. Once she was diagnosed and "had a name for it", she decided that she might now apply for Canada Pension Plan disability benefits. Following is her account of her efforts to obtain benefits:

> My application was refused first because they judged that my symptoms should not prevent me from working--that they weren't "prolonged and severe". So I appealed and they refused again, saying that there shouldn't be any reason why I couldn't work in an environment free of chemical exposures and allergens. So they didn't

> accept that I was sick with the normal low levels you have in any office. Then I appealed again and included a lot of information from the Human Ecology Foundation and from the Thompson committee report. It had said that the diagnosis should be considered valid. So then a representative of CPP told me that the Thompson report was an Ontario, provincial report and it wasn't accepted by the federal government. They required that I see a doctor who is head of allergy at a hospital in Toronto. When I saw this allergist, he interviewed me about what was going on and then did some of the usual allergy skin tests. These were negative and so he said I was not allergic to anything and never had been. After that, it (the application) was refused again. Eventually they had a lay review committee review my applications and this committee said I should be granted the benefits. But it didn't end there. CPP appealed this decision saying the weight of medical evidence was against the decision. I waited and waited, and then had to go to court in London about it. When I got there, the CPP officials didn't even show up, so they left me with the benefits. It seemed like they just wanted to put me through the wringer on the whole thing.
> (Interview #23)

In his report to the Canada Pension Plan, the allergist to whom this woman was sent during this process clearly indicated his hostility to the ecological diagnosis. In a photocopy of his report, provided by the woman, he wrote:

> This patient presents with a long list of symptoms,...She is presently seeing a clinical ecologist who has tested her with the usual unscientific procedures used by this group of alternative physicians. I am quite sure that her food sensitivities are either imaginary, based on other than allergic factors, probably the result of suggestion by previous physicians of

> alternative medicine...Relative to her concept of environmental hypersensitivity: I doubt that there is any physical or immunological basis to any of these sensitivities. There is no doubt that she perceived them as being offensive and somatosizes, so that she reacts with a physical complaint, as well as psychological complaint. (Interview #23)

According to another respondent who has been active in the lay organization, the Human Ecology Foundation, the allergist whose report is quoted above is regularly consulted by a number of government agencies and insurance companies to assess disability claims based on sensitivity problems. In addition to the woman just quoted, two other people interviewed for this study had also been refused disability benefits on the basis of this doctor's assessments. One of these assessments was for an insurance company and the other was for the Workman's Compensation Board. In the latter case, the woman had applied to Workman's Compensation after apparently becoming disabled by fresh paint and pesticide spraying in the school in which she was teaching. When she was sent to the allergy specialist, she reacted positively to skin tests. Despite this, however, the woman said that the doctor did not endorse a sensitivity diagnosis:

> During the testing, I not only reacted on my skin, but I began coughing uncontrollably. It went on for about ten minutes before I could stop....Then, in the interview after the testing, Dr.___ sat back and said, "This is very interesting. You've given the best demonstration of hysterical behaviour that

> I have ever seen. I think you do have some allergy, but your reaction is hysterical." He said I was just too nervous,...that I just needed to have more fun in my life, and that I should avoid seeing clinical ecologists--that their ideas were probably partially the source of my problems. I later saw a copy of his report. It said that because of my hysterical reactions, it had not been possible to determine conclusively whether I was sensitive to various things; and that my reaction in his office was likely partly the result of notions suggested to me by clinical ecologists. (Interview #32)

The third woman who had been examined by this allergy specialist was similarly assessed as having either imaginary or psychosomatic problems. These respondents' experiences indicate the way in which medical opposition to the concept of environmental hypersensitivity prevented or delayed access to formal sick role benefits. With other doctors to whom they were referred by insurance companies or government agencies, other respondents had similar difficulties in obtaining support for an "official" hypersensitivity sick role. In terms used by Freidson (1970), whether or not hypersensitivity is a bio-physical possibility for being sick, it is clearly not a widely sanctioned medical or social possibility for being sick.

As a consequence of the marginal status of their diagnosis several respondents felt that they were handicapped in their efforts to improve their health and lead more normal lives. In addition to the difficulties of negotiating sick role considerations described above, respondents also found that government and private insurance schemes would not cover ecological testing. In many cases, people with private extended health insurance found that such plans also refused reimbursement for costs of neutralizing treatments. Due to expenses involved, some people felt prevented from making necessary modifications in their homes, or from regularly obtaining foods free of chemical residues. Many respondents were bitter that, while health insurance plans covered many years of what they considered to be unhelpful or harmful tests, drugs, and surgical treatments, they could now obtain little or no support in taking measures that they and their present doctors considered important to their health.

Living with Sensitivities: Long-term Management and the Hypersensitivity Identity

With the remedial measures that respondents did take, there was great variation in the extent to which they felt that they had improved their health. When interviewed, ten people said that their problems had improved only slightly or not at all. Seven of these people had been quite sick, and were still restricted by their sensitivities and their health to the point that they could not work. They were quite isolated, able to circulate very little outside their homes. The other three people who experienced little improvement were somewhat less restricted and isolated (two of them were working part-time), but continued to be strongly affected by many everyday exposures. This was true also of many of those who said that they had experienced significant improvements in their health. Four of these people had previously left jobs or school because of their health and despite improvements, still felt incapable of returning to work. Others who had experienced significant improvements had achieved varying degrees of success in increasing their ability to circulate freely and function effectively. Five people said that sensitivity problems were no longer a major aspect of their everyday lives. For most respondents, however, taking measures to minimize and cope with symptoms, and to improve their health generally, were continuing, sometimes preoccupying, considerations. Previous uncertainties regarding the long term course of their problems, described in Chapter Four, had gradually been answered through months or years of coping with them. For most people, being hypersensitive was an abiding aspect of self that, to a greater or lesser degree, played a role in shaping both day to day decisions and activities, and longer term plans.

The day to day management of hypersensitivity not only entailed avoiding or minimizing problematic exposures, but also the social management of this aspect of self: whether generally to disclose or not disclose one's hypersensitivity to others; and how to best explain or otherwise handle socially awkward or disruptive symptoms, or measures taken to avoid symptoms. As was noted in chapter three, before obtaining the hypersensitivity diagnosis, many respondents did not know how to explain their troubles to others. They often either did not know what to think of their problems themselves, or they felt that they were psychologically troubled. In either case, they frequently felt at a loss to give explanations. The inability to adequately share their experience left them feeling isolated and unable to give face-saving accounts when troubles were obvious. For several respondents, part of the relief of diagnosis was that they felt they would have an adequate and socially acceptable way of explaining their problems to others. As one woman put it: "I finally felt like I could justify things; that I could tell people, 'It's just a reaction to this or that', and not have them thinking I was nuts." (Interview #28)

Several respondents said that, for a period of time following diagnosis, they were very open in explaining their sensitivity problems, not only to family members, but also to others. In addition to socially "justifying" functional lapses or odd behaviour resulting from reactions, in some instances respondents more generally simply wanted family members and close friends to understand and support what had become an important part of themselves and their lives. This type of sharing of their experience appears to have been somewhat similar to what Schneider and Conrad (1983) have termed "therapeutic telling" in their discussion of people with epilepsy. By sharing their experience with others, and hopefully having it understood and supported, people might feel less set apart and isolated with their problems. A few respondents said that they talked about their hypersensitivity problems also because they wanted to educate others. They wanted to inform others who might also be affected by undiagnosed food and chemical sensitivities, or increase others' awareness of hazards such as the use of pesticides or strong chemical cleaners.

Whether simply sharing their experience or trying to educate others, most of those respondents who said they were initially very open about their sensitivity problems indicated that they subsequently became less so. They felt that others often reacted with scepticism or misunderstanding. Three women recalled the following experiences of talking about their sensitivity problems:

> I've told some friends about it and they're sympathetic. But even with a couple of my friends--you say you have reactions or sensitivities, and they think it's just some allergy and think "Oh-that's nothing". They don't understand the scope of it and how much it affects everything. So they're kind of suspicious that you think it's so important. Other times, it was obvious people were sceptical....I went through a phase where I wanted to educate everyone, because a lot more people are

> affected by these things than realize it. But now I usually don't say much unless I know somebody is really interested. Most people don't want to hear all that much about it. (Interview #13)

> I sometimes felt people thought that this is just some kind of health fad. They tend to think you're off the deep end with it if you say too much about it, so I don't talk so much about it now. (Interview #11)

> When I understood what was going on, I could finally explain to others why I was having so much trouble....And anyway there's a need to make people aware that this is a real illness--that it's more than just a few allergies....A couple of friends were quite receptive and I told them all about it; but with some people, you know they're sceptical, or they seemed to sort of dismiss it, like it was just allergy. At this club that I belong to, I wanted to explain things to them, because I felt guilty not being more involved and helping out. But people didn't understand. They just seemed to get the impression that you never want to go anywhere--that you're no fun; like I was exaggerating it. So then I decided to shut up about it, and let them think whatever. (Interview #23)

Like the last woman quoted above, other respondents also said that, despite attempting to excuse themselves by explaining the extent to which sensitivities affected them, they felt regarded by others as anti-social, obsessive, or caught up in a health fad. In other words, like some family members' reactions described earlier, in some cases, friends and acquaintances seemed to be sceptical of hypersensitivity as a medical account. Another woman who had similarly tried to explain her reduced contacts with others also talked about feeling regarded by others as anti-social rather than challenged by health problems:

> Now that I was able to explain what was happening with me, some of my friends found it all a bit much. Parties or get togethers are a real problem for me because I can't drink or eat a lot of regular foods or stand the smoke....But it just isn't plausible to a lot of people that you can be so affected by things. So they think I'm into some kind of extreme moral trip, that I'm anti-social or a party-pooper....I know from things that have gotten back to me that some people at work just think I'm too anxious and turned inward now, and they say things like, "She needs to lighten up and be more active". Well hell, I'd love to be more active--I hate being so eccentric all the time; being so concerned with details about foods and where you can and can't go; but I don't see much choice in it at this point. I'm just able to keep working. That would go too If I'm not careful about things. I have a couple of friends who understand and accept that this is something I have to deal with....But generally now, I try to manage things without saying any more than I have to about it. (Interview #10)

As indicated by the accounts quoted above, respondents felt themselves discredited or stigmatized as a consequence of others' scepticism regarding their sensitivities. Rather than feeling their identity spoiled primarily by their illness problems themselves, they felt discredited by others' failure or refusal to recognize their illness problems.

Several people felt similarly discredited in situations in which others were sceptical of the necessity of treatment or management measures. The most frequently mentioned examples of such situations were social occasions involving food or drinks. Some respondents had become flexible enough with their diets that they could manage such situations merely by selecting carefully and saying nothing. Also, in some cases, people successfully explained their refusal of one or two items by referring to a food allergy. Others, however, had to be highly selective or managed by bringing their own food. Two women recalled the following about their efforts to explain their diet management measures:

> I play Bridge with a group of women, and we always have a lot of things to eat. I would have licorice and nuts and wine; but I was always miserable the next day. Once I knew that I couldn't eat all that stuff I'd just have tea. The whole thing is really a routine and like a ritual though, and some of the others clearly felt uncomfortable with this. So I explained it to them that I found out that I'm quite sick with certain things and can't eat a number of things. A couple of them asked me a couple of questions, but I could tell from the response and then some little comments at other times after that, that they thought I was just on some health kick. They didn't really accept it and they'd make little comments now and then. I feel uncomfortable with it, but there's not much more I can say. (Interview #11)

> I still have daily reactions with foods, and am pretty restricted. So I take serums to control things, and I have to take my own food if I'm out somewhere. The hardest thing socially is trying to explain it. When I do, people seem sceptical. I often feel like I'm being challenged about it, like I'm being called upon to justify these measures....One time at Christmas, I took some bicarbonate after eating because I could feel problems coming on and my

> sister-in-law said, "C'mon, you just ate too much. You don't really need all that stuff." People wouldn't say things like that to someone with diabetes or something. (Interview #8)

As indicated by these accounts, adaptive measures that were socially awkward in any case, became more so as others viewed reasons for them as suspect, and, in some instances, challenged them. Partly because of this, several respondents said that they carefully considered whether to become involved in certain social events or activities. They considered how important it was to them or someone close to them; whether or how long they could be involved without developing symptoms; who might be there and how people might react to adaptive measures. A few respondents said that they sometimes weighed the importance or pleasure of involving themselves in a "normal" way, against having to accept a day or two of being quite sick as a consequence. In this regard, one woman said:

> If it's something special and I think I won't get too bad, I'll just go along with things and take the consequences. You pay for it later, but sometimes it's worth it....Other times, though, if it's not worth getting sick for, or if I think it's going to be a hassle if I take my own food, then I just don't go. (Interview #25)

Respondents' comments above indicate that environmental hypersensitivity is a stigmatized illness. Compared with the ways in which other illnesses are commonly stigmatizing, however, the stigma most often felt by respondents was distinctive. Some illnesses are stigmatizing, at least in part, because the sick person is viewed as having been wholly or partially responsible for becoming sick. Some examples of this type of illness stigma are venereal disease or, more recently, AIDS. Illnesses may otherwise be stigmatizing because the illness carries other, particularly negative, identity-spoiling associations. By virtue of their permanence, almost all chronic illnesses may be stigmatizing to some degree. In Scambler's (1984:208) terms, such conditions carry connotations of "ontological deficiency". In other words, insofar as they are judged as essentially less than normal, chronically ill people violate norms of identity or being. Highly stigmatizing illnesses are those that are viewed as particularly frightening or revolting in some way; for example, epilepsy or leprosy. Such illnesses commonly have a long history of stigmatizing associations.

In contrast to illnesses such as these, however, environmental hypersensitivity has a short, relatively unknown history. While it may have an undesirability common to any persistent illness problem, it does not carry the moral freight that epilepsy or leprosy do. Compared to the ways in which illnesses are usually stigmatized, the discrediting responses referred to in people's accounts above were distinctive. They do not seem to have been responses primarily to the condition of being hypersensitive, or as a result of seeing respondents as blameworthy for becoming hypersensitive. Rather, respondents felt discredited for the implausibility and lack of legitimacy associated with this interpretation of their troubles. Whereas Freidson (1970) has suggested that some illnesses are socially illegitimate because they are stigmatized (in the usual senses outlined above), it would appear that environmental hypersensitivity is stigmatizing primarily because it is medically illegitimate.

In addition, however, apart from the question of medical legitimacy, it is possible that the concept of multiple food and chemical sensitivities is simply implausible to many in that it challenges some of the most taken-for-granted assumptions of order in people's lives: that common foods eaten by most people are not only safe, but healthy; and that, while the environment contains certain threats such as bacteria, viruses, or, in some places, toxic exposures, it is not generally threatening. It may be that the questioning of such assumptions, represented by people's concerns with sensitivities, was more provocative than the socially awkward management measures that some of them occasionally took.

Summary

As evidenced by the accounts above, many respondents found that to manage hypersensitivities was to manage health problems that are generally considered to be highly questionable. Respondents claiming to have multiple sensitivities were variously challenged by acquaintances, family members, doctors, insurance companies and others as they sought to adapt to limitations and improve their health. While, before diagnosis, people frequently lacked a medically sanctioned definition of troubles that supported their complaints, after diagnosis, the hypersensitivity diagnosis itself, contributed to continuing discrediting of their concerns. Consequently, following diagnosis, many people continued to face opposition in the negotiation of informal or formal sick role considerations. As they managed their problems, the stigma that people felt would seem to have been primarily due to the implausibility and illegitimacy of their problems rather than the problems themselves.

CONCLUSION

Ecological illness or environmental hypersensitivity is a controversial diagnostic category within medicine. The diversity of frequently vague "physical" and "mental-emotional" troubles which some people consider to be symptoms of environmental illness, are frequently not regarded as significant physical health problems by most physicians. Given this situation, this study of the experience of ecological illness has been guided by an interest in the ways in which people make sense of and cope with highly ambiguous and medically controversial troubles. The study has focused on the interpretive frameworks and meanings that become applied to people's troubles at various points in their experience; by those affected, by significant others, and by physicians from whom they seek help. In connection with this focus, the analysis has been concerned with the nature of various parties' definitions of trouble-related identity, and the consequences of such definitions for people's experience of coping with their problems.

While interpretations of troubles by respondents themselves varied as they coped with them, most of those interviewed sought help for what they considered to be primarily physical health problems of some kind. They sought a diagnosis that was consistent with their experience of problems and that suggested means of effectively treating them. In seeking a diagnosis, however, they also sought to have their experiences of trouble validated as "real"; to have them medically legitimated. An important social psychological and practical issue for people making illness claims is the extent to which such claims are credited and, thereby, legitimated by others.

For the people whose illness experience has been examined here, the related tasks of making medical sense of non-specific troubles and of having illness claims medically legitimated were frequently felt to be as challenging as coping with the functional impacts of troubles themselves. Whereas respondents defined themselves as sick, and, in many cases, felt pushed by their debility to assume some variant of a sick role, physicians, and sometimes significant others also, tended to define them as psychologically troubled or simply "not sick". This disjunction and tension between people's subjective distress and self-identity as sick, and the frequently discrediting ways in which their troubles were interpreted by others, characterized the experience of nearly all respondents to some degree. For many, this contradiction between self and social identity relative to their complaints persisted after they were medically diagnosed as environmentally hypersensitive. The diagnosis of hypersensitivity resolved people's cognitive and practical needs to make medical sense of their problems, but did not, in many cases, resolve their social (and also practical) need to have troubles authoritatively legitimated. Because the diagnosis of ecological illness is commonly regarded with scepticism, both within medicine and generally, it often contributed to further discrediting of people and their problems.

✓

As before the diagnosis, the continuing problem of legitimation had practical and financial consequences in that respondents were often denied compensations and benefits normally available to people with chronic illness. As before the diagnosis also, the continuing problem of legitimation had consequences for identity and for social aspects of living with hypersensitivity problems. In many cases, respondents continued to feel set apart and stigmatized by the experience of illness problems of which others tended to be sceptical.

finance

In conclusion, it would appear that the limited medical and social currency of ecological illness has a number of distinctive consequences for the illness careers of many who experience ecological health problems. The most significant of these can be summarized as follows:

1. An extremely small number of physicians sympathetic to the concept of environmental hypersensitivity, or capable of making such a diagnosis.
2. Related to (1), long and distressing help-seeking efforts, frequently involving both informal and formal application of discrediting labels; the continued experience of discrediting responses following the diagnosis of hypersensitivity.
3. Related to (2), the experience of secondary personal, family and social distress due to definitional ambiguities and conflicts.
4. Related to (1) and (2), financial hardships due to unrecognized and uncompensated disability, either before or after diagnosis; financial hardship due to lack of medical insurance coverage of diagnostic tests and treatment measures.

Implications of the Study

To the extent that this study of the experience of environmental illness has focused on issues similar to those surveyed by Rippere (1983) (reviewed in Chapter One), certain comparisons of findings can be noted. These comparisons reveal several remarkably similar findings. Although the types of "symptoms" most frequently reported varied somewhat, in both this study and that of Rippere, respondents typically attributed a combination of "physical" and "mental-emotional" kinds of trouble to sensitivity problems. Respondents in both studies also reported similar frustrations with contacts with physicians: having troubles commonly dismissed as trivial or as psychosomatic. As in this study, Rippere's respondents also said that they had been subject to discrediting responses from others with respect to their claims of significant problems with sensitivities; some of the same epithets were mentioned in both studies (eg. obsessive, anxious, anti-social). As a result of ridiculing responses to respondents' management measures (such as bringing one's own food to an occasion), respondents in both studies also said that they were often faced with a choice between ridicule, participating normally in events and becoming sick as a consequence, or not participating. These correspondences between findings in this study and that of Rippere, suggest a similar overall pattern in the experience of ecological illness in Britain and Canada.

Beyond the particular issue of ecological illness experience, this study also has implications that relate to broader issues in the sociology of health and illness. One of these issues concerns the personal and social significance of medical diagnosis. As noted in Chapter One, with the influence of the labelling perspective and the interest in stigma during the last two decades, several discussions of the medical application of diagnostic labels have emphasized their identity-spoiling consequences for those to whom they are applied (eg. Freidson, 1965, 1981; Waxler, 1981; Schneider and Conrad, 1983). While medical diagnoses clearly do sometimes carry such consequences, the present study, along with those of Hilbert (1984), Hunt (1985), Singer et al. (1987) and Stewart and Sullivan (1982), highlights the ways in which medical diagnosis can also be critically important to people as a social resource. The social psychological and practical significance of medical diagnosis is clearly illuminated in situations of people seeking but failing to find diagnoses to account for puzzling, debilitating problems.

Akin to the labelling perspective's critical analysis of medical diagnosis, at a societal level of analysis the "medicalization thesis" (Zola, 1972, 1975; Conrad and Schneider, 1980) involves a critical analysis of the ever-widening influence of medicine as an institution of social control. Zola (1972) and Conrad and Schneider (1980) argue that medical interpretations of social problems have increasingly been extended to various categories of deviance. Freidson (1970) also has noted that the profession of medicine is prone to continually create new categories of illness. At first glance, the diagnostic category of ecological illness might seem to be an example of this medicalizing trend. It interprets in health-illness terms a great number of "mental-emotional" states that are traditionally thought of in other terms. However, while this diagnosis would seem to be slowly growing in popularity, it is not because it is popularly embraced and promoted within the profession of medicine itself. On the contrary, the medicalization of various problems using the category of ecological illness is largely discouraged within medicine. If, as a medicalization thesis would suggest, the profession of medicine is prone to ever create and use new diagnoses, then the question arises as to why certain diagnoses, such as ecological illness, seem to be actively discouraged within medicine.

This also raises a more general question for further research, regarding the character of modern medical knowledge and practice, and what accounts for the growth and proliferation of some types of diagnosis and practice as opposed to others. Given the significance of medical diagnosis as a social resource, and medicine's monopoly authority over the legitimation of illness claims, this question has implications for anyone who might seek medical attention.

APPENDIX A

TO THOSE CHALLENGED BY FOOD/ENVIRONMENTAL HYPERSENSITIVITIES:

I am a graduate student in the sociology of health and medicine at McMaster University. I am doing research on peoples' experience in recognizing and coping with food/environment related health problems.

If environmental sensitivities have been a significant challenge for you, I would very much like to talk with you about your experience. In an interview at your convenience, I would like to ask you about problems and challenges you have faced and their impact upon your day to day life. I am particularly interested in learning of peoples' experience with mental or emotional symptoms related to sensitivities.

As a participant contributing your experience, your identity will be confidential. Findings will be presented in a generalized way. When specific quotes are used they will be anonymous.

I would like to hear from you. Your participation in this study will contribute to a systematic illumination of the problems faced by individuals coping with sensitivities. When complete, a report outlining the study and its results will be provided to the Human Ecology Foundation, and thus made accessible to you.

Please contact me: Rob Phripp
80 Liverpool St.
Guelph. N1H 2L1.
Tel: (519) 699-4600 (Waterloo)
(519) 763-5243 (Guelph)

APPENDIX B

CONSENT TO PARTICIPATE IN A STUDY OF THE EXPERIENCE OF ENVIRONMENTAL HYPERSENSITIVITY

The research in which you have volunteered your participation is being conducted by Rob Phripp, a graduate student in sociology at McMaster University. The purpose of the study is to examine the illness and help-seeking experience of people with food or environmental hypersensitivity.

For those volunteering to share their experience, participation involves an interview of approximately one hour. Written and tape recording of the conversation will be made. The identity of volunteers and the records of interviews will be confidential. When not being used in analysis, records of interviews will be kept in locked storage. Findings will be reported in a generalized way; where specific quotes are used, they will be anonymous.

A report summarizing the findings of the study will be provided to the Human Ecology Foundation of Canada, and will, thereby, be available to those who have participated in the study.

Participants have the right to refrain from answering any questions they wish, and/or to withdraw from the study at any time. Should you have any concern or complaint regarding your involvement in the study, you may discuss it with Rob Phripp or, alternatively, with the supervisor of this research, Dr. Ralph Matthews, Sociology Dept., McMaster University [(416)525-9140].

I have read and understood the information above regarding participation in the study of peoples' experience of environmental hypersensitivity. Being informed of the purpose and nature of the study, I consent to be interviewed. I understand that I may withdraw my participation at any time if I so wish.

____________________________ ____________

(signature) (date)

APPENDIX C

Interview Schedule

General Information:

1. Sex: M F

2. In what year were you born? ______

3. What is your marital status?

____married
____permanent relationship/common-law
____separated
____divorced
____single

4. Do you have any children?

y n

If yes, how many boys; how many girls; in what years were they born?

Boys: Girls:

5. What was the highest level of schooling that you finished?

____grade 6 or less
____ 7 or 8
____ 9 or 10
____ 11 - 13
____some post secondary; specify:
____post secondary diploma or certificate;specify:
____bachelor's degree; specify:
____post graduate degree; specify:
____apprenticeship; specify:
____other; specify:

6. What is your usual or main occupation or job title?

7. Are you presently employed?

y n

If y, are you employed _____full-time?

or _____part-time?

8. What is your religious preference or affiliation?

_____Anglican
_____Baptist
_____Jehovah's Witness
_____Jewish
_____Lutheran
_____Muslim
_____Pentecostal
_____Presbyterian
_____Roman Catholic
_____Salvation Army
_____United Church
_____Other Christian; specify:
_____Other Non-Christian; specify:
_____no preference or affiliation
_____don't know/can't remember
_____refusal/no answer

9. Do you consider yourself a practising (religion)?

y n

sometimes/perhaps___ don't know___ refusal/no answer___

10. What is your ethnic background?

_____Dutch
_____English or Scottish
_____French
_____French Canadian
_____German
_____Irish
_____Italian
_____other Western European; specify:
_____Other Eastern European; specify:
_____don't know/can't remember
_____refusal/no answer

11. In what country were you born?

____Canada
____other; specify:

If born outside Canada:
In what year did you move to Canada?___________

12. What is your total annual income?

____no income
____less than $5,000
____$5,000 to $9,999
____$10,000 to $19,000
____$20,000 to $29,000
____$30,000 to $39,000
____$40,000 to $49,000
____$50,000 to $59,000
____$60,000 to $69,000
____$70,000 and over
____don't know/can't remember
____refusal/no answer

Family of Origin Information:

13. What were your parents' main occupations when you were growing up?

Mother:

Father:

14. Do you have any brothers or sisters?

y n

If y, in what years were they born?

Brothers:

Sisters:

Background Medical Information:

15. In your family background, has anyone (among parents, brothers, sisters, or other relations) had a serious or chronic health condition of some kind? (such as heart disease, diabetes, cancer, etc.)

y n

don't know/can't remember___ refusal/no answer___

If y, who (what relation) and what condition(s) were/are they?

16. In your family background, has anyone had any problems with allergies or sensitivities to things?

y n

don't know/can't remember___ refusal/no answer___

If y, who (what relation) were they?

What kinds of problems have they had?

How old were they when they began having these problems?

Were/are these allergies/sensitivities significant problems for them, or would you say that they were/are minor annoyances for them?

(list person, problems, age of onset, and evaluation of seriousness)

Relation	Age of onset	Types of problems	Seriousness

If respondent has married, is in a permanent relationship or has children, ask:

17. Have your wife/husband or children had serious or chronic health conditions of any kind?

y n

don't know/can't remember____ refusal/no answer___

If y, who, and what condition(s) were/are they?

Relation	Condition

18. Have your wife/husband or children had any problems with allergies or sensitivities to things?

y n

don't know/can't remember___ refusal/no answer___

If y, who (what relationship to you) were they?

What kinds of problems have they had?

How old were they when they began having these problems?

18. continued...

Were/are these allergies/sensitivities significant problems for them, or would you say that they were/are minor annoyances for them?

(list person, problems, age of onset, and evaluation of seriousness)

Relation	Age of onset	Types of problems	Seriousness

Personal experience of hypersensitivities:

19. Do you have ongoing or recurring health problems of some kind?

y n

don't know/can't remember___ refusal/no answer___

If y, what are they?

(If n, clarify whether interview should continue.)

20. Do you consider any of these problems to be related to sensitivities or reactions to foods, chemicals or other things?

y partly___ n refusal/no answer___

If y or partly, what kinds of problems with sensitivities do you now have?
(note how respondent is affected, and to what they believe they react?)

21. Since you began having trouble with sensitivities, have you experienced problems continuously or only at some times and not others?

continuous___ episodic___ don't know/can't remember___

If episodic, how frequently have you had trouble with sensitivities?

____once every few years
____about once per year
____a few times per year
____a few times per month
____weekly
____every few days

Comments:

22. <u>Chronology of Experience prior to diagnosis of problems as hypersensitivity</u>:

I'd like you to think back to your first experiences of troubles that you now understand to have been related to some type of sensitivity.

At this point, obtain an account of problem-related experience, from the first experience of problems now believed to be related to sensitivities up to the point at which such a diagnosis was made. Ensure that the following questions are answered as the respondent tells his/her story:

(a) What was your age when you first had some problems that you now understand to have been related to sensitivities?

(b) In what ways were you affected with sensitivity-related problems? (Probe: Were you affected only physically, only mentally-emotionally, or in a variety of ways?)

(c) At that time, what did you (or, if a child at the time, your parents) first think about what kind of difficulties these were? Did you (your parents) see them as relatively minor or of some concern?

(d) Did you (your parents) seek some type of outside help?

(e) What type of outside help did you see?

(f) What tests, if any, were done; with what results?

(g) What did the person say about your problems?

(h) What suggestions or prescriptions were given?

(i) Did you (your parents) feel that your difficulties were taken seriously when you sought help?

(j) Did you and members of your family accept what was said about your problems?
If not, in what ways did various people see things differently?

(k) After seeing this person, what, if anything, was done to try to resolve or manage your difficulties; with what results?

(l) As time went on, did your problems improve, become worse, or otherwise change in any way? At what age?

(m) What other help, if any, was sought? (Continue with above questions, up to the point at which a hypersensitivity diagnosis of problems was made.)

Regarding childhood period (up to age 16):

If the respondent experienced sensitivity problems as a child, ask the following additional questions when discussing that period:

23. Did any of these problems affect your ability to do things that were important to you at the time?
If yes, what things?

24. Did any of these troubles give you difficulty in relationships with other children or other people at that time?

25. Do you think that your problems made any difference to how you felt about yourself as a child?
If yes, in what way?

Regarding adulthood period (after age 16) prior to diagnosis:

If problems were felt by the respondent to be some kind of physical health problems, and yet a medical diagnosis felt to be adequate was not made, ask:

26. Having been unable to get a medical diagnosis that seemed to you to be adequate, did you sometimes doubt your own feeling that your troubles were some type of physical health problem?
If yes, what other kinds of things did you think about your problems or yourself?

27. Before you came to understand your problems as sensitivity-related, did you ever feel that you were responsible in some way for their development?
If yes, in what way?

28. Did the problem of figuring out what your troubles were become a major pre-occupation for you?

29. With whom, if anyone, do you remember talking about the trouble you were having?
What did you say to them?
How did they respond?

31. During this period, do you think that your problems or attempts to cope with them affected how others saw you--their attitude towards you?
If yes, in what way? How did they see you? (Specify who.)

32. During this period, did your experience of problems affect your relationships with other people--family or others?
If yes, with whom, and how were they affected?

33. Did you ever try to hide your problems from others, in your family or other people?
If yes, in what situations? Why?

34. Before you were diagnosed for sensitivities to things, were there some types of family or social situations that you tried to avoid because of the problems you were having?
If yes, what situations?
Why did you try to avoid them?

35. If people unfamiliar with your problems could notice that you were not functioning normally, how did you explain it to them?

36. Before you were diagnosed for sensitivities, were you away from work or school frequently or for prolonged periods because of your problems?
If yes, how did you explain your absence?
Were your explanations accepted?

37. Before being diagnosed for sensitivities, did you ever apply for sick leave, disability, or social assistance benefits because of the problems you have described?
If yes, describe what happened.

38. Did you ever quit a school program or job because of your problems?
If yes, what were the circumstances?

39. Were there any valued activities--social or leisure activities--that you either gave up or limited because of your problems?
If yes, what activities did you limit; which, if any, did you give up? Why?

40. Before being diagnosed for sensitivities, were there any things that you wanted to achieve, goals that you had, that you had to give up because of your problems?
If yes, what were they?
Did the experiences you have described affect the way you felt about yourself as a person at that time?
Comments:

Diagnosis of hypersensitivity or ecological illness:

41. What type of doctor was it that first suggested that your problems might be due to hypersensitivities?

____GP
____allergist
____clinical ecologist
____nutritionally-oriented doctor
____psychiatrist
____other; specify:

42. What were the circumstances that led you to see this doctor?

____was my family doctor
____referred by another doctor
____lay referral;specify:
____read about or heard of doctor on radio or television

Comments:

43. Before being diagnosed by a doctor as sensitive to certain things, had you heard of or read about illness cause by food or environmental sensitivities?

If y, how had you heard of this?
____relative
____friend/acquaintance
____lay health organization; specify:
____through reading, radio, or television

Comments:

44. What year was it, and what was your age, when your difficulties were diagnosed as hypersensitivities?

______

45. When you saw the doctor(s) who diagnosed sensitivities, what tests, if any, were done?
With what results?

46. What did the doctor(s) say to you about your problems?

47. Did what the doctor(s) said make sense to you according to your experience of your problems?
In what way did it make/not make sense to you?

48. If response to above question was not yes, ask:
What eventually led you to believe that you had sensitivity problems?

(Obtain an account also of any further help-seeking related to sensitivity problems.)

49. How did you feel when you found out that your problems were related to sensitivities? (Probe: Relieved, disturbed, anxious, angry,...?)
What difference, if any, did this understanding of things make to how you thought or felt about your problems and yourself?

50. Was it important to you that you now had a diagnostic name for the problems you were having?
If yes, why? Can you describe how you felt?

51. Did you feel any sense of relief of responsibility for any of your problems?
If yes, can you describe how you felt?

52. When you first discovered that you had sensitivity problems, did you talk with your family, friends, employer or others about this interpretation of your difficulties?
If yes, who did you talk to?
What did you say to people? (Specify who.)
How did they respond?

Post-diagnosis: Treatment/management and living with hypersensitivities

53. What kinds of things have you done to treat or manage your sensitivity problems?

> What changes, if any, have you made in your home?
>
> Have you moved at any time because of sensitivities?
> If yes, why?
>
> Have you changed jobs or your occupation to avoid troublesome exposures?
> If yes, what were the circumstances?
>
> What changes, if any, have you made in leisure or social activities in order to avoid or limit exposures?

54. (a) Do you have any idea of how much money you have spent on health care services and treatments not covered by government or other insurance?

(b) What kinds of uninsured services, treatments or other things have been expenses for you?

55. Since you have known what your problems are, have you been away from work or school for frequent or prolonged periods?
If yes, how did you explain your absence?
Were your explanations accepted?

56. Since being diagnosed for sensitivities, have you ever applied for sick leave, disability or other benefits that you felt you needed because of your problems?
If yes, what were the circumstances; what resulted?

57. Would you say that being careful about exposures and trying to improve your health have become major aspects of your life?
Comments:

58. At present, is your ability to do things that are important to you affected by your problems with sensitivities?
If yes, what things are made difficult or impossible?

59. How, if at all, have your problems affected your thinking or planning regarding working, your family, or other aspects of your life?

60. How have other people--family, friends, co-workers, or others--reacted to the ways in which you have been handling your problems?
(To what extent have they been cooperative or supportive? What kinds of things have they said about you and what you are doing to deal with your problems? Has there been any tension or argument related to how you are dealing with things?)

61. Now that you know that your problems are related to sensitivities, are you generally more open or less open about your problems than before?
(Specify with whom--what types of people.)
Why?

62. In what situations or circumstances would you tell someone about your sensitivity problems?

63. Are there any situations or people with whom you are particularly careful not to reveal the extent of sensitivity problems that you have had?
Why?

64. Have reactions to things ever caused problems for you in social situations--at work or school, social gatherings, in public?
If yes, what has happened? How did others react to you?

65. Are there some things that you do to cope with your sensitivities that sometimes attract unwanted attention from other people?
If yes, what things; in what kinds of situations?
How have others reacted?
How do you handle these situations?

66. Have other people--family, friends, employer, co-workers or others--ever done anything, whether intentionally or not, that has made coping with things more difficult?
If yes, describe.

67. How, if at all, have your relationships with people changed since you learned that your problems are related to sensitivities? (Specify family, friends, others.)

68. In general, what do you think that other people who do not have these problems think about them?
Do you think that they understand?
What kinds of situations or conversations have given you this impression?

69. Do you know others with challenging sensitivity problems?
If yes: Have you discussed sensitivity problems with them?
What kinds of things do you talk about together?

70. Have you had contact with any groups or organizations of others with similar problems?
Why/why not?
What kind of involvement have you had?

71. Do you think that sensitivities will always be a major challenge for you, or that these problems are temporary?
Comments:

72. In general, what effect has your experience with these problems had upon how you feel about yourself?

73. Do you feel that your problems with sensitivities to things have prevented you from being the person that you want to be?
If yes, how?

74. How do you feel generally about how physicians have treated you and your problems? (Probe: both before and since sensitivity interpretation.)

75. What, for you, is the most challenging thing about living with sensitivities to things?

76. What changes, if any, in the health care system would most help you in coping more effectively with sensitivity problems?

77. Is there anything that I have not asked you about that is an important part of your experience with sensitivities?

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