THE MEANING OF LUMPS:

A CASE STUDY IN THE AMBIGUITIES OF RISK

AND BENIGN BREAST DIS-EASE

by

Sandra Margaret Gifford

PREFACE

Early in the year of 1981, I began working as a research assistant on an epidemiology project where I conducted structured interviews with women concerning their risk factors for benign breast disease and breast cancer. One late Friday afternoon, I interviewed Barbara, a woman in her late 30's who had recently undergone bilateral prophylactic mastectomies. Barbara did not have cancer nor did she have a family history of cancer. However, she had been diagnosed with several risk factors for breast cancer. After the end of the interview, I asked Barbara how she felt about her surgery. She broke down in tears and explained that she had had no idea how terrible it would feel not to have her breasts.

Barbara's experiences angered me and I began to wonder what kind of medicine was being practiced when surgery was performed on women who did not have cancer. Shortly after my interview with Barbara, the case of a young woman was presented at a breast conference. Molly was 26 years old and had a late stage breast cancer. The cancer had spread to her spine and her x-rays looked as if shot gun pellets had been shot through them. After the impersonal facts of her case had been presented, all conference participants (12 in total) went into the examining room to examine "the case". Molly sat on the hard examining table, her mother standing anxiously in the corner. Her surgeon introduced the group of practitioners to Molly and then proceeded to examine her. Molly's affected breast was hard and swollen and she flinched in pain as fingers poked and prodded. After the exam, the practitioners returned to the conference room in stunned silence. A

young resident broke the silence by blurting out, "But why didn't she do something earlier?" An older surgeon turned and replied, "That's the wrong question! Why didn't her doctor do something earlier?"

And why didn't her doctor do something earlier? How could Barbara, a woman without cancer, have both breasts removed as a precaution? And how could Molly, a woman with no risk factors at all, be diagnosed with breast cancer at such a late stage? These are the issues which I set out to explore and understand in this research. There are no easy answers to these questions nor are there any simple solutions to prevent these tragic events from reoccurring. However, I believe that a greater understanding of the dilemmas that both clinicians and women face can lead to more a responsible practice of medicine and can empower women to take greater control over their own health.

I would like to thank all the woman who shared with me their experiences concerning their breast health. I hope that my interpretations of their experiences will help women and clinicians make "good" decisions about breast health. On a more personal level, I I have learned much about the courage it takes when one is faced with the tragic possibility of an early death. My life has been made richer through those who shared these experiences with me.

I am grateful to the surgeons and other medical practitioners who agreed to share with me the dilemmas they face when managing women with risk factors for breast cancer. I believe that each practitioner who I interviewed cared deeply about his or her patients and each in his/her own way, believed that he/she was making the best clinical decisions possible. I hope that by sharing some of the dilemmas that

these clinicians face and their personal feelings about these difficult situations, steps can be taken to help medical practitioners cope more adequately with the uncertainties of their profession.

Many of my collegues and friends have contributed to the development of my ideas and I thank them all for their challenges and support. Kimberly Dovey pushed my ideas through numerous transformations and gave me the encouragement to finish the research and write the dissertation. I thank him for the friendly arguments and for sticking with me along the way. Fred Dunn deserves special thanks for the letters from afar, assuring me that I was always "on the right track". To Byron Good and Mary Jo Del Vecchio Good, thank you for opening the doors to medical anthropology. Virginia Ernster has been instrumental in encouraging my explorations of epidemiology and for providing direction and assistance in integrating the two disciplines. Len Syme has challenged my thinking concerning the logic of epidemiology and has encouraged the search for alternative epidemiologic models of the etiology of chronic diseases. Warm thanks to Suzanne-Heurtin Roberts, Ron Stall and John O'Neil for the debates and friendly arguments that helped push my ideas along.

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I owe much to the women in my family, especially Margaret Gifford, Stella Barnes, Jean Gifford and Susan Gifford, who believed in me. And a big warm hug of thanks to Kess Dovey to whom writing a dissertation on lumpy breasts is a throughly mystifying adult ritual. Her perceptions of the world have kept me grounded.

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This research explores the ambiguities of the meaning of risk as it applies to benign breast disease and breast cancer. The focus is on understanding how the concept of risk comes to take on multiple meanings; meanings that express scientific, clinical and lay uncertainties surrounding the prevention, diagnosis and prognosis of breast conditions. Using a hermeneutic approach, fieldwork was conducted over a one and a half year period in two large hospitals in California. The focus of the fieldwork was to explore how clinicians, who specialized in breast health, diagnosed and treated women whom they believed were "at risk" for breast cancer, and how women experienced being diagnosed as "being at risk".

The findings presented in this study support the argument that the concept of risk is coming to play a central and powerful role in the practice of medicine. For the epidemiologist, risk is a scientific concept that has emerged in relation to the difficulties in explaining the etiology and distribution of chronic disease in populations. However, for the medical practitioner, risk is more than a scientific concept as the clinician is faced with translating epidemiologic risk into the diagnosis and treatment of individual patients. This gives rise to another dimension of risk, the doctor's own personal risk of making a wrong diagnosis. Arising from these two dimensions, a fundamental shift in meaning takes place and epidemiologic risk becomes understood, spoken about and treated as a disease of an individual.

Within this context, clinicians diagnose and treat risk in the same way they diagnose and treat other diseases. Removal of risk is carried out through the prescription of drugs, biopsies and in the extreme case, through prophylactic mastectomy. However, while the doctor may be successful in removing her or his own risk of making a wrong diagnosis, treatment does not remove a woman's risk factors for breast cancer. For women, being at risk represents a new state of illness, and being diagnosed with risk factors often leads to greater medical surviellance and intervention.

The dissertation concludes with some speculations about how this case study of risk, benign breast disease and breast cancer can be generalized to the understanding of risk for other chronic diseases.

Frederick Dunn
29 August 1986

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CHAPTER 1: INTRODUCTION

One of the dilemmas of modern life is that we are all at risk for developing an array of diseases. We have become quite used to hearing our doctors or public health professionals giving us various risk statistics associated with the things we do or the things we are exposed to. Those of us who are health professionals have become quite comfortable with the language of risk as we measure it, estimate it, observe it, or create programs to reduce or remove it from individuals or from the environment. Concepts of risk have become a part of the every-day language of health and illness. Yet, few people have paused to reflect upon the meanings and uses of the concept of risk. How is risk understood as used within epidemiology and how might it be differently understood in preventive medicine? How do non-health professionals understand concepts of risk? How does a person experience being diagnosed as "being at risk" or as "having risk factors"?

This dissertation explores the meaning and use of the concept of risk as it applies to benign breast disease and breast cancer. The focus is on understanding how the concept of risk comes to take on multiple meanings; meanings that express scientific, clinical and lay uncertainties surrounding the prevention, diagnosis and prognosis of breast conditions.

Like most chronic non-infectious diseases, the cause of breast cancer remains unknown. And, indeed, it is likely that no single cause of the disease will ever be isolated. Instead, notions of cause may be

more appropriately thought about within a language that speaks about multiple risk factors that appear to be associated with the incidence and prevalence of the disease. Here we find a shift from concepts of cause to concepts of risk. This shift is reflected in the epidemiologic and clinical language used in speaking about non-infectious diseases in general and about breast cancer in particular.

Because medical scientists have been unable to isolate the cause(s) of breast cancer, there exists no method of preventing the disease short of removing the breasts. Thus, the major focus has been directed towards developing technologies that can aid in early detection and treatment. Efforts within epidemiology have been directed towards defining risk factors for the disease, thus enabling those in public health and preventive medicine to identify, screen and follow women who have been diagnosed as having one or more of the identified risk factors. However, identification of risk factors does not guarantee that a woman will develop the disease and in fact, many women who do not have any of the identified risk factors develop breast cancer. The problems surrounding the meaning of risk factors, coupled with the often ambiguous meanings concerning the clinical relevance of pathological and radiologic findings, act to produce much uncertainty on the part of clinicians who must diagnose and treat women with breast conditions. For a woman, being diagnosed as having one or more risk factors for breast cancer can act to change her experiences of health and illness.

In this research, I spent one and a half years exploring how clinicians, who specialized in breast health, diagnosed and treated

women whom they believed to be "at risk" for breast cancer. At the same time, I explored how women experienced being diagnosed by their doctors as "being at risk" for developing breast cancer. Based upon this fieldwork, I argue that the concept of risk represents the cultural creation of a new category of health and illness; a liminal state of being that for clinicians, exists between health and disease. For women, being at risk represents an experienced state of being that is between health and illness. Using risk, benign breast disease and breast cancer as a case study, I pose a more general question: is the concept of risk as it applies to other non-infectious diseases, coming to be thought about, diagnosed and treated as if it were, in fact, a disease entity? And if so, are we in danger of diagnosing larger portions of our population with a new culture-bound disease/illness?

This dissertation is divided into 7 chapters. Following this introduction, in the second chapter, I discuss my philosophical assumptions and methodology for the study. In chapter 3, I provide an overview of the epidemiology and pathology of benign and malignant breast conditions. The focus of this chapter is to explore the areas of controversy surrounding the scientific understanding of breast conditions. Chapters 4 and 5 are devoted to a detailed presentation of my data. In chapter 4 I discuss clinician's experiences of diagnosing and treating breast conditions. In chapter 5, I explore women's experiences of being diagnosed with a benign condition and women's experiences of being diagnosed with breast cancer. Chapter 6 is concerned with developing a multi-dimensional understanding of the concept of risk as it relates to clinical and lay uncertainty about

benign breast conditions. Finally, I conclude by exploring how the concepts of risk might be understood, in the anthropological sense, as a culture-bound illness and how insights, derived from this study of risk and breast conditions, might be applied to other non-infectious diseases.

CHAPTER 2: PHILOSOPHICAL ASSUMPTIONS AND METHODOLOGY

2.1 INTRODUCTION:

> It is true that meaning is in use, but it is equally true that use is always in flux. Perhaps it is even such that human action is inherently so ambiguous that it will resist any attempts to catch it in the firm categories of formal reasoning. Since thinking about action is itself an action, it becomes impossible to break out of our conceptual prison. --Olsson 1979:290

Problems in both clinical and popular understandings of the meaning of disease and illness states and consequent uncertainties in disease prevention and management are becoming increasingly common (Fox 1980). In part, these problems stem from inadequate knowledge of the natural history of the many non-infectious diseases and to rapid increases in the production of scientific and medical technology.

While technological advances have enabled us to extend our knowledge of the human body and to more precisely detect minute changes in physiologic states, our understanding of what these changes mean lags behind. The discovery of new pathological or biochemical mechanisms may take on more than one meaning at the same time. Within the scientific realm, this ambiguity provides the stimulus for the formulation of new hypotheses and theories resulting in further research. Gunnar Olsson argues that:

> The driving force of both science and technology is indeed in the quest for certainty. The goal is to fight ambiguity and to do so by employing all means. (1979:289)

While ambiguity within the scientific realm pushes the frontiers

of knowledge into new and challenging directions, ambiguity within the clinical context often results in uncertainty and frustration. The practitioner is faced with translating knowledge into practice and since knowledge is often incomplete, it becomes transformed into a kind of clinical uncertainty. Scientific ambiguity, which describes a state of knowledge, becomes transformed into clinical uncertainty in the application of knowledge.

This research explores scientific ambiguity within the context of scientific, clinical and popular understandings about the meaning and management of "benign breast disease". Specifically, I am concerned with understanding the relationship of ambiguity to the shaping of scientific, clinical and lay knowledge of a health condition that has been estimated to occur clinically in 50% and histologically in up to 90% of all American women (Love et al., 1982).

There exists at the start a fundamental contradiction in the very meaning of the term "benign breast disease". The etymology of the word "benign" can be traced to the Latin word, "beniginus" which means "kind, a variant of good". And a dictionary defines benign as "good-natured; little or no harm". The etymology of the word "disease" traces it roots first to the latin prefix "dis" meaning apart, and the word itself stems from the French term meaning "want of ease" (Skeat 1980). Benign breast disease then describes a physical condition of the breast that is a "good dis-ease". The term describes a condition that is both good and harmful at the same time. Thus, the very meaning of this physical condition is fraught with ambiguity.

I argue that the term more clearly describes the state of

medical scientific understanding and clinical knowledge and practice than the "reality" of the physical condition itself. That is, there exists an inherent ambiguity in the current medical scientific thinking where certain pathologic changes in the breast are understood to be both normal and abnormal at the same time. This ambiguity in turn gives rise to clinical dis-ease and uncertainty in the sense that it is difficult for the clinician to translate ambiguous scientific understanding into clinical knowledge and practice. Thus, benign breast disease represents a particularly vivid example of a medical dilemma where ambiguity in the understanding of the meaning of physical changes and clinical uncertainty in the diagnosis, treatment and prognosis of the condition, has become a key factor in the relationship between knowledge and practice.

The goal of this research then, is to explore clinical and lay understandings and practice as they relate to the condition of benign breast disease. In this chapter I will first discuss the way in which I have defined and used the key concepts of "ambiguity" and "uncertainty" in the context of this research. Second, I will discuss the underlying philosophical assumptions that guide the way in which I have defined and explored the research problem. Third, I shall discuss the rationale behind my methodological approach and describe the research setting and study participants. And finally, I will discuss specific research methods and the analysis of the data.

2.2 CONCEPTS OF AMBIGUITY AND UNCERTAINTY:

The concepts ambiguity and uncertainty have been used both in the medical and social science literature to loosely describe various states of knowledge and practice surrounded by conflict, confusion and

controversy. In the initial stages of this research I too used these two terms interchangeability but soon found that such uncritical usage became problematic. For example, even when the meaning of a physical condition is clear, there can still remain much clinical uncertainty as to the appropriate kind of management. For example, even when the pathological diagnosis of cancer can be clearly established, the clinical choice of treatment can be uncertain. One clinician explained:

> In breast cancer it (chemotherapy) is pretty clear cut. You know, you clearly have a stage two disease, clearly the patient isn't too old. But in other tumors the indications for therapy are less clear cut. Where the therapies are less reproducibly effective, then it really starts to thicken up.

Here, the meaning of the disease for the clinician, is clear. The uncertainty lies in the choice of therapy to treat the disease. Another example where the meaning of the disease is clear but where there exists clinical uncertainty is in prognosis.

> The longer I've been at this specialty, the less certain I've become of my ability to prognosticate because I've been fooled so many times. The outcome depends upon all kinds of factors. How extensive the tumor is, how aggressive looking it is under the microscope, how responsive it is to the applied therapy and whatever innate patterns there are of the particular cancer, every cancer is individual. And every individual is individual so that mixture of biological factors ends up producing a different variable in each patient.

On the other hand, I encountered situations that were not solely a matter of uncertainty in terms of clinical management but also of ambiguity in terms of the meaning of the condition itself. Take for example, the following statements by clinicians,

> Well, I frankly have not been involved in too many cases in the grey zone. I've got some just short of cancer but I've been taken off the hook because the pathologist hasn't quite given it the name cancer and so I've treated it by local means.

Whether these minimal breast cancers actually represent cancers,

> Is really a pathologist's definition at this time and I am not a hundred percent convinced that there is a cause and effect relationship between these in-situ tumors, so called cancers, and the ultimate development of advanced cancer.
>
> I had one patient of mine last month, she almost had some invasive cancer. They talked about it for three weeks, the pathologists. But they finally all agreed that there was no invasive cancer.

What emerges from these above statements is a kind of clinical uncertainty arising from a fundamental ambiguity in the meaning of a pathological condition. This ambiguity becomes even more obvious in the pathologic context.

> I see my role as a pathologist not just as interpreting whether something is benign or malignant because a lot of what we think of as benign or malignant is somewhere in between...a lost of the lesions we created as in-situ carcinomas were in fact created very arbitrarily...a lot of the basic assumptions that were made are really incorrect. So what I see myself doing is really defining it over again. I'm using customary pathologic terminology to describe the histology of the lesion but the important thing is to ask what does that mean? And there's [sic] two things that are important. One is to establish what it actually means and the other, is to understand what the clinician means. That is part of the translation.

What begins to emerge is a problem of interpretation and meaning. That is, clinical uncertainty stems from what is unknown or from what is ambiguous. When the meaning of a condition is unknown or ambiguous, the relationship between the actor and the phenomena is one of uncertainty. The clinician will be unsure as to what the condition means and uncertain about how to act.

When I speak of a condition is <u>ambiguous</u>, I am referring to a context where the condition takes on two or more <u>meanings</u> at the same time. Take for example the following two statements by clinicians about benign breast conditions:

> I've always felt that this was not a disease...The largest percentage of people who have benign disease are not likely, I don't think, to get cancer.

> Disease may not be the correct terminology because it has connotations to patients that create excessive worry. But the incidence is high in the general population. And there are some reports that show an increased incidence of breast cancer in that group of patients. There has to be some element of concern for all women because it is an epidemic disease. I don't think we should single out the fibrocystic breast for undue alarm. They need to be followed closely, do self exams, get regular exams and they need a higher index of suspicion simply because they're harder to examine.

Here, benign changes are understood to be both normal and abnormal at the same time. The first clinician states that he believes that the condition is not a disease yet refers to it as a disease in the next sentence. The second clinician says although one should not be overly concerned about fibrocystic breasts, they must be examine regularly. And here, if we look deeper into the last statement, we find, that the cause of concern rests with the clinician's uncertainty over his ability to detect a cancer and with his uncertainty about the clinical significance of ambiguous scientific meanings of benign breast conditions.

Ambiguity and uncertainty then, describe two dimensions of benign breast conditions; scientific understandings about the meaning of the condition and the clinical dimensions about how to translate those ambiguous meanings into practice. In this dissertation, uncertainty refers primarily to the dimensions of clinical practice while ambiguity refers to dimensions of meaning.

My use of these concepts becomes clearer when we examine their etymological roots. Ambiguous derive from Latin roots meaning driving about. The prefix ambi means on both sides, related to both. The dictionary defines "ambiguous" as meaning, "to wander about and around, to have two or more possible meanings, not clear; indefinite." The

etymological roots of the word "uncertain", if we remove the prefix, un can be traced to the Latin word "cernere" meaning "to discriminate, to separate or decide." With the prefix "un", we have unseparated, undecided. Adding the prefix to the dictionary definition of "certain" we have, undetermined, unfixed, unsettled, undistinguished, unresolved, unsure, unreliable, undependable, uncontrolled. Although the meanings of the two concepts ambiguous and uncertainty are similar, I have chosen to draw upon and emphasize their differences in order more fully to understand the relationships of knowledge to practice. In this respect, I use the word ambiguous to refer to a condition that has two or more meanings at the same time. I use the word uncertain to describe the state of action or practice in relationship to ambiguous meanings.

Ambiguity and uncertainty describe different types of relationships between a physical condition and its interpretation. And these relationships ultimately are expressed in the dialectics of knowledge and practice. In this research, the exploration of the relationships between ambigious knowledge and uncertain practice is carried out though the discourse of social science. But it must be pointed out that social science discourse is not free of ambiguity or uncertainty. Thus, at yet another level, we must remain aware of social science's own dialectics of uncertainty and ambiguity, of knowledge and practice. Olsson has pointed out:

> If we slavishly attempt to transpose statements from the language of social science into the realm of human action, then we run the risk of imposing on reality a strictness which it neither has nor ought to have. In the Hall of One-Dimensionality, ambiguity would be laid limp, lowly raped by the dominating forces of certainty. What was meant as a tender kiss becomes a deadly throat bite. (1979:292-3)

2.2a Research Questions:

The specific questions guiding this research are as follows:

1. What is the meaning of benign breast disease for:
   a. scientists
   b. clinicians
   c. laywomen
2. What is the relationship between knowledge and practice in the management of benign breast disease?
3. How is knowledge transmitted and/or transformed in spoken discourse between medical scientists, clinicians and laywomen?

Thus, the subject of this research concerns scientific, clinical and popular understandings and practices surrounding breast health.

2.3 PHILOSOPHICAL ORIENTATIONS:

Because the problems that the research questions explore concern the creation of knowledge and the translation and application of meaning, I have chosen the methodological approach of interpretative anthropology, a system of inquiry well suited to exploring problems of meaning.

Two theoretical assumptions have informed my choice of methodology and specific methods of data collection and analysis. The first assumption concerns the relationship between "objective" and "subjective" systems of inquiry. I believe the dichotomy between qualitative (subjective) and quantitative (objective) methodologies is a false one as both are dependent upon the implicit assumptions that the researcher holds about the relationship between the individual,

society and science. Thus, all research is from the start, rooted in subjectivity; all data or "facts" being influenced by the theories and methods which the researcher chooses (Feyerabend 1975). These theories and methods are in turn, dependent upon the researcher's philosophical orientations. This assumption states that they way in which research problems are defined, where one will look for evidence or data and the way in which the data will be analyzed will be very much determined by the world view of the investigator.

Even in pure survey research, where responses are quantified and grouped into patterns of relationships, it is the researcher who must bring meaning to the numbers. The data can not speak for themselves; there must always be an interpretator or a translator. Thus, knowledge is always a function of the individual investigator as well as the inquiry system used to conceptualize the problem. Different investigators and different systems of inquiry will generate different interpretations of a given problem and will result in different kinds of information (Ratcliffe 1980).

The second assumption I hold is that no form of inquiry is bias free. Different modes of inquiry will be subject to different forms of bias but no one mode can be judged as inherently more bias free than another. No one particular system of inquiry is best suited for demonstrating "truth". Some modes of inquiry are better suited to certain classes of problems that are other modes. Good research should attempt to understand sources of bias, to control for those where it is possible and to make explicit any remaining biases.

These two theoretical assumptions have informed my choice of an interpretive anthropological approach to explore problems of meaning.

This approach is firmly grounded in the theories of American symbolic anthropology and in the philosophies of phenomenology and hermeneutics. I shall briefly review these orientations in order to provide the context from which my own research emerges.

2.3a American Symbolic Anthropology:

Much of the focus in American symbolic anthropology is directed towards understanding culture in terms of systems of meaning. The aim of inquiry within this tradition is not to generate universal laws about the nature of human behavior but rather to understand the processes by which humans give meaning to (or create) their world. Clifford Geertz argues for a semiotic approach to the study of culture. The concept of culture can be understood as "webs of significance man has spun himself. Analysis is an interpretive one in search of meaning" (1973:5). For Geertz, cultural analysis is always incomplete because there are innumerable ways of understanding culture. The goal of anthropological understanding is to describe symbolic systems as they are manifested through social discourse.

The assumption that all human social action is imbedded in webs of meaning gives rise to a basic paradox: how is one to obtain an "objective" reading of meaning when that reading is itself embedded within socially constructed meanings? How do we understand how meaning means? How do we create a cultural theory of meaning when that theory is predefined by a priori meaning? In attempts to deal with this paradox, American symbolic anthropology has turned to the philosophies of phenomenology and hermeneutics. The incorporation of these philosophies into a meaning-centered theory of culture represents a shift from describing what it is to be human

towards understanding how it is to be human.

2.3b Phenomenology:

Edmund Husserl has often been regarded as the father of phenomenology. The fundamental problem which Husserl addresses concerns the relationship between consciousness and objective knowledge. Husserl's major thesis concerns the attempt to suspend the functioning of our everyday or "natural attitude" to our world. To do so, he argues that we should "bracket" the social affirmation of the actual existence of the world. The result is that we can then discover the essential nature or "essence" of the phenomena (Linge 1976). Husserl's aim is to reveal something which is pregiven, something that precedes cultural experience. He argues that the ultimate foundation of objectivity is to be found in the transcendental ego and that it is the ego that serves as a reference for all other physical bodies in the world.

To understand the objective essence of any given phenomena, Husserl argues for the suspension of the "natural attitude"; the suspending of the everyday functioning of the consciousness. Through this process of suspending the everyday taken-for-granted horizons of lived meanings, the phenomena can be reduced to their fundamental essences (Husserl 1960).

Two major problems arise out of Husserl's phenomenological investigations. The first concerns the transition from the private world of the ego into a world of the intersubjective Other. Second, a complete reduction of the phenomena to their essences is impossible because in the final analysis, reduction is always an act of consciousness, an act of meaning, without which essences (for humans)

do not exist.

Addressing the first problem, that of the relationship between the ego and the world of the intersubjective other, Alfred Schutz attempts a reformulation of the intersubjective social world (1967, 1970). Combining Husserlian phenomenology with Max Weber's sociology, Schutz argues that the primacy of the ego is misplaced and that the whole of human experience is founded in the primacy of the we-relationship. The Other is given without question and is a precondition of all experience. Schutz does not deny subjective experience but rather suggests that the constitution of the subjective self arises first from the intersubjective world. Within the general pregiveness of any social situation, there are an infinite number of variations of biographies, or individual ways of being. Society, therefore, is not the invariant predeterminant element in the creation of the individual; just as individuals internalize the various structures of their cultures, so do they modify and recreate the cultural situation. Within the negotiation of any given social reality, the actor must always presuppose a common point of view. These common points of view are referred to by Schutz as systems of relevances, and culture is made up of these systems of relevances. Thus, the problem of the relations between the subjective ego and an intersubjective world becomes irrelevant as being is first and always within a socially meaningful world. Self-awareness is always a product of a pre-given world.

The solution to the second problem, that of uncovering the essences of, or the pregiveness of the phenomena, becomes impossible because the world is always a totality of experience and experience is the pregiveness from which consciousness cannot be removed. We are

engaged in being. Experience is total, and therefore a true bracketing or suspension of the lifeworld in order to discover essences of things in themselves is not possible or is possible only in not-being. Thus we are faced with another paradox.

2.3c Hermeneutics:

The philosophy of hermeneutics is helpful in resolving this paradox. Hermeneutics is concerned with problems of meaning and intersubjectivity, with bridging the gap between the familiar world and the meanings which are beyond the horizons of the everyday world. The interpretation of hermeneutics as given by Gadamer has been most influential within American anthropology. Gadamer (1976), combining ideas of phenomenology with hermeneutics, argues that the understanding of an event is not reconstruction but mediation, mediation between the past and the present situations of both the interpreter and the text. He claims that it is our prejudgements that constitute our being and that any scientific understanding based upon the ideal of unprejudiced objectivity is impossible. Thus, hermeneutical understanding calls for reflection:

> Reflection on a given preunderstanding brings before me something that otherwise happens behind my back. And only in this manner do I learn to gain a new understanding of what I have seen through eyes conditioned by prejudice.(1976:38)

Like the phenomenologists, Gadamer's hermeneutics requires that knowledge be situated within particular historical patterns; within a certain pre-giveness of the world. Therefore, the interpreter must become aware of her/his historicality. Hermeneutic understanding becomes illuminated through the dynamic never ending dance of interpretation between the interpreter and the textual situation.

Thus, the task of hermeneutical understanding is never finished. Understanding is always in the process of becoming.

The importance of hermeneutics to anthropological interpretation is that it reasserts that understanding is clearly situational (contextual). It emphasizes the importance of making explicit the historicity of the researcher's situation as well as the people with whom she/he is entering into dialogue. It situates the researcher and the people within a dynamic interacting framework, a framework that produces understandings which are always open to reinterpretation. As Michael Agar argues:

> ...an increased understanding of the hermeneutical circle of ethnographer and group is also an increased understanding of the hermeneutical circle for the people that constitute that group, and conversely. (1980:254)

Incorporating this orientation into the American tradition, Rabinow and Sullivan (1979:65) argue that an understanding of human behavior from within a hermeneutical framework is critically against positivist, structuralist, and neo-Marxist positions and that understanding cannot be reduced to systems or categories defined only in relation to each other. Rather understanding must flow from a view which conceives the social world as composed of a circle of meaning outside of which the ethnographer cannot ever fully stand. Taylor has emphasized this primacy of context. He argues that we need to go beyond empirical science based upon verification to the bounds of common meanings which are embedded within social reality. A hermeneutical science not founded upon brute data but rather upon readings of meanings, readings which are in part constituted by self-definitions, would be a step in the correct direction (1979:65).

In sum, the importance of both hermeneutical and phenomenological orientations is that they make explicit the argument that the generation of meaning is a process which is always incomplete and in which the researcher is an active participant, not an "objective", distant observer.

2.3d Interpretative Approaches in Medical Anthropology:

The desirability of an interpretative approach for the understanding of sickness states rests on the argument that disease, or pathological changes in the structure and function of the body are experienced and given meaning by both doctors and patients within a cultural framework. Culture, conceived as systems of meanings, has a major influence upon the ways in which sickness is perceived, understood and experienced. Biological realities of underlying pathological conditions are given individual meaning when culturally interpreted. Good and DelVecchio Good argue that:

> Human illness is fundamentally semantic or meaningful and that all clinical practice is inherently interpretive or "hermeneutic". First, while all disease has biological or psychological correlates or causes, sickness becomes a human experience only as it is apprehended, interpreted, evaluated and communicated - that is, as it enters the world of human meaning and discourse. (Good and DelVecchio Good 1981:175)

This approach, by which sickness phenomena are viewed as fundamentally semantic, has been used by both medical historians and philosophers to understand the evolution of medical thinking and practice (Eisenberg 1977, Engel 1977, Engelhardt 1975, Foucault 1973, King 1982, Reiser 1978). A meaning centered approach has been taken by medical anthropologists and sociologists to understand the cultural assumptions underlying biomedical and popular models of knowledge and

practice. Methodological approaches are interpretative and phenemonological in nature and analysis is directed towards understanding cultural meanings of popular and medical discourse.

Within this framework, several studies have explored scientific medical and clinical knowledge and its translation into practice. The scientific and clinical modes of knowing can be best understood as acts of cultural interpretation given order and meaning to biological chagnes within the body. Biomedical interpretations of physical phenomena are not based on the scientists or clinician's "objective" readings of reality but rather are grounded in culturally shared assumptions about how the body is to be understood (Englehardt 1975, Rawlinson 1982, Treacher and Wright 1982, Young 1978).

This meaning centered approach ahs also been utilized for understanding popular models of sickness and for exploring differences between these and biomedical models. These studies have pointed to a basic distinction between popular and biomedical ways of experiencing sickness. Comparisons are made between biomedical discourse of "disease" and popular discourse of "illness". Here, the discourse of disease refers to abnormalities in the structure and function of the body whereas illness discourse refers to the personal, interpersonal, cultural experiences of disease (Engel 1977, Fabrega 1972, Kleinman, Eisenberg and Good 1978). This approach has been instrumental toward understanding problems in doctor-patient negotiations in the diagnosis, treatment and prognosis of sockness (Good 1977, Kleinman, Eisenberg and Good 1978). This approach has also given rise to considerable interest concerning phenomenological

understandings of illness experiences (Engelhardt 1982, 1982, Kestenbaum 1982).

The theme of ambiguity and uncertainty in the understanding and treatment of disease and illness is common to both the medical and social science literature. However, few anthropological studies have explored in depth the meanings of this ambiguous discourse and its translation into uncertain practice. Rosser and Maguire (1982) have explored problems that the general practitioner faces in the care of cancer patients. They argue that these problems flow from clinical uncertainties concerning etiology and treatment. Comaroff and Maguire (1981) have explored the dilemmas facing both clinicians and parents in the search for knowledge about childhood leukemia. They argue that gains in medical knowledge and technology often serve to highlight the remaining uncertainties in the search for meaning and predictability:

> Observation....revealed how medicine can be seen as ambiguous in a double sense: the more it appears to control, the more threatening is the domain where knowledge is still lacking; and the more it controls, the more alienated the layman himself from control over its effects. (Comaroff and Maguire 1981:1)

Rosser (1981) has explored the problem of uncertainty in relation to women's experiences of breast cancer. After reviewing the literature concerning women's reactions to breast cancer, she concludes that most articles have a narrow focus, are based upon unquestioned assumptions about women, and fail to address the women's experiences of clinical uncertainty created by medicine's inability to precisely define and treat the disease.

2.4 METHODOLOGY

I use the term methodology as distinct from method, to refer to the guiding sets of principles that informs the selection specific

operational procedures or tactics (Ratcliffe 1980). A methodology is like a strategy, general in nature and is context-independent as it can be applied to many different settings. Methods on the other hand, are context-dependent and are chosen according to the kinds of specific data needed. Methodological principles should be viewed as general guidelines providing the context within which a particular mode of inquiry is to be carried out.

The central problem which this study explores concerns the relationship between ambiguous knowledge and uncertain practice. A qualitative methodology is most suited to this type of inquiry. As I have argued, all systems of inquiry are ultimately grounded in the philosophical assumptions held by the researcher and thus, are reflective of a particular subjective worldview. By implication then, the generation of "objective" data is not possible. Rather, "facts" are determined by the theories and methods that create them. Quantitative as well as qualitative methodologies arise out of the subjective nature of the researcher (Bateson 1979, Feyerabend 1975, Lakatos 1972, Toulmin 1972), and no one kind of methodology can be considered to be inherently more biased than another. Data must then be interpreted or given meaning and this process is, again, embedded within the world view of the researcher. It is important, however, to make explicit the biases of each approach. In this section, I will make explicit problems of bias in this study as reflected in notions of validity and reliability.

2.4a Problems of Validity:

The validity of a measurement describes the

degree to which a measurement measures what it purports to measure. Guarantors of validity are those rules which assure that a given system of inquiry measures what it is supposed to measure. Qualitative research is often criticized on the grounds that if "reality" is not "objectively" apprehended, then it is difficult to determine whether the research findings can indeed by extended beyond the study group and beyond the research's own interpretations of the data. With qualitative research, how can we be sure that the interpretations generated by the researcher are comparable to the interpretations of those observed or interviewed?

Singer (1959) has argued that all forms of inquiry are relative, that the rules that guide any system of research are not "real" in and of themselves but rather that they are a human creation. He further argues that any information generated is valid only relative to the goals of the research. Singerian forms of inquiry tend to be holistic in that the problem under investigation is seen as dynamic and always in the process of unfolding. Furthermore, he argues that the observer and the observed can never remain separate and that the observer's own history must be made explicit in the research. This is in line with the assumptions underlying a hermeneutic approach. A Singerian mode of inquiry is particularly well-suited to addressing complex social problems which are ill-defined, dynamic and complex. They require an eclectic methodology. Validity in this system of inquiry is enhanced by included as much possible relevant data from all relevant populations and disciplines which bear upon all dimensions of the problem (Ratcliffe 1980:15). In such cases, validity can never be more than approximate. This argument is shared by other philosophers of science addressing the

complex problems of social inquiry (Churchman 1979, Feyerabend 1975, Ratcliffe 1980).

The problem considered in this research, that of ambiguity in knowledge about, and uncertainty in the application of knowledge to the management of benign breast conditions, can be defined as a "wicked problems", one that is forever changing and one that includes many dimensions; practical, ethical, and multidisciplinary (Mitroff and Sagasti 1973, Ratcliffe 1980, Rittel and Webber 1973). In terms of the validity of the present study, to what extent can the understandings derived it increase our understanding of similar dilemmas arising in other contexts?

This question forces us to ask another more fundamental question, a question concerning the ethical dimensions of inquiry. That is, whose ends are being served by the inquiry process and product? How well does this research serve these ends? This research is aimed at serving four different parties, myself, medical anthropologists, medical professionals, and laywomen. The goal of the research is to increase understandings within and between each of these four parties with the aim to create better forms of medical knowledge and practice. The extent to which this research serves these ends will in part, determine its validity.

This introduces several problems in that validity cannot be assessed until those whose ends this inquiry are to serve, read and react to the research. But aside from waiting for responses from these parties, there are four methods by which I have assessed validity during the research process. The first concerns the validity of the research problem itself. How do we know that the problem of ambiguity

and uncertainty in the understanding and management of benign breast disease is a real one? There are several ways to assess this mode of validity. First, my investigation of this problem arose quite by accident as a result of a dilemma I encountered while employed as an interviewer on a large case-control epidemiology project exploring the risk factors of benign breast disease and breast cancer. My role was to conduct formal structured interviews with women who were assigned to three separate groups; two groups of cases being women diagnosed with benign breast conditions and those diagnosed with breast cancer and a control group of women who never had a breast biopsy. After finishing the interview I would teach women how to do a breast self exam and then we would often chat informally about the kinds of questions they had about their breast health. Often without my proving they would raise many of the issues which form the questions of this research. I would then ask them to explain in more depth their concerns and what they thought could be done about the problems they raised. The questions and issues raised by women within this context formed the basis for the development of this research and I continued to draw upon these informal conversations to refine the direction of my inquiry. The following quotes illustrate the kinds of issues women raised. These quotes were collected within the first few weeks of my involvement as an interviewer in the epidemiology project and I had no idea at this time that I would use them as a basis for a further research project. The first statement is from a woman who was diagnosed with a benign breast condition:

> I have a criticism of your study, the letter you sent said you were studying breast disease. You know, I don't have a breast disease. You should change the wording.

We did change the wording of the letter and the incident drew my attention to the ambiguities of discourse in epidemiological and medical thinking about benign breast conditions. I elicited the second statement from a woman when, upon completing the interview, I asked her if she had any questions she'd like to ask or comments she'd like to make:

> You know, the way I got to the Breast Screening Clinic was through Planned Parenthood. I went there for birth control pills and they referred me to the Breast Screening Clinic. I chose to have the lump removed instead of...needle aspirated. When I went back to Planned Parenthood with my clean bill of health, the nurse told me, "You know, you have this disease!" I was flabbergasted! They didn't tell me I had a disease at the hospital. I had the same thing when I was 16 and they didn't label it! I was shocked!

When I asked a woman if she had any questions about the breast self exam she replied:

> I don't know what I'm suppose to be looking for!

And finally, one woman explained:

> Its frustrating, nobody knows what causes it (breast cancer) so you have no control!

At the same time, I became aware of the controversy and confusion that existed within medicine and epidemiology concerning the meaning of benign breast conditions. An article appeared in the New England Journal of Medicine in January 1982, that summed up this controversy (Love et al., 1982). The authors pointed out that valid histological criteria defining benign conditions as a distinct process did not exist and microscopic differences between the normal breast and those clinically defined as fibrocystic were ones of degree and not of quality. They argued that the distinction between normal physiologic changes and clinical disease were dependent upon a woman's age, the level of concern and the expertise of the clinician. They concluded

that "The label fibrocystic disease is non-specific and ill-defined and the point where the condition becomes both a clinical and histological disease depends to a large extent upon the observer's frame of reference" (Love et al., 1982:101).

The validity of the research problem was further confirmed when I began to call clinical practitioners to arrange interviews with them. When I first contacted them, I explained that I was interested in talking to them about some of the problems invoved in the diagnosis of breast conditions. One doctor forcefully replied:

> I'll tell you what the problem is. Nobody knows what the hell they're talking about!

The validity of the problem within epidemiology became apparent in the literature concerning risk factors associated with benign breast disease and breast cancer. There is much controversy as to whether the risk factors for benign breast conditions are the same as those for breast cancer. Until recently, it has been assumed that women diagnosed with benign breast conditions were at higher risk for developing breast cancer. However, this assumption is being questioned on the grounds that it is unclear as to just what benign changes mean. In her article reviewing the risk factors of benign breast disease, Ernster points out:

> To understand the problems involved in the study of BBD (benign breast disease), it is important to appreciate the diverse and ill-defined histopathologic labels applied to its various forms.....Thus, within the group of biopsied lesions that are clearly not carcinoma, there exists a spectrum of conditions, some of which may be more benign than others (Ernster 1981:194-85).

In sum, I argue that the validity of the problem of ambiguity and uncertainty about benign breast conditions is a valid one in both the popular and medical context.

The second way that I have assessed the validity of this research concerns the problem of how one "knows" that the responses the informants are giving are true? How do I know to what degree their responses accurately answer the the question? This problem of validity is no greater with qualitative open-ended unstructured interview techniques than it is with formal structured methods. In fact, assessing the validity with the use of the latter methods may be more of a problem than with the former. One way to assess the validity of responses in the use of unstructured interview methods is to assess the the degree to which the interviewer is able to establish rapport. Denzin (1975) has described rapport as the extent to which the interviewer and respondent are able to accurately take on one another's role. Rapport is affected by class, social status, degree of consensual meaning, and interpretations of respective roles. The closer the degree of fit in these dimensions between the interviewer and the researcher, the greater the rapport.

On these grounds, I was able to establish good rapport between myself and the women as I had already interviewed them at length in a more structured interview, I had taught them a breast self-exam or had discussed their concerns of breast cancer, I was of similar socio-economic background and I had myself been diagnosed with a benign breast condition. The women and I shared a good deal of common ground before I interviewed them in their homes. After completing the interview, we would often chat about my research, their work or activities. I was invited by several women for coffee and lunch, and on one occasion visited one woman socially. Many of the women thanked me and said that doing the interview had been a good experience for

them. Several said that more books needed to be written which dealt directly with benign breast conditions rather than with breast cancer.

Rapport with the medical practitioners was more difficult but again, I had the advantage of having met them in a clinical context before our interview. I had been attending breast conference tumor boards at the two hospitals for about a year before I conducted individual interviews. My involvement in these conferences was initally a part of my employment in the epidemiology project. My own research grew out of the issues raised in these conferences. Thus, most of the clinicians were aware of who I was and placed me among the group of people conducting the epidemiology study. My initial introduction to them was not as an anthropologist but rather in the role of an epidemiologist. I shared with the clinicians a common background of the knowledge of epidemiology, of research on a problem that they needed to know more about, and they knew that I was interviewing many of their own patients. This familarity helped to establish rapport and all but one of the clinicians allowed me to tape record their interviews, all felt free to express their points of view, none refused an interview and in many cases, especially with the clinicans at the private hospital, the interviews went on past the time alloted. Many of the clinicians said that they had enjoyed talking about the issues I was concerned with as they were very relevant to their own experiences.

I employed a third method of checking validity by testing out my propositions on respondents after our home interview was complete and on other women not formally part of my own study. In this way, I was able to gain new insights, refine current propositions, correct false

assumptions, and explore new areas of inquiry. I attempted to involve those to whom my findings would be generalized, in the formulation of problems and insights. This allowed me to change the direction of my inquiry in such a way as to create a better fit between the various interests that this research serves; personal, anthropological, medical and lay interests.

Finally, I employed the strategy of triangulation, or the use of multiple methods to assess the validity of my observations and interpretations (Denzin 1975). I have explored the problem of ambiguity and uncertainty from a number of different modes. These include open-ended interviews with both women and physicians, the attendence of tumor board conferences, casual conversations with women at the time of the first structured interview, and analysis of the issues in the popular and medical literature. By using these different methods of data collection, I was able to explore the issue in a number of different ways.

Thus, the findings of this research should be valid specifically to the larger population of women who are currently dealing with the diagnosis of benign conditions, with understanding the implications of risk factors to breast cancer, and dealing with a diagnosis of breast cancer. They should also be valid to those medical practitioners who must translate ambiguous meanings of physical findings and risk factors to the management of their patients.

2.4b Problems of Reliability:

Reliability refers to the degree of stability when a measurement is repeated under identical conditions. Reliability is most often used to assess the "goodness" of a particular research instrument, "...to be

reliable, a measuring instrument must yield stable responses under conditions of repeated observation" (Denzin 1970:102). Denzin argues that, "The act of measurement assumes that observations of concepts may be transformed into statements concerning the degree to which they are present in a given empirical instant" (1970:99). In this study, I am not primarily concerned with the measurement of observations and empirical translations but rather, with understanding. The etymology of "understand" can be traced to the Anglo-Saxon word "understandan", meaning to stand under or among, hence to comprehend. The process of understanding is an interactional one, one in which the investigator can not retain a distant, objective stance from what she is attempting to comprehend. This is consistent with the assumptions of hermeneutics. Linge argues that:

> Understanding is not reconstruction but mediation. Understanding is an event, a movement of history itself in which neither interpreter nor text can be thought of as autonomous parts (1976:xvi).

Gadamer has described the process of hermeneutical understanding as:

> Understanding itself is not to be thought of so much as an action of subjectivity, but as the entering into an event of transmission in which past and present are constantly mediated (1976:xvi).

The process of understanding is never finished and always changing. Understanding represents "...an inexhaustible source of possibilities of meaning rather than (as) a passive object of investigation" (Linge 1976:xix).

Within this mode of research, traditional notions of reliability are problematic in several respects. First, unlike in the laboratory, it is impossible to control for the many historical and situational

factors which influences the interview process. But these historical and situational variations are seen as positive factors in this research as such differences can act to increase the depth of understanding. Second, the research instrument itself is represented by the perceptions of the investigator and these perceptions are given meaning through the interactive discourse between the researcher and the participant. New meanings lead to new perceptions and understandings which in turn lead to new meanings.... Such is the nature of the hermeneutical circle, a circle of contextual meaning.

> The universal task of hermeneutical reflection...is to hearken to and bring to language the possibilities that are suggested but remain unspoken in what the tradition speaks to us. This task is not only universal-present wherever language is present-but it is also never finished. This is the mark of our finitude. Every historical situation elicits new attempts to render the world into language. Each makes its contribution to the tradition, but is it self inevitably charged with new unspoken possibilities that drive our thinking further and constitute the radical creativity of tradition (Linge 1975:iv).

The strength of research such as this lies not in generating repeatable explanations nor in findings of cause-effect relations but rather in discovering themes of understanding that once identified, may lead to new, broader, and perhaps better, understandings.

2.5 RESEARCH SETTING AND SAMPLE:

2.5a Epidemiology Research Project for the Study of Breast Disease:

This research grew out of my involvement in an epidemiology research project designed to assess the risk factors for benign breast disease and breast cancer. A great deal of my participant observation research was carried out in this setting. The epidemiology research

project was conducted in a department of epidemiology at a large medical school. The research team was multidisciplinary and included the co-operation of clinicians, pathologists, chemists, epidemiologists, nurses and other health professionals from two hospitals in a large U.S. city.

The study design included two case groups and one control group. Of the two case groups, the first consisted of women diagnosed with breast cancer and the second, women diagnosed with benign breast conditions. The control group consisted of women who had never had a biopsy or surgery for malignant or benign breast conditions. Women between the ages of 18 to 75 who had been seen by co-operating clinicians at one of the two hospitals were invited to participate. For women, participation consisted of a one hour structured interview, a breast examination, and the collection of blood, saliva, and breast fluid samples. The interview, lab work and breast exam were conducted by myself and a research nurse.

2.5b Breast Conference Tumor Boards:

A second setting in which this research was carried out was breast conference tumor boards at the two hospitals. I attended these conferences for a period of a little over a year. The objectives of these conferences were to discuss "cases" (patients or women) that were problematic in terms of either diagnosis, treatment or prognosis and to provide clinicians with a forum for discussion, debate and sharing of new information concerning the epidemiology, diagnosis and clinical treatment of breast conditions. The conferences were held weekly at the teaching hospital and monthly at the private hospital. They were attended by approximately ten to twenty persons including

surgeons, oncologists, pathologists, residents, epidemiologists, a geneticist and nurses.

Although the conference objectives at both hospitals were similar, the structure and content differed. Because of this, the conferences played different roles in their relationships to clinical practice. That is, the kind of hospital, the structure and the content of the conference and the degree to which practitioners became actively involved in the conference played an important role in shaping the way in which a particular clinician incorporated knowledge from these conferences into his or her daily clinical practice.

The first hospital (University hospital) is a teaching hospital and a part of a larger medical center that supports a school of medicine. The second hospital is private and is used by practitioners in private practice (although it is also a teaching hospital, with residency programs, etc.). The University hospital has established a special breast screening clinic that provides a number of services including diagnosis and treatment of breast conditions and patient education. The clinic employs two full-time nurses who are responsible for teaching breast self exams, conducting breast examinations and providing support and back-up for the surgeons, radiologists, pathologists, and oncologists who practice in that setting. The clinic also provides a place where community health clinics and general practitioners can refer women whom they feel need further evaluation. At the time of this research, the private hospital did not have a separate breast screening clinic although a full-time nurse had been employed to work with the private practitioners to establish one.

The structure of the breast conferences differed between the two

hospitals. At the University hospital, the conferences were held weekly from 8 to 9 a.m. before the breast clinic opened. The woman whose "case" was being presented was usually available so that the conference members could examine her. The woman waited in an examination room near the conference room until the details of her "case" had been presented by her physician. She would then be examined by the rest of the team. After examining the woman, the members would return to the conference room to discuss the "case" and to give advice about diagnosis and treatment. Because most of the women presented at these conferences represented diagnostic or treatment difficulties, an attempt was made to reach some kind of joint "management" decision. A team consensus served to provide support for an individual clinician's recommendations. These weekly conferences also served as ongoing working team meetings where current diagnostic and management problems were discussed, where new information concerning clinical trials, new treatment techniques and diagnostic methods were shared and where the members could enter into open debate concerning the everyday concerns of the breast clinic and the management of their patients.

At the private hospital, conferences were a more formal affair being held monthly at noon during which time lunch was served. The conferences were led by a pathologist whose special research interests concerned in situ and minimal breast cancers. Often he would organize a special presentation for the clinicians concerning specific types of benign or malignant problems, diagnostic techniques or treatment procedures. Individual cases were often selected to illustrate current dilemmas and directions in breast cancer research but the woman was never present for examination by conference members. While individual

physicians did present cases about which they were uncertain, these conferences tended to be further removed from the everyday working problems of the clinicians. As one private clinician told me:

> Tumor boards are only for ideas and nothing more and never should they ever dictate therapy for any given patient. I know what's best for my patient. The people who sit and pontifically make statements at tumor board must always be taken with a grain of salt because they haven't met the patient and they don't know the patient's personality. They can never have all the information about a patient.

Thus, conferences at the private hospital tended to be update sessions concerning new and emerging knowledge within the field. As one young surgeon explained:

> Well, I don't know the pathogensis of fibrocystic disease. I don't honestly know. And the discovery in a pathological specimen that there are in-situ lesions is an area that I don't know what it means. That is what I am going to that breast conference for.

Despite the differences between conferences held at the two hospitals, both provide a context where clinicians can enter into open debate concerning what is known, what is unknown, and what is ambiguous. These conferences represent one of the few safe contexts within which clinicians can freely admit uncertainty. It is within this setting that exploration of the ambiguities of medical meanings is encouraged. And it is within this context that the clinician can seek support from colleagues in his or her attempt to translate ambiguous meanings into clinical practice.

2.5c Medical Practitioners Interviewed:

In addition to my participant observation of the two research settings described above, I conducted open-ended interviews with medical practitioners from both hospitals. My goal was to interview all medical practitioners who attended the two conferences. All of the

practitioners who regularly attended the conferences at the private hospital participated (n=16). I had more difficulty persuading practitioners from the university hospital to participate as they complained of lack of time, several went on sabbaticals before I was able to schedule an interview, and one physician canceled at the last minute on four different occasions. Thus, at the university hospital, I interviewed 8 out of 13 practitioners. In total, I interviewed 24 medical practitioners. The specialties of practitioners break down as follows: 2 pathologists, 2 radiologists, 1 oncologist, 3 nurses specializing in breast conditions, 1 geneticist, 2 gynecologists, and 13 surgeons. The sample was selected to illuminate general themes and dilemmas that many of these practitioners deal with in their everyday practice. thus, the sample was selected for exploratory purposes rather than for testing particular hypotheses.

2.5d Women Interviewed:

The purpose of interviewing women was to understand law or popular meanings of breast conditions. Thus, the aim was to explore the "illness" dimension of breast problems; the social and cultural construction of lumpy breasts as a state of ill-health. Therefore my method of sampling was based on the logic of "theoretical" sampling, a strategy well suited for exploration and theory construction rather than for specific hypothesis testing (Denzin 1970, Glaser and Strauss, 1967).

My sample units consisted of two groups of women; 15 diagnosed with breast cancer and 30 diagnosed with benign conditions. The rational for sample size was based on several considerations. First,

owing to the time required for each non-structured interview, only a relatively small number of women could be included. The greater number of women with benign disease than with cancer is due in part to the fact that only 22% of women diagnosed at the University hospital had a malignant diagnosis. Second, the focus of the research is upon the experiences of women with benign conditions rather than those with breast cancer.

Both groups of women were selected from those participating in the epidemiology project. Women with benign conditions were selected from those I had interviewed over a four month period. I asked each woman if she would be willing to participate in a two hour open-ended interview that I would conduct at a later date. The first 30 women to accept made up this sample. Women with breast cancer were selected in similar fashion. However, because I had not personally interviewed 15 of these women, I invited women who had been interviewed by two other research nurses to participate. All the women diagnosed with breast cancer particpated and only one woman with a benign breast condition declined. This woman explained that she was too busy with her work and family.

All the women were selected from those attending the university hospital. Initially I chose not to interview women from the private hospital because I was told that I would probably encounter problems in obtaining permission from their doctors and that I would run into difficulties gaining approval from the hospital research committees. However, I now believe that the private clinicians would not have discouraged me from interviewing their patients as I found that they were much more willing to discuss problems in managing patients with

breast conditions than were their university hospital counterparts. Obviously it would have been better if I had interviewed some women from the private hospital. However, I was able to informally talk with women from the private hospital who participated in the epidemiology study and they voiced concerns and uncertainties similar to those of the women who attended the university hospital. But it must be made clear that the quotes by women about specific interactions they had with their physicians refer to practitioners at the university, not private hospital, unless otherwise noted. A more detailed description of the sample has been included in appendix A.

2.6 METHODS:

The methods used in this research are those common to anthropological inquiry. One of these methods is participant observation which I employed at breast tumor conferences, epidemiology project meetings, and in my involvement in the everyday activities of the epidemiology project.

The second method I utilized was the use of open-ended in-depth interviews conducted with women and medical practitioners. All the interviews were tape-recorded and later transcribed. Only one medical practitioner asked that I not tape the interview. Interviews with the women lasted from 1 to 2 hours. Interviews with clinicians lasted from 20 minutes to one hour. Because the interviews were unstructured I used a list of themes I wanted to explore as a guide. The theme lists for women and practitioner are provided in Appendix B.

It is important to describe how I introduced the research to the participants and how I opened the interview. As I have mentioned, interviews with women were conducted in their homes and before I turned

on the tape recorder we would chat about various things that may have occurred since we last saw each other. Often the women would offer me a cup of tea or coffee which I would accept. When we sat down for the interview, I would begin by telling the participant something of myself. I described some of my experiences as an anthropologist, the kinds of places I had worked and briefly, how I became interested in this research. While it can be argued that this approach may have seriously biased the research, I believe that in order to build rapport, it is important for the researcher to share a bit of herself, especially when the participant is being asked to reveal intimate and often painful personal experiences.

I began the interviews by asking the participant to remember back to when she first became aware that there might be anything wrong with her breast; to remember where she was, what she was doing, who she was with, what was going on in her life at that time. I asked her to tell me her story from that moment to the present. My aim was to have her re-live her experiences and feelings. My aim was to have her re-live her experiences and feelings. I then guided and focused the interview towards the themes I wanted to explore. I found this approach to be very successful as it provided a non-threatening but in-depth context in which we could explore together various themes.

Interviews with medical practitioners were similar to those conducted with women. After introducing myself and my research, I began by asking them to describe their practice and how they became interested in their particular specialty. Then I asked them to describe the procedures they carried out beginning with when a women was first referred to them. This set the context for further exploration of interview themes.

In sum, I was immersed in the field research for approximately a year and a half. In addition to my interviews with women and medical practitioners, I took field notes describing the breast conferences and notes of my interactions with women during the structured epidemiologic interview and while I taught them how to conduct breast-self exams. I noted comments women made to our research nurses. I observed informal interactions between the epidemiologists, medical practitioners and research assistants who were involved with the epidemiology project. I read the reports of the pathologists and surgeons concerning diagnosis and management of patients. I observed the everyday creation and translation of knowledge into practice within several different and interacting contexts and from many different perspectives.

2.7 ANALYSIS:

The analysis of field notes and interviews is directed towards illuminating themes in an area characterized by contradiction and confusion. The goal here is to achieve a deeper understanding of the meanings of medical knowledge and how these meanings are translated into practice. I am specifically concerned with understanding the themes that emerge from the content of interviews and participant observation rather than with the frequency or number of times subjects or themes were mentioned. Therefore, I have used methods of content analysis to bring to light the various dimensions of knowledge and practice.

After the interviews were transcribed, I coded them for major themes and subthemes. I then created a filing system for coded themes on index cards. Each theme had its own care and on the care, I noted

the page number and the interview where the theme was located.

The analysis presented in this dissertation ultimately remains my own interpretation of the data. Descriptive statistical analysis is provided only to describe the characteristics of the sample of women interviewed. In keeping with the hermeneutical philosophy and assumptions upon which this research is based, analysis of the "data" takes the form of understanding, and understanding is never complete. The process of analysis in this research can be understood as an example of the hermeneutical circle. That is, as the reader interprets my own understanding of the "data" new understandings should emerge. And these new understandings should feed back into the old in such a way as to continue the process of bringing new meanings to themes explored in this research. Thus, the process of analysis might be understood as an ongoing dynamic dance between research participants, myself the researcher, and the audience or interpreters of the dissertation itself.

CHAPTER 3: DILEMMAS IN SCIENTIFIC UNDERSTANDING OF BENIGN BREAST CONDITIONS AND THEIR RELATIONSHIP TO BREAST CANCER

> "At a recent influential scientific Congress, held in England, and at which all the most advanced thinkers in the realms of Science were present, the King publicly declared that the scientist who discovered a cure for cancer, by which the races of the world would be freed from its curse, would be deserving of all honor....It seems a pity that something cannot be done to conquer this awful growth, which is as sure an emissary of Death as the lightning bolt from the skies. Year after year it appears amongst the people, and, so surely as it does, are Specialists puzzled as to its origin. Will it ever be cured? This is the question asked daily by the people, and as yet no reply has come from the Halls of Science." -- Freeman and Wallace Electro-Medical and Surgical Institute, 1898.

3.0 INTRODUCTION:

Current clinical and lay dilemmas surrounding the diagnosis, treatment and prognosis of benign breast conditions stem from uncertain understandings concerning their relationship to breast cancer. First, because there exists no accepted method of preventing breast cancer, emphasis has been placed upon early detection. This has required that attention be directed towards defining more subtle changes in breast pathology. However, the scientific and clinical understanding of these changes is often unclear. Second, until recently, epidemiologists, pathologists, and clinicians have believed that women diagnosed with benign breast conditions were at significantly higher risk for developing breast cancer. This belief however, is being called into question because it is now recognized that there are many different kinds of benign conditions, some of which may be less benign than others. Third, between conditions that are clearly benign, and those that are clearly invasive cancer, there exists a set of conditions

known as atypical hyperplasias and in situ carcinomas. These conditions do not constitute an immediate threat to the health of the individual. However, the difficulty arises in that they may lead to invasive carcinomas in the future.

This chapter consists of four sections. First, I will briefly summarize the histopathological understandings of and issues about benign and malignant breast conditions. Second I shall review epidemiological understandings about the relationships between benign and malignant conditions. Third, I will discuss issues in breast cancer screening protocols and technology. Finally, I will explore some of the the major problems arising in the management of both benign breast conditions and in situ carcinomas. The purpose of this chapter is to provide the reader with a basic understanding of the medical and scientific dimensions of benign breast conditions and their relationships to breast cancer.

3.1 PATHOLOGY OF MALIGNANT AND BENIGN BREAST CONDITIONS:

The pathology of both breast cancer and benign breast conditions is varied and complex. Within these two broad classifications the differentiation of specific histopathologic types is important as each carries different implications for diagnosis, management, and prognosis. If one were to imagine breast conditions on a spectrum from clearly aggressive cancers to clearly benign conditions, one would find a large grey zone comprising the center. To the right of invasive cancers but to the left of center, are in situ carcinomas, or conditions that are considered to be cancer but are somewhat anomalous as they are not invasive. On the other side, there are benign conditions that are considered to be potentially more aggressive, or

less benign than others. The conditions that make up this central grey zone give rise to both scientific ambiguity and clinical uncertainty.

In this section, I will briefly describe the pathology of breast conditions, beginning first with invasive carcinoma and concluding with benign breast conditions. My aim is not to give an exhaustive account of the many dimensions of breast pathology but rather, to highlight those areas that, at the time of this study, were ambiguous and therefore, most controversial and those areas where there was much clinical uncertainty concerning diagnosis, treatment and prognosis.

3.1a Invasive Breast Carcinoma:

There are many different kinds of invasive breast cancer and they are classified both according to the specific kind of breast tissue from which they arise and by the type of cell composing the tumor. The most common type of breast cancer involves the glandular tissue and is referred to as adenocarcinoma. Adenocarcinomas arise in the milk ducts, the lobes or in the lymphatic system and can be invasive or non-invasive (see appendix C). Of the invasive adenocarcinomas, duct carcinoma is the most common, comprising 75% of all breast cancers. Infiltrating lobular carcinoma is the next most common, making up about 7% of all breast cancers. Other less common invasive cancers of the breast whose names reflect tumor cell type include medullary, colloid, papillary and, tubular carcinoma and comedocarcinoma (Carter and Eggleston 1977, Haagensen 1971, Baker 1977).

Most often the pathologist is able to easily classify breast cancers. However, in some cases it is difficult to precisely identify the types of tissue from which the cancer arises or the type(s) of cells composing the tumor. For example, Paget's disease is a form of

cancer that affects the nipple and represents approximately 2 to 3 percent of all breast cancers. Its cancer cells are found in the epidermis and there is much debate about the exact characteristics of these cells and their origin:

> These cells are regarded by most observers as carcinoma cells and the most popular interpretation is that they arise from an intraductal carcinoma of the breast and permeate through the epithelium of the collecting duct system to reach the overlying skin of the nipple. Since the associated underlying carcinoma is not infrequently multifocal in the breast, an alternative hypothesis is that these cells arise at the location in which they are found, just as do the carcinoma cells of the other multiple foci within the breast (Carter and Eggleston 1977, p 32).

This gives rise to the controversy as to whether Paget's disease represents an invasive or non-invasive carcinoma. The clinical consequences of this controversy became apparent during several of the Breast Conferences held at the Private Hospital. The condition is ambiguous in the pathological sense because it can come to take on multiple meanings at the same time; invasive and non-invasive, arising from an intraductal carcinoma of the breast and arising from the epidermis of the nipple itself (Lagios, Gates and Westdahl et al. 1979). Because of the ambiguity in the histopathologic meaning of Paget's disease, surgeons expressed much uncertainty concerning appropriate therapy. On the one hand, if the disease is believed to be non-invasive, then treatment should be confined to the nipple only. However, if the disease is believed to be invasive and/or if it is thought to arise from the underlying tissue, more radical treatment of the breast might be indicated.

Another example of pathological ambiguity occurs with the distinction between infiltrating <u>ductal</u> carcinoma and infiltrating

lobular carcinoma. The cell patterns of ductal carcinoma are of three types, one being an "Indian file" pattern as the cells form a single file. The cell pattern of lobular carcinoma is almost entirely in an "Indian file" pattern. Thus, some types of ductal carcinoma can resemble lobular carcinoma. The distinction between the two cancers is, at times, unclear. One approach to resolve this dilemma has been to classify ambiguous cases within the group that represents the greatest risk to the patient.

> The cases which are ambiguous we classify as either scirrhous duct carcinomas (if that is the predominant pattern) or as infiltrating breast carcinoma with features of both lobular and duct carcinoma. This is done to reserve the lobular carcinoma diagnosis for a cancer which has a heightened risk of bilaterality (Carter and Eggleston 1977:43).

Another important feature of cancer pathology concerns the potential and/or actual degree to which a cancer spreads through out the breast and body. This obviously has important clinical implications for both treatment and prognosis. One aspect of cancer spread is tumor multicentricity; defined as, "...the presence of separate independent foci of carcinoma within the breast--separate from the lesion which is clinically or mammographically evident, that is, the reference tumor" (Lagios, Westdahl and Rose 1981:84). The concept that a cancer lesion might be distributed through out the breast is one of the reasons for continuing the current practice of total mastectomy. But as Lagios et al. point out:

> For the clinician interested in assessing the potential risks of segmental mastectomy or other breast-conserving procedures, an understanding of the concept and practical significance of multicentricity is essential. A cursory review of the literature on this subject, however, would provide much confusion, as the frequency of multicentricity alone has been stated to vary from 9 percent to 75 percent in individual series. It should be no surprise that some degree of advocacy--on the one hand for

> conservative resection and on the other for total mastectomy--is espoused by the cited investigators. These differences are, in large part, the result of varied definitions of multicentricity, different techniques of examination employed, and the extent of tissue sampling (Lagios, Westdahl and Rose, 1981, pp 83-84).

Here we find that within the domain of pathology there are unresolved problems concerning the determination of multicentricity. This creates difficulties for the clinician in determining the best form of treatment for a patient. Problems in determining multicentricity also play a central role in the pathological understanding and clinical management of minimal and in situ carcinomas.

Determining the degree to which the disease has spread throughout the body presents additional problems. The presence or absence of cancer cells in the axillary lymph nodes has been considered to be a significant indicator of the degree of spread and of patient prognosis. It is currently accepted that the extent of lymph node involvement has a greater influence on prognosis than does the tumor size and that patients with three or fewer lymph nodes containing metastatic tumor have a better chance of survival than those with four or more affected nodes.

Pathological understandings of the role of lymph nodes in tumor metastasis are changing. Until recently, the primary tumor was thought to be confined to one particular locale of the breast, where it remained for a period of time and then spread to the lymph nodes where, again, it remained before disseminating further. It was believed that the lymph nodes acted as a barrier to the spread of tumor cells. These assumptions formed the basis for radical mastectomy to treat breast

cancer. Patients who did not do well were thought to have had disseminated disease before or at the time of the operation. However, the pathological model of the relationship of lymph node functioning to the dissemination of breast cancer is being challenged. New concepts are emerging which suggest that tumor cells may bypass the lymph nodes entirely and enter directly into the blood system. The implications are that negative lymph nodes do not necessarily indicate that dissemination has not occurred (Carbone 1981).

These shifts in histopathological understanding suggest that new forms of clinical treatment are needed. First, early treatment of minimal cancers and premalignant or benign conditions may be all the more important in preventing the possibility of an invasive disease. Second, the effectiveness of established therapeutic options are thrown into question.

Numerous classification systems have been created in an attempt to bring order to both the histopathologic understanding and clinical management of breast cancer. The current system of classification most commonly used has been prepared by the American Joint Committee for Cancer Staging and End Results Reporting (Robbins 1977). This system classifies cancers according to the characteristics of the tumor, the conditions of the lymph nodes and the presence of metastasis. This information is combined to divide cancers into four stages (see appendix D). Although this system provides a source of standardization for classifying and describing the spectrum of breast cancer, it does not resolve many of the clinical dilemmas that result from histopathological ambiguity.

3.1b In Situ Carcinoma:

The term carcinoma in situ describes a cancer confined to the site of origin without invasion of surrounding tissues. Many in situ carcinomas are not clinically detectable and are most commonly discovered when breast tissue is biopsied for some other reason. Since an in situ carcinoma confined to the breast is asymptomatic and non-life threatening, some argue that the condition should require no therapeutic action. However, treatment dilemmas arise out of the uncertainty as to whether the condition will become invasive at some time in the future.

In situ carcinoma of the breast can be divided into three types: Paget's disease, duct carcinoma in situ, and lobular carcinoma in situ. Paget's disease was first described in 1874 and comprises about 2 to 3% of all breast cancers. The disease itself is confined to the epidermis of the nipple and is often but not always associated with an underlying invasive carcinoma. Until recently the accepted mode of therapy involved treatment of the entire breast rather than being confined to the nipple.

Duct carcinoma in situ is found in the large ducts of the breast and is often associated with infiltrating carcinoma. Until recently, duct carcinoma in situ in the absence of infiltrating carcinoma, was considered a rare lesion, representing only 1-2% of all new breast cancer carcinomas. However, with the introduction of routine mammography, this disease is being detected more frequently. The few published studies that have investigated the rate at which the disease becomes invasive show that up to 57% of women with the condition develop an invasive cancer over a 15 year period, the average interval being 9.7 years (Betsill et al. 1978, Rosen et al. 1980). These

findings have been interpreted to mean that ductal carcinoma in situ has a relatively limited pre-invasive phase. For this reason, ductal carcinoma in situ is most often treated as if it were an invasive cancer. The natural history of this disease remains unknown and experimental studies are underway to determine whether less radical treatment of the breast is an acceptable alternative in women with limited duct in situ carcinoma (Lagios et al. 1982).

There are many problems concerning the classification and management of lobular carcinoma in situ (also referred to as lobular neoplasia). The lesion is multifocal, is often found in both breasts and remains in its preinvasive phase for long periods of time. It is considered to be relatively rare but this is perhaps because it is almost always discovered by accident when the breast is biopsied for another condition. It is difficult therefore, to determine the prevalence of the disease among the general population. A woman who has been diagnosed with lobular carcinoma in situ is thought to be at risk of developing inflitrating cancer. Controversy surrounding treatment of the condition arises because the condition is theoretically 100% curable if removed. However the disease in and of itself is not life threatening and it becomes invasive in only approximately 9% of women. Moreover, because multicentricity within the breast is thought to be as high as 90% and bilateral involvement occurs in as many as one third of patients, cure would require removal of one or both breasts. Those who advocate close follow-up rather than treatment use this evidence to interpret the condition as a "laboratory" cancer rather than a "clinical" one (Lagios et al., 1982, Rosen et al. 1980).

In sum, the in situ carcinomas currently represent a problematic area both within medical science and clinical practice. Dilemmas arise for the pathologist in that the natural history of these conditions is unknown, and it is often difficult to distinguish the point at which a transformation takes place from a laboratory disease to a clinical disease. This in turn creates much uncertainty for the clinician in choosing an appropriate mode of patient management. Lagios (1980), in a seminar concerning the pathology of minimal breast cancer, summarized the problems of patient management with a series of questions for which there are, as yet, no agreed upon answers:

1. What percent of a given non-invasive lesion will become invasive?

2. What is the lag time between a documented non-invasive lesion and subsequent invasive cancer events?

3. What percent of specific non-invasive lesions are:

   a. multicentric
   b. associated with occult invasion
   c. associated with axillary metastasis
   d. associated with spontaneous regression?

4. Is segmental mastectomy a reasonable therapy for non-invasive breast cancer?

Many of these questions form the basis for much clinical uncertainty concerning the the translation of pathologic findings into clinical practice. They will be further discussed in detail in chapter 4.

3.1c Benign Breast Conditions:

The histopathologic understanding of benign breast conditions are undergoing rapid changes and this has led to problems in both

epidemiologic knowledge about, and clinical management of these conditions. As early as the 19th century, efforts were made to distinguish benign conditions from those classified as breast cancer (Ernster 1981, Lewison and Lyons 1953) and in 1893 benign conditions became referred to as "chronic cystic mastitis" (Konig 1893). Despite several detailed studies of breast pathology conducted over the last 80 years, there continues to be a variety of ill-defined histopathologic labels applied to the various forms of benign conditions (Ernster 1981, Love et al. 1982, Love 1984). At the time this study was conducted, there existed no universally accepted standardized system of classification. This has led to diverse terminologies where different terms often refer to the same conditions. And until very recently, benign breast conditions have been commonly labeled as fibrocystic breast disease.

The major difficulty with the use of the term fibrocystic disease is that it does not distinguish between different kinds of histopathologic and clinical breast changes. This lack of specification has given rise to two areas of confusion. First, the term does not differentiate between conditions some of which which may be less benign than others. This in turn has given rise to questions concerning the degree to which "fibrocystic disease" represents a distinct disease process. Love et al. (1982) critically reviewed the literature since 1964 for evidence that supports the argument that fibrocystic disease is a distinct disease entity. Because of the liberal use of the term within pathology, they found that in one study, up to 90% of women could be histologically defined as having fibrocystic breast disease. Based upon this evidence, they posed the

question "Is it reasonable to define as a disease any process that occurs clinically in 50 per cent and histologically in 90 per cent of women?" (p:1011).

Such a definition has serious consequences as it combines individuals who are not at risk with those who are. There is much debate concerning which kinds of benign changes should be considered normal and which abnormal. Breasts are organs in a state of constant change due to the influence of hormonal fluctuations. Thus, many histopathologic changes might actually represent a range of normal responses to hormonal variation. This has led Love et al. to argue that "...the point at which a normal condition becomes a disease, histologically as well as clinically, depends to some degree on the observer's frame of reference" (Love et al. 1982, p. 1011). Because it is becoming increasingly clear that not all benign breast conditions carry the same risks of breast cancer, the use of a term to describe conditions present in up to 90% of all women would seem not only meaningless but irresponsible. Love et al. argue:

> The term "fibrocystic disease" has lost its specificity and therefore should be abandoned. "Lumpy breasts" or "physiologic nodularity" are more descriptive of the clinical situation, and specific histologic designations are more useful in describing the pathology, as well as the prognosis (1982, p:1014).

In attempts to solve the above dilemmas, several classification schemes have been proposed to standardize the histopathology of benign conditions (Azzopardi 1979, Haagensen 1971, Wellings et al. 1975). Dupont and Page (1985) have separated histologic lesions into three catagories. First are lesions tha are not proliferative (nonproliferative lesions). These lesions include mild hyperplasia

such as cysts, and fibroadenomas. In their retrospective cohort study of 3,330 women, Dupont and Page found that 70% of women in the study with excised benign breast tissue were diagnosed with nonproliferative lesions and were not at increased risk for breast cancer.

The second and third categories as defined by Dupont and Page, do carry an increased risk of brest cancer, as compared with the risk for women in the general population. Proliferative conditions without atypia (abnormal cells) include moderate and florid hyperplasia (too many cells), papillomas and sclerosing adenosis. In their study, Dupont and Page found that only 26% of the women had proliferative conditions without atypia and their risk of cancer was 1.9 times the risk in women with nonproliferaive lesions.

However, a third category, atypical hyperplasia (too many abnormal cells) was found in 4 per cent of the women. This category is made up of conditions that have some of the morphologic characteristics of carcinoma in situ. Women diagnosed with atypical ductal or lobular hyperplasia were found to have a fivefold increased risk for breast cancer. Women at highest risk were those who had atypical hyperplasia and a family history of breast cancer.

The study by Dupont and Page has demonstrated that the majority of women who undergo breast biopsies for benign conditions are not at increased risk of breast cancer and many clinicians are currently reassessing the way in which they manage women with these conditions (Hutter 1985). However, at the time that I collected data for this study, there was still much confusion concerning the different types of benign breast conditions and the degree of risk they carried. Although the results of studies such as Dupont and Page's are beginning to

clarify these issues, there remain a number of histologic categories along the proliferative continuum which overlap and thus make diagnosis and management difficult (Hutter 1985).

3.2 EPIDEMIOLOGY OF BREAST CANCER AND BENIGN BREAST CONDITIONS:

3.2a Epidemiology of Breast Cancer:

At the time of this study, breast cancer was the leading cause of cancer incidence and mortality and ranked second to heart disease as the leading killer of American women. Between 1973 and 1977, cancer of the breast comprised 27% of new cases among women annually and was responsible for 19% of all female cancer deaths. In the United States, the annual age-adjusted incidence rate for white females in 1976 was 84.9 per 100,000 and the age-adjusted mortality rate was 27.0 per 100,000 women. It is estimated that at the present rate, 1 out of every 11 women will develop breast cancer in her lifetime (SEER 1984).

While mortality rates have remained relatively constant (26.4 in 1969 and 27.0 in 1976), incidence rates have risen (from 73.9 to 83.5 per 100,000 between 1969 and 1976). Various explanations have been given to account for these trends. However, the increase may be due to better screening techniques and thus, more cancers are being detected that would not have been detected before. Alternatively, the increase may be real (Kelsey 1979, Urban 1976). Survival trends by stage of breast cancer have remained virtually unchanged since 1950 (National Cancer Institute 1975).

The literature on the epidemiology of breast cancer has been comprehensively reviewed by Kelsey (1979) and readers are referred to her article for a more in depth discussion. Here I shall provide only a brief summary of epidemiologic findings regarding the disease.

Increasing age is one of the strongest risk factors and in the United States and other western industrialized countries the age-specific incidence rates increase rapidly until 45-50 and continue to increase at a slower rate thereafter. Demographically, breast cancer occurs more frequently in white females than in black although among young women, this gap has disappeared. Internationally, rates range from low in most Asian and African countries to medium in Southern Europe and South America and high in North America and Northern Europe (Doll et al. 1966, Kelsey 1979). The risk among women in the upper social classes is higher than those in the lower social classes (Cohart 1955, Menck et al. 1975).

The specific causes of breast cancer remain unknown although the disease appears to be one related to a number of different factors. At highest risk are women who have already had a cancer in one breast. These women have 4 to 5 times the risk of developing a cancer in the other breast when compared with similar aged women in the general population (Schoenberg 1977).

Several reproductive variables are associated with breast cancer. Women who have never married and those who have never had children are at higher risk than married women and those with children (MacMahon et al. 1970). Many studies have found early age at first birth to be protective and that a first birth in women over the age of 30 is associated with an increased risk relative to first births at a younger age (Craig et al. 1974, MacMahon et al. 1970, Thein-Hlang and Thein-Maung-Myint 1978). Early age at menarche and late age at menopause are associated with an increased risk of breast cancer (Choi et al. 1978, Kelsey 1979). Artificial menopause may confer a

protective effect (Lilienfeld 1956). Explanations concerning the association of reproductive factors to breast cancer remain unclear.

Many studies suggest that women who have a mother, sister, or grandmother with breast cancer have two to three times the risk compared to those in the general population and that risk is greater when cancer has occurred in premenopausal as opposed to postmenopausal first-degree family members (Anderson 1974, Anderson 1977, Lynch et al. 1978, Petrakis 1977).

The role of endogenous hormones has received considerable attention. Kirschner (1977) has reviewed the evidence in this area and concluded that despite much research, it is still unclear which hormones are involved and the manner in which they operate. For example, estrogen has been long known to be carcinogenic in animals but the nature of the relationship of estrogen exposure to breast cancer in humans is not clearly understood. Other endogenous hormones that may be etiologically associated with breast cancer include progesterone, prolactin and androgens. Progesterone may confer a protective effect against estrogens although the evidence to support this hypothesis remains weak (Kelsey 1979, Sherman and Korenman 1974). Prolactin has been found to have a stimulating effect on mammary tumors in rodents but its role in the etiology of human breast cancer is unclear (MacMahon et al. 1973). Some researchers have hypothesized that subnormal levels of androgen metabolites may be associated with an increased risk of breast cancer but again, little research has been done in this area and the possible etiologic role remains unclear.

Some studies have suggested that exogenous estrogens could play a possible role in the etiology of breast cancer. Studies have been

conducted investigating the relationship of oral contraceptives to breast cancer however the bulk of the evidence does not support an effect. A few studies have found that use may increase risk among certain subgroups of women (Brinton et al. 1979, Paffenbarger et al. 1977). Other studies have found that the use of oral contraceptives for four years or longer is associated with a decreased risk of benign breast disease (Fasal and Phaffenbarger 1975, Kelsey et al. 1974, Ory et al. 1976). Overall, there is little evidence to suggest that oral contraceptive use increases the risk of breast cancer. The few studies that have investigated the association between estrogen replacement therapy and breast cancer have found neither an increase or a decrease in risk (Brinton et al 1979, Casagrande et al 1976).

A number of studies have investigated the role of diet. There is a strong correlation between high fat intake and breast cancer incidence and mortality rates across countries. Several studies have found high fat diets to be more strongly correlated to breast cancer than other socioeconomic variables (Armstrong and Doll 1975, Drasar and Irving 1973). In both the United States and Japan the incidence rates of breast cancer have increased along with dietary fat intake (Wynder et al. 1976). Similar trends have been noted for England and Iceland (Stocks 1970, Miller 1977) One study found that breast cancer rates were lower than average among Seventh-Day Adventists who also have low intakes of fat (Phillips 1975).

The etiologic relationship of a diet high in fat to breast cancer is unclear and various explanations have been proposed. A high fat diet may affect age at menarche and the amount of adipose tissue, both of which influence hormone levels. Or, high fat diet may have more to

do with influences on gut bacteria that could result in the production of carcinogenic estrogens (Kelsey 1979). The exact mechanisms between high fat intake and breast cancer remain unknown and studies of individuals as opposed to those conducted at a country level have produced mixed results (Kelsey 1979). However, while the biological mechanisms remain to be explained, evidence is convincing of the importance of this relationship.

Several studies have suggested an association between radiation and breast cancer. Women who have been exposed to radiation for treatment of postpartum mastitis and tuberculosis as well as survivors of the atomic bombs in Japan show higher than normal rates of breast cancer (Boice and Monson 1977, Mettler et al. 1969, Wanebo et al. 1968). Much controversy has arisen over the risk of exposure to radiation through mammography screening programs. Several studies investigating this issue have contributed to conclusions drawn by the National Cancer Institute that mammography is potentially associated with an increased risk, that the radiation dose in mammography should be reduced as much as possible, that mammography should not be used routinely in women under the age of 50 years and that randomized trials should be conducted to further investigate the benefits and risks of mammography (Bailar 1976, Shapiro 1977, National Cancer Institute 1977). This issue will be discussed at greater length in the third section of this chapter.

Interests in the possible etiological relationships of certain viruses to breast cancer arose from the discovery of a mammary tumor virus in mice. However, the evidence for the role of a virus in human breast cancer was reviewed by MacMahon et al. (1973) and they concluded

that there is little evidence to support this hypothesis (Kelsey 1979).

Several reports have suggested that permanent and semipermanent hair dyes are mutagenic and could play an etiological role in breast cancer (Searle et al. 1975). However, studies conducted of hairdressers and of women who dye their own hair have produced little convincing evidence to support this hypothesis (Kelsey 1979).

Finally, three case-control studies conducted in the early 1970's reported an increase in risk among women who used antihypertensive drugs containing reserpine (Armstrong et al. 1974, Heinonen et al. 1974). Again, subsequent findings from several additional studies have not found a greater risk among women exposed to this drug (Kelsey 1979).

In sum, the specific causes of breast cancer remain unknown, and as yet, there is no known method of prevention. The disease appears to be dependent upon multiple factors. It has been difficult to adequately define and measure these risk factors and thus, much uncertainty remains concerning the extent to which each contributes to the disease. Summing up the state of epidemiologic knowledge about breast cancer, Kelsey concludes:

> Since the majority of relative risk estimates are fairly modest, our current state of knowledge indicates that in most women there are many variables acting together to determine risk for breast cancer . Whether several of the known risk indicators can be related to some common underlying mechanism, such as a particular hormonal profile, remains to be determined. Also, most of the risk factors identified so far do not readily lead to the implementation of preventive measures (Kelsey 1979:98-99).

The epidemiological uncertainties about risk factors for breast cancer provide a context for understanding why benign conditions come to take on their importance.

3.2b Epidemiology of Benign Breast Conditions:

As discussed, there are many different types of benign conditions some of which may simply represent a range of normal changes within the breast and some of which may indeed carry more risk. The great diversity of benign breast conditions has made it difficult to conduct accurate epidemiologic studies. A comprehensive review of the epidemiological literature of benign breast conditions has been conducted by Ernster who concluded that:

> The existence of benign lumps and other nonmalignant disease processes of the breast has long been recognized, though attempts to classify these conditions and estimate their frequency have suffered from a lack of standardized clinical criteria and terminology...Different investigators have concluded either that BBD displays impressive epidemiologic similarity to breast cancer (Nomura et al. 1977, Sartwell et al. 1978, Staszewski and Koloza 1979) or that there are sufficient epidemiologic differences to assume the two conditions are etiologically distinct (Cole et al. 1978, Soini 1979)(1981:200).

In this section, I will first discuss some of the difficulties in carrying out epidemiologic studies of risk factors associated with benign breast conditions. Second, I will review the evidence for the associations between certain risk factors and benign breast conditions and the evidence for the association between benign breast conditions and breast cancer. The aim of this section is to provide the reader with an overview of the the problems in understanding the relationships between concepts of risk, benign breast conditions and breast cancer.

The design, implementation, and analysis of epidemiological studies of BBCs are limited by three major problems. First, obtaining accurate case definitions has been difficult because of problems in histopathological and clinical classifications and the absence of an universally accepted standardized terminology. Thus, it has been

difficult to clearly delineate cases from non-cases (or controls) as BBCs are often asymptomatic and even when detected, can be given different labels.

A second problem is that while many women have breast lumps, not all women seek medical attention for their condition. This has made it difficult to obtain accurate data concerning the occurrence of BBCs in the general population. Finally, most studies of the occurrence of BBCs have been confined to cases defined by biopsy. This has introduced sampling biases in that not all women with lumps undergo biopsy. The decision to perform a biopsy is often based upon the clinician's subjective assessments about the amount of risk present. Women at risk for reasons other than the presence of a lump are more likely to be biopsied (Love 1984). One would obviously expect to find a higher incidence of breast cancer among a group of women at high risk. Even among those high risk women whose biopsies were normal, the expected incidence of breast cancer would be higher.

In sum, because of problems in obtaining clear case definitions, because not all women seek medical attention for their BBC and because the associations between BBCs and breast cancer have been derived from biopsies among high risk women, it has been difficult to obtain valid descriptive and analytical epidemiological data (Love 1984).

Several different types of studies have attempted to estimate the occurrence of BBCs in the general population. These include biopsies taken from autopsied women who died of causes unrelated to breast conditions, biopsies conducted in case-control and prospective studies and one population-based study conducted by Cole et al. (1978). Despite wide variations in the estimates of occurrence, all studies

indicate that BBCs are very common. Between 8-15 per cent of women may undergo a biopsy before the age of 50, up to 50% of all women may have palpably irregular breasts and as many as 90% of women may have some type of histological changes (Kramer and Rush 1973, Love et al. 1981).

While the risk of breast cancer associated with a diagnosis of a BBC has probably been overestimated it is appropriate at this point to take a closer look at the evidence for an association. One method of examining this association is to compare the previous history of BBCs among women without breast cancer to those who develop breast cancer. Most studies of this nature have been prospective follow-up studies of women who have had a biopsy diagnosed BBC (Black et al. 1972, Clagett et al. 1944, Davis et al. 1964, Donnelly et al. 1975, Lewison and Lyons 1953, Monson et al. 1976, Page et al. 1978, Potter et al. 1968, Shapiro et al. 1968, Veronesi and Pizzocaro 1968, Warren 1940). These women are followed through time to see which ones go on to develop breast cancer (Ernster 1981). While different methods have made comparison of estimated risks difficult, most studies have confirmed that a history of a biopsied-defined BBC is associated with an elevated risk of breast cancer and that the association is strongest for atypical hyperplasia (Dupont and Page 1985). However, retrospective studies investigating the prevalence of BBC among women with breast cancer have shown that only a small minority have a history of biopsy diagnosed BBC (Love 1984).

A second type of study investigating the association between BBCs and breast cancer has explored whether risk factors for BBC are similar to those for breast cancer. However, again results have been mixed.

Studies investigating menstrual and reproductive factors have

produced little evidence of epidemiological similarities between benign and malignant breast conditions. Studies exploring two factors associated with breast cancer, early menarche and late age at the birth of the first child, suggest either a weak association or no association for BBCs (Cole et al. 1978, Fasal and Paffenbarger 1975). Studies investigating obesity and the use of oral contraceptives have suggested that weight and oral contraceptive use may protect against BBCs. The negative association for obesity might be explained by the fact that disease is perhaps more difficult to detect in large breasted women. The protective effect of oral contraceptives is somewhat paradoxical in that studies investigating the association between oral contraceptive use and breast cancer have suggested either a weak positive association or no effect at al (Ernster 1981).

At the time of this study, considerable attention was being directed towards factors which might be associated with BBCs but not with breast cancer. In 1979, two reports suggested an association between methylxanthines and BBCs (Minton et al. 1979a, Minton et al. 1979b). Methylxanthines are found in coffee, tea, cola and chocolate and studies conducted on the use of these products have argued that among women who eliminated these products from their diets, the amount of BBD diminished. However, further investigation was carried out by Ernster et al. (1982) and they found little difference between intervention and control groups in either clinically palpable breast findings or in before-after mammograms. Furthermore, no evidence exists that suggests that methylxanthines might be associated with breast cancer. Nonetheless, the methylxanthine theory has gained considerable popularity among the lay public and while it is probably

more healthy to eliminate products containing methylxanthine from one's diet, the research reported in this thesis show that many women wrongly assume that the health benefits are protective against breast cancer.

In sum, the evidence of an association between benign breast conditions and breast cancer remains unclear. The problems inherent in the epidemiology of benign breast conditions are due in large part to the lack of clear patho-histological and clinical definitions that distinguish between different types of these conditions. Haagenson (1971), who is perhaps one of the world's leading authorities in diseases of the breast has summarized these problems by arguing that:

> Things have come to such a pass that most pathologists diagnose almost every specimen of breast tissue as showing "chronic cystic mastitis". The scrap basket that this diagnosis provides is an easy way of avoiding careful microscopic description and thoughtful classification of breast lesions (1971:156).

As previously discussed, research efforts are directed towards refining pathological, histological and clinical diagnosis and findings are suggesting that excess risk for breast cancer may be restricted to those benign conditions known as ayptical hyperplasia (Dupont and Page 1985). However, further epidemiologic studies of histopathologic specific types of BBs are needed.

3.2c Epidemiology of Minimal Breast Cancer:

Little epidemiologic data exists concerning the incidence of and risk factors associated with minimal breast cancers. As we have seen, until recently, in situ carcinomas were most often discovered quite by accident when biopsies were performed for other breast conditions. However, improvements in mammographic techniques and the increasing use of this technology in routine screening programs has led to an increase

in the detection of small invasive lesions and in situ cancers. For example, the frequency of duct carcinoma in situ increased tenfold between 1972 and 1979 at Children's Hospital in San Francisco and is accounted for by the mammographic detection of small lesions (Lagios et al. 1981).

Several clinical follow-up studies have been carried out (Rosen et al. 1979, Rosen et al. 1978, Betsill 1978) and epidemiologic studies of these conditions are still in their infancy. The importance of epidemiologic studies is to describe the natural history of these conditions and to determine whether minimal cancers share similar risk factors with invasive conditions. One case-control study conducted as a part of the Breast Cancer Detection Demonstration Project compared risk factors for benign breast disease, in situ cancer, small invasive cancer and larger invasive cancer. The researchers found that risk factors of family history of breast cancer, age at first live birth, history of bilateral oophorectomy and obesity were similar for small invasive and large invasive cancers but in situ cancer was affected only by family history and age at first childbirth (Brinton et al. 1983). The researchers interpret their data to support the hypothesis that "minimal cancers" are biologically closer to invasive cancers than to benign disease and that in situ and invasive cancers are at different stages in the process of malignancy. However, further studies are needed to clarify the epidemiological relationships between in situ cancers and invasive conditions.

3.3 SCREENING FOR DISEASE:

Because the specific causes of breast cancer remain unknown and as yet, there exists no known method of prevention, the best hopes of

control are through early detection. Methods of early detection are directed towards screening asymptomatic or healthy women for signs of disease. The most common screening techniques include monthly breast-self exams, routine clinical exams by a health professional, and mammography. Ultrasound and thermography are also utilized but are considered to be less reliable. In this section, I will discuss both the advantages and problems of these screening techniques.

3.3a Breast Self Examination (BSE):

It has been estimated that 80 to 90 percent of all breast cancer symptoms are discovered by women themselves and this is one of the major arguments in favor of breast self-exams (Feldman et al. 1981, Foster et al. 1978, Goldstein et al. 1982, Greenwald et al. 1978, Huguley and Brown 1981, Senie et al. 1981, Strax 1978). However, for many reasons, few women practice BSE on a monthly basis and there is much concern in the medical literature about the effectiveness of BSE (Cole and Austin 1981).

Two issues must be addressed if we are to assess the effectiveness of BSE in detecting early stage cancers. First, in order for BSE to be effective, women must practice it at monthly intervals. Yet many studies report that few women conduct monthly examinations of their breasts. A Gallup poll conducted in 1975 reported that only 18 percent of women interviewed regularly examined their breasts and a study carried out by the American Cancer Society (1973) reported that only 27 percent of women had examined their breasts monthly. Furthermore, 37 percent reported never having examined their own breasts. However, in a study of a BSE program for high school students, Carstenson and O'Grady (1980) report that younger women are more willing than older

women to learn and perform BSE on a regular basis. Thus, the practice of BSE may become more widespread among the younger generation of women.

A second issue concerns the effectiveness of BSE in reducing cancer mortality rates. The assumption underlying the practice of BSE is that if a cancer can be detected in its earliest stage, then life can be prolonged. Few studies have been conducted that assess the effectiveness of BSE and those that have been conducted report conflicting results. Foster et al (1978) conducted a study in which they reported that among 60 women with breast cancer who reported regular BSE, 55 percent had disease in clinical states 0-1 while among 117 women with breast cancer who did not practice regular BSE, only 19 percent had early stage disease.

However, another study conducted by Smith et al (1980) failed to confirm this positive association between BSE and early stage disease. Smith et al (1980) classified 220 breast cancers according to the method of detection and found that among 75 percent of women who reported discovering the cancer themselves, there was no difference by stage or lymph node involvement between these women and those who discovered their lump by accident.

These studies suffer from several limitations including small sample size and the fact that none were a part of a larger study designed specifically to test the effectiveness of BSE (Cole and Austin 1981). Two more recent studies overcoming some of these limitations have been conducted by Huguley and Brown (1981) and by Senie et al. (1981). Both studies included larger samples and both have shed more light on the effectiveness of BSE.

The work of Huguley and Brown reports that of women who practiced BSE, 29 percent had early stage disease as compared with only 19 percent of women who did not practice BSE. However, the authors concluded that only about 25 percent of the benefit among BSE women was due to the practice of BSE itself while the remainder could be explained by the fact that women who practice BSE are also more likely to discover their lumps by accident and are more likely to make use of mammography. In fact, a large number of women practicing BSE had their lumps discovered by mammography.

Finally, a study by Senie et al. (1981) reports that BSE had little relationship to smaller tumor size and the absence of involved axillary lymph nodes. Rather, these variables were closely associated with the frequency of medical examinations.

These mixed findings have lead some researchers to argue that BSE should remain as an "adjuvant" to other primary screening procedures (Cole and Austin 1981) while others have argued that BSE plays an important and primary role in breast cancer screening (Goldstein and et al 1982, Moore 1978).

BSE is not practiced regularly by most women and even among women who discover their own lumps, there is often a long delay time before they seek medical advice. Many studies have explored the reasons for these patterns (Howe 1981, Magarey et al. 1977). This issue will be explored further in chapter 5 of this dissertation. Suffice it to say that while BSE might indeed reduce the overall mortality rate due to breast cancer, there are currently many problems inhibiting regular and effective practiced by the majority of women.

3.3b Clinical Examination:

One of the most useful screening techniques for all women consists of a physical examination of the breast by a woman's doctor or other trained medical professional. Most women see medical professionals at regular intervals for their reproductive health, (e.g. birth control advice, annual pap smears, pregnancy care or other conditions.) Therefore, nurse practitioners, midwives, obstetricians, gynecologists and other primary care providers are in an excellent position to carry out routine exams.

However, these health professionals receive little training in breast care and thus are not properly prepared to conduct thorough examinations or give out adequate advice about breast health. Currently, cases of malpractice for missed diagnosis of breast cancer are a major problem facing obstetricians and gynecologists. This has resulted in more referrals to surgeons for diagnostic decisions (Weekes 1983). It would seem that a practical, simple, effective and inexpensive method of reducing breast cancer mortality would lie in training primary care providers to become skillful in the art of breast examination. Furthermore, the American Cancer Society has devoted much time and energy convincing women of the importance of BSE and it is therefore only logical that similar efforts be directed towards the training of clinicians. Yet work in this area has only just begun.

3.3c Mammography:

Mammography is a process of x-raying the breast and is an important tool for screening and diagnosing breast cancer. As a screening device mammography is a highly effective and non-invasive method for detecting cancers too small to be felt through palpation. "Suspicious" findings are often represented by the appearance of white

flecks or "calcifications". While mammography has great potential in mass screening programs, the technology is not without its problems.

In the early 1960's, the New York Health Insurance Plan (HIP) conducted controlled clinical trials to determine if yearly screenings of asymptomatic women with a combination of mammography and physical exams could bring about reductions in breast cancer mortality rates. The study and control groups each consisted of 31,000 women between the ages of 40 to 64 years. After 7 years, the results of the HIP data indicated that a combination of mammography and physical exam reduced deaths in women between 50 and 59 years by over 40 percent. However, there was no similar reduction in women under the age of 50. (Shapiro et al 1971, Shapiro et al. 1982).

In 1973, based upon the results of the HIP study, the American Cancer Society in conjunction with the National Cancer Institute sponsored 27 Breast Cancer Detection Demonstration Projects (BCDDPs) throughout the United States. The BCDDPs were designed to screen women between the ages of 35 to 74 years annually for a period of 5 years with 5 additional years of follow-up (Baker 1982). However, in 1975 concerns were raised about the possible risks of mammography. The HIP studies had shown no benefit to women under the age of 50 and critics of mass screening began to question whether exposing young women to periodic x-rays could actually increase their risk of developing breast cancer. Furthermore , there were charges that the screening centers were operating in violation of informed consent regulations and that many of the mammography machines were poorly calibrated (Bailar 1976, Greenberg 1977).

These criticisms lead the National Cancer Institute to set up

three expert committees to re-examine the HIP data. The committees investigated the epidemiological and biostatistical data, the pathological data and the effects of radiation carcinogenesis. All three committees reached the consensus that because it was difficult to assess the benefits of routine mammography to women under the age of 40 and because of the possible risks of x-ray exposure, routine screening for women under the age of 40 who were not at high risk, should be terminated. (American Cancer Society 1982).

In the thirteen years that have elapsed since the first HIP reports, mammography technology has been improved. Modern machines give lower doses of radiation and new screening techniques are more sensitive than previous methods. Several trials have been conducted in Sweden, Canada, and the United Kingdom to further test the HIP findings (Tabar 1981, Miller et al. 1981, UK Trial of Early Detection of Breast Cancer Group 1981). The results of two case-control studies carried out in the Netherlands have confirmed the benefits of population based screening programs. These two studies reported a 50 to 70% reduction in mortality among screened women (Verbeek et al. 1984, Collette et al 1984). Furthermore, these studies suggest that modern mammographic screening may be of benefit in reducing mortality among women under the age of 50 years. The study by Collette et al.(1984) screened women between the ages of 35 to 65 years of age and in contrast to the HIP findings, reported that the relative risk of dying of breast cancer for women at the lower age-limit was equal to that of women at the upper age limit. Additionally, the study suggests that mammography alone might be effective in reducing risk of dying of breast cancer.

Despite the increased sensitivity of mammography, there are still

many problems which need to be resolved before it is introduced as a mass screening technique for general populations. First, there is a possible increase of unnecessary biopsies due to mammography. In the HIP study, among cases where screening lead to biopsy, only 21 percent (or 1 in 5) were positive. Verbeek et al. (1984) reported a lower but still high false positive rate; for every detected case, two women had a referral and one of them had a biopsy that they would not have had if there had been no screening (1984:1223). This points to the need to improve the sensitivity of mammographic techniques.

Second, increased use of mammography has lead to the diagnosis and treatment of non-cancers. The BCDDPs have been criticized for identifying cases that resulted in the treatment of non-cancers or borderline cancers:

> "A third pitfall of mammography is also related to these so-called minimal cancers. Slides from those 506 cancers just mentioned were recently reviewed by an expert pathology team. It found that more than 80 of the growths were clearly not cancer or borderline. A chain reaction of mishaps has ensued. The least of them is that mammography has been given credit for saving lives that were not endangered in the first place. More importantly, the women in question, besides having unnecessarily lost a breast, have been living in needless fear of cancer recurrence (Randal 1977:39).

This finding was reported in the press and has contributed to public awareness about the need for caution concerning benefits of mammography. Even the recent studies conducted in the Netherlands report caution about the diagnosis and treatment of non-cancers. Verbeek et al. (1984) reported a higher annual diagnostic rate of primary breast cancer than before the screening program. They suggest that this might be partially due to the diagnosis of non-cancers.

Another difficulty with mammography concerns the false-negative

rate. Various studies have reported the sensitivity of mammography to be between 60 and 80 percent (Hicks et al. 1979, Verbeek et al. 1984). Verbeek et al. report the sensitivity of mammography to be about 80% and explain a third of the false-negative cancers to be the result of technical faults, a third to be radiologically occult and a third to be fast growing tumors that were not detectable at the time of screening. Mammography alone can not be expected to detect all cancers and sensitivity is increased when combined with a clinical exam.

Finally, one must consider whether mass screening is cost effective. Currently, mass screening is expensive and thus raises the question of whether screening should be selective; aimed only at high risk groups. If it is to be selective, it is important to clearly identify which risk factors are predictive of disease and to select only women with these risk factors for screening. Yet, as we have seen, epidemiologists have been unable to clearly identify risk factors that are strongly predictive of most cases of breast cancer. In their report on the failure of selective screening for breast cancer, Soini and Hakama (1978) observed that one-fifth of breast cancer cases studied remained in the low risk group and that selective screening was of only limited application in public health work. They concluded that savings in cost of up to one third could be attained if it was accepted that every fifth cancer patient was to remain in the population not screened. Obviously, this raises ethical issues in addition to economic ones.

3.3d Additional Screening Techniques:

Other screening methods less commonly used in the United States include thermography and ultrasound. Thermography is a technique that

measures the temperature of the skin. It has been shown that cancers give off more heat than normal tissue and thermography measures this heat difference through infra-red radiation emitted by the skin. This method is more commonly use in Europe. In the United States, its use is largely experimental. One reason for its low use in the United States is that about a third of all cancers do not produce heat. Furthermore, thermography can pick up other heat producing conditions such as sunburn and insect bites. If the accuracy of thermography can be improved, this technology would be advantagous to women under the age of 40 as it involves no exposure to ionizing radiation.

Another non-invasive detection technique is ultrasound. This method detects abnormalities by projecting high-frequency sound waves into the breast. The different echo patterns given off are then converted into a computer image and abnormalities are interpreted from the attenuation and speed of the sound waves as they pass through the breast. The limitations of ultrasound are related to the accuracy of the equipment. This method is still in its experimental stages but is of potential value to women under the age of 40.

3.3e Summary Discussion:

Screening techniques, no matter how accurate, cannot prevent cancer. They are only valuable in secondary prevention. Thus, while it is important to develop accurate and low cost screening technologies, this effort should not draw attention away from research into risk factors that might lead to prevention activities. Currently, the extent to which screening actually increases life expectancy is unknown. And there are risks attached to general screening for breast cancer. Screening programs may cause considerable anxiety among women

being screened. They may also confer a false sense of security in women who are screened and receive a clean bill of health. Finally, increased screening can lead to unnecessary biopsies and unnecessary treatment.

3.4 DIAGNOSIS:

Ultimately, the diagnosis of breast cancer is a pathological one requiring microscopic examination of breast tissue by a pathologist. The clinical indications for a biopsy are a palpable mass in the breast and/or a nonpalpable lesion detected by mammography (Carter and Eggleston 1977). There are two general types of biopsies, aspiration and surgical biopsies. An aspiration biopsy, also commonly referred to as needle biopsy, is a procedure where the surgeon inserts a needle into the breast mass and attempts to withdraw some breast cells and tissue. There are two types of needle biopsies, one of which is referred to as a fine needle biopsy (FNA). This procedure is used to withdraw fluid and is commonly indicated for draining cysts. Some of the fluid withdrawn may be spread on a slide and sent to the pathologist for inspection. If the withdrawal of fluid causes the cyst to disappear, often no further action is taken.

The other type of needle biopsy is used when breast tissue, rather than fluid is withdrawn. A wide needle is used and tissue is spread on a slide and sent for pathological examination. If the biopsy is positive, it enables both the doctor and woman to begin considering different types of treatment. However, false negatives are a potential problem as the needle may have simply missed the cancer cells. Therefore, negative needle biopsies are often followed by surgical biopsies in order to rule out cancer. This problem of false negatives

has discouraged many surgeons from utilizing this method of biopsy. I will discuss this issue in more depth in chapter 5.

A second type of biopsy is the surgical biopsy. Again, there are two general types, incisional and excisional biopsies. With an incisional biopsy, only a part of the lump is removed. Excisional biopsies remove the entire lump. Both types of biopsies can be performed under a local anesthetic on an outpatient basis or under general anesthesia on an inpatient basis. The former procedure is becoming the more common.

Once the tissue is removed, the specimen can be examined in two ways. First, it can be examined quickly by a frozen section. In this procedure, the tissue is frozen in liquid nitrogen for about 45 seconds so that a thin section of tissue can be cut. The section is then placed on a slide, stained, and then mounted for microscopic examination. In a frozen section, only the most suspicious tissue is selected for freezing and it is possible, as with needle biopsies, to sample the wrong tissue. While this method can give rapid feedback to the woman and the surgeon it is not as accurate as permanent section. Therefore, pathologists and surgeons are often hesitant to give a clean bill of health until confirmation with a permanent section. This second method consists of a more exhaustive examination of the tissue as a permanent section. This method takes about 48 hours but provides a more definitive diagnosis (Carter and Eggleston 1977).

If a pathologic diagnosis is negative, a woman may be followed closely by her surgeon for a while to see if other breast problems develop. If she is not considered at high risk, then she will be often be referred back to her general practitioner or gynecologist. However,

if she is considered to be at high risk, the surgeon may recommended that she return for exams at three or four monthly intervals.

If a pathologic diagnosis of cancer is made, several additional diagnostic techniques will be performed in order to determine the extent of the disease. X-rays, blood tests, body scans and urinalysis are used to determine the how far the disease has spread. Estrogen-receptor assays are performed to determine whether or not the tumor growth is affected by female hormones. Once these diagnostic tests are evaluated, the cancer can be classified, staged and treated.

3.5 TREATMENT:

Currently there is much controversy concerning treatment options for both benign and malignant breast conditions. In the case of benign conditions, often an excisional biopsy represents both a diagnosis and treatment. That is, an excisional biopsy removes all of the tissue under question. However, for women with more extensive benign conditions, other forms of treatment may be recommended. If a woman suffers from pain and lumpiness before her menstrual period, she may be advised to cut down on her salt intake and sometimes a mild diuretic will be prescribed. She may also be given dietary advice such as taking vitamin E and cutting down on her caffeine intake.

Other more extreme treatments have been used in the treatment of benign breast conditions. A male hormone (Danazol) has been used in the treatment of fibrocystic disease. While Danazol is effective in reducing breast lumps and discomfort, it has a number of side effects including cessation of menstrual periods and the growth of facial hair. It is expensive, costing about $200 a month, and when a woman stops taking the drug, her breast lumps and discomfort return (London et al.

1982, Love 1984). A more extreme treatment consists of bilateral subcutaneous mastectomies for women with fibrocystic breast disease (McCarty et al. 1981, Shocket et al. 1972). The justification for this treatment is based on the belief that the operation will prevent breast cancer. However, new studies are beginning to show that because not all of the breast tissue is removed, that subcutaneous mastectomies do not guarantee against the future development of breast cancer (Goodnight et al. 1984). Therefore, in order to prevent cancer, the appropriate procedure would seem to be total mastectomy which results in removal of all breast tissue.

As I have argued, there is much controversy concerning the extent to which benign conditions can be considered disease entities. If in fact, many benign conditions are simply normal variations of breast tissue or if most are not strongly associated with malignant disease, this raises the question of why treat a non-disease?

The treatment of breast cancer is also an area of much controversy. Carbone (1981) has written a concise and easy to read review of the state of the art in breast cancer therapy and the reader is referred to this article for a more in-depth discussion of these issues. Briefly, surgical treatment choices range from removal of the tumor only, to removal of the breast, pectoral muscles, axillary and internal mammary lymph nodes and sections of the rib. Radiation, chemotherapy, endocrine manipulation, and immunotherapy are also used to control the spread of the disease.

One of the greatest therapeutic controversies has revolved around the question of whether survival is better with the Halsted radical mastectomy or with less extensive surgical procedures. Those in favor

of less extensive forms of surgery cite studies that show for certain types and stages of cancer, there is no difference in survival rates between women who elect to have the more extensive surgery as compared to those with less extensive procedures. The current trends are to perform a partial mastectomy followed by radiation (Fisher et al. 1985). This allows the woman to retain some of the breast tissue that can be augmented later by plastic surgery. Radiation therapy is given in order to kill any remaining cancer cells in the breast.

Those against this treatment procedure argue that breast cancer is a multicentric disease and that therefore it is likely that it will reoccur in another part of the breast or in the opposite breast. Proponents in support of less radical surgery argue that although the rate of reoccurence may indeed be higher, this has little effect on overall survival rates. (American College of Surgeons Commission on Cancer 1982, Carbone 1981).

Chemotherapy is used to destroy cancer cells that have spread through the blood to other organs of the body. While the use of chemotherapy has the effect of killing cancer cells, it also affects normal cells. It is administered orally or through injection, weekly or monthly in conjunction with local surgery and/or radiotherapy. Studies have shown that some forms of chemotherapy may be more effective in premenopausal women than in postmenopausal women and in women who's tumors do not respond to estrogen (Glass et al. 1977, Lippman et al. 1978). Current chemotherapy drugs have serious short and long term side effects and the toxicity must be carefully monitored.

For tumors that respond to estrogen, endocrine manipulation is possible. The ovaries, adrenal glands and the pituitary gland are the

three endrocrine glands that appear to affect breast growth. These glands are manipulated by either removal or by the injection of hormones. Studies have shown that of the women who have positive estrogen-receptor assays, two-thirds will respond to this form of therapy (National Cancer Institute 1980).

In sum, treatment for benign and malignant breast conditions remains an area of much controversy. Carbone has summed up the field by stating that:

> Expanding knowledge of the biology of breast cancers has led into an era of therapeutic uncertainty. The role of radical mastectomy is no longer unassailable. The value of postoperative radiation is dubious at best, that of chemotherapy is being confirmed. And oncologists are becoming increasingly appreciative of the importance of lymph-node and estrogen-receptor status in a patient's prognosis...In this era of therapeutic uncertainty, clinicians are faced with a number of options in the management of patients with breast cancer. The treatment options include modified radical mastectomy; simple, or total, mastectomy; segmental mastectomy; lumpectomy; and irradiation alone. Other choices are when to do the biopsy and whether to do it as a one-stage procedure at the same time definitive surgery is performed or as a two-stage procedure, with treatment instituted at some time after the biopsy (1981:53).

3.6 SUMMARY:

In this chapter, I have outlined some of the key areas of uncertainty in scientific knowledge about benign and malignant breast conditions. As we have seen, knowledge in the areas of pathology, epidemiology, screening, diagnosis and treatment is rapidly changing and many current beliefs and practices are under question. Major problems in understanding the relationship between benign changes in the breast and breast cancer stem from the difficulties in determining their clinical meanings and implications.

In the following chapters, I shall explore how uncertain medical knowledge is translated into practice. This chapter provides the foundation for understanding the kinds of dilemmas that doctors and women face in the care of breast health.

CHAPTER 4: THE MEANING OF LUMPS: THE CLINICAL DILEMMA

4.1 INTRODUCTION:

> Between unmistakable instances of disease and cases of unquestioned health there may be a broad gray zone. This uncertainty, however, arises largely from an ambiguity of language. --King 1982:140

> To be uncertain is to be uncomfortable but to be certain is to be ridiculous. --Chinese Proverb

The problem of ambiguity and uncertainty in medicine is a familiar one shared by both clinical practitioners and medical researchers. This ambiguity and uncertainty is due in part to the changing characteristics of disease phenomena and in part to attempts to reduce ambiguity and uncertainty through the rapid production of medical knowledge.

Non-infectious diseases represent the major health challenges facing industrialized societies, the leading causes of death being heart disease, cancer, stroke, and diabetes. Explanatory models of the etiology and management of these conditions have been shaped by our understandings of infectious diseases. Models of infectious disease define both the infectious agent and the factors leading to host susceptibility. Etiology or concepts of cause play a central role in the understanding of infectious disease. The major activities in medical research have been directed towards isolating the infectious agent and intervening in the path of infection. Thus, control measures have focused upon eradicating the agent and reducing host susceptibility (Mausner and Bahn 1974).

The rapid increase in the incidence and prevalence of

non-infectious diseases has introduced new complexities to models of agent-host relationships. Current dilemmas in scientific and clinical thinking and practice center around the concept of cause. With non-infectious diseases, the multifactorial nature of their etiology is often unclear and the absence of a known causal agent makes diagnosis, management and prognosis difficult (King 1982, Mausner and Bahn 1974). These problems have pointed to the need for reassessing old explanatory models in order to create new ways of thinking about the relationships between disease and health. It is thus becoming more common for both researchers and clinicians to find themselves operating within ambiguous and uncertain contexts (Bursztajn et al. 1983, Comaroff 1982, King 1982).

While the quest for new knowledge has produced greater certainty in some areas it has ironically increased ambiguity and uncertainty in others. Medical technology has increased the range of human perception and has allowed, at least in theory, for more precise and effective discrimination between normal and abnormal states. At the same time however, technology has introduced a number of difficult problems as, ultimately, "data" do not speak for themselves, they must be interpreted and given meaning. The interpretative act is conducted within a context where the known and the unknown merge and more often than not, new discoveries are given many different interpretations. For a time, they come to take on multiple and competing meanings. Ultimately, interpretative acts should result in the production of new knowledge, in that a meaning comes to be accepted as being both "objective" and "true". However, the acceptance of new knowledge as "objective" and "true" is often a long and problematic process. The lag

between the production of new medical data, its interpretation, and its transformation into knowledge can be conceptually understood as an ambiguous space where "data" are given multiple meanings at the same time.

The transformation of multiple interpretations into knowledge requires that this ambiguous space be replaced by one where there is shared consensus concerning the meaning of data. This ambiguity has different consequences for medical scientists and clinicians precisely because the uses of knowledge differ between the two. The scientist is concerned with the production of knowledge in order to promote explanation whereas the clinician is more directly concerned with the use of such knowledge to increase the precision of diagnosis resulting in more effective therapy and prognosis (King 1982, Murphy 1982). For the medical practitioner, the rapid production of new laboratory and epidemiological data and the lag in production of explanations about the meaning of these data has increased the uncertainty of the clinical act. Thus, medical practitioners are faced with the dilemma of translating often ambiguous scientific meanings into clinical knowledge and practice.

In this chapter I am concerned with understanding the relationship between ambiguous scientific knowledge and uncertain clinical practice. The goal is to explore and understand how clinicians experience and control uncertainty in the diagnosis and management of benign breast conditions. The chapter is ethnographic in nature and provides the foundation upon which the central argument of this research is based. That is, that surgeons experience uncertainty as clinical risk and that they control risk by transforming it into a clinical entity. Through

this transformation, risk becomes understood not as a property of clinical practice but rather, as a property residing within the body or tissue of a particular patient. Within the clinical model, risk becomes transformed into a sign of a currently hidden or future disease. Risk as understood as a clinical entity allows surgeons to control uncertainty by manipulating the part of the body at risk. Surgeons control clinical uncertainty by removing risk from the body, thereby bringing about greater clinical certainty. Surgeons, then, manage risk as they do other disease entities by removing the physical condition that is understood as being "diseased".

In this chapter, I explore the dilemmas surgeons experience when practicing within a context defined by scientific ambiguity and clinical uncertainty. By understanding these dilemmas, we can better understand how uncertainty becomes transformed into the clinical entity of risk and how clinical uncertainty is controlled through the treatment and management of risk. The chapter is divided into three sections. In the first section I discuss the assumptions upon which current models of diagnostic processes are based. I argue that current models are no longer adequate for dealing with physical conditions about which the meanings are highly ambiguous. In the second section, I explore the uncertainty surgeons experience in the diagnosis of benign breast conditions. The third section explores how, when faced with ambiguous diagnostic results, surgeons manage benign conditions.

4.2 THE ART OF DIAGNOSIS:

> In diagnosis, the young are positive and the middle aged tentative; only the old have flair! Lancet 1951:795

The art of diagnosis consists of the clinical act of bringing

order and meaning to a series of signs and symptoms. The clinician transforms a patient's subjective complaints into a disease entity; an objective clinical reality that can be classified, understood and acted upon. In theory, clinicians should be able to draw upon knowledge that enables them first to distinguish a number of possible classes or categories that might explain the phenomena and second, to place the phenomena in an appropriate disease category. The clinician should then be able to argue why the phenomena belong in that category and not in any other (King 1982:91).

The medical model within which most clinicians operate is based upon two assumptions. First, that there exists an objective physical reality that scientific and clinical knowledge can discover. Second, that signs and symptoms can be understood as referring to some underlying physiological or chemical change, the meaning of which can be established and agreed upon (Feinstein 1973, McGehee et al. 1979). These assumptions form the foundation of medical thinking and are imparted early within medical education. Thus, most medical texts aim at making explicit the defining criteria demarcating each disease category while lectures and clinical experience teach the medical student the practical activity of diagnosing, or being able to 'see' these disease states and to know their meanings. Through this process, the physician learns to give form and meaning to "abnormal" changes in the body. In theory, this process should be straightforward. However, in reality it is complicated by the fact that the meanings of states of ill-health are forever changing. The history of medicine has been characterized by dynamic shifts in the way that we understand the relationship between health and disease and the meanings of

patho-clinical states (Foucault 1975, King 1982).

> Diagnosis depends on the existence of classes that are ever shifting in their meaning, definitions, and relationships, as well as their persistence and usefulness (King 1982:104).

4.2a Signs and Symptoms, Disease and Illness:

A physician's skill in diagnosis depends to a large extent on his or her ability to interpret signs and symptoms. Stedman's medical dictionary (1976) distinguishes between signs and symptoms by defining a sign as "...any abnormality indicative of disease, discoverable by the physician at his examination of the patient: a sign is an objective symptom of a disease: a symptom is a subjective sign of disease." A symptom then, is defined as "...any morbid phenomenon or departure from the normal in function, appearance, or sensation, experienced by the patient and indicative of disease." These definitions point to the difference between the subjective experience of the patient as compared to the objective experience of the doctor. However, within a biomedical model, both definitions are based upon the assumption that states of ill-health as experienced by both patient and physician can be confirmed by some underlying patho-clinical abnormality.

Prior to the 19th century, little difference was made between a patient's experience of sickness and the doctor's reading of disease. A patient's subjective symptoms were the physician's objective signs. That is, there was not much difference between what both patients and doctors perceived. The difference lay in the interpretation of what the phenomenon meant (King 1982). Thus, Foucault argues that:

> Beneath a gaze that is sensitive to difference, simultaneity or succession, and frequency, the symptom therefore becomes a sign-...the sign is the symptom itself, but in its original truth. At last there emerges on the horizon of clinical experience the possibility of an exhaustive, clear, and complete reading: for the doctor whose skills would be carried to the highest degree of

> perfection, all symptoms would become signs; all pathological manifestations would speak clear ordered language (1975:94).

Current medical thought assumes that the clinician's objective reading of signs provides a more reliable understanding of disease than the patient's experienced symptoms. This change has been brought about in part, by technological advances that have changed the physician's ability to observe the body. Percussion and ausculation allowed for indirect ways of perceiving the body and allowed the physician to elicit and interpret data not directly accessible to the patient (King 1982, Reiser 1978). Through these technologies, the physician has come to have access to a new body of data, data that do not rely upon the patient's subjective experiences of ill-health. The diagnostic task becomes one of discovering and transforming objective signs into a disease reality. Thus, in the contemporary act of diagnosis, there is a fundamental separation between signs and symptoms, the former representing more clinically objective and therefore more reliable readings of underlying pathological or chemical change.

The separation of signs and symptoms into two realms of experience and the legitimization of signs at the expense of symptoms often results in patients and doctors holding different explanatory models of sickness realities. Symptoms represent the expression of the patient's illness reality. Illness can be understood as, "...the psychosocial experience and meaning of perceived disease" (Kleinman 1980:72). Signs represent the clinical experience of disease. Disease then, can be defined as, "...the malfunctioning of the biological and or psychological process" (Kleinman 1980:72). While the clinician operates within a biomedical model where he or she elicits signs

leading to diagnosis, treatment and cure of disease, this approach may not heal a patent's illness (Kleinman, Eisenberg and Good 1978, Engle 1977, Fabrega 1972, Good 1977, Kleinman 1978). That is, the patient's experience of ill-health often goes beyond the clinical encounter. The subjective or lived experience of ill-health is embedded within a social and cultural context. Perceptions in changes of well-being have social and cultural meanings which are often not shared by clinicians trained within a scientific medical model. In a very real sense, patients and doctors do not share the same cultural realities. Problems of patient dissatisfaction, clinician dissatisfaction, non-adherence, dropping out of care and medical-legal problems often stem from these differences in the meanings of biomedical and lay experiences of sickness.

The clinical process of diagnosis is fundamentally an interpretative one as clinicians must bring meaning to elicited signs. But clinicians often fail to interpret the patient's symptoms in such a way as to understand the patient's illness reality. To readdress this problem, Good and Good (1981) argue for the incorportation of a cultural hermeneutic model of clinical practice.

> The cultural hermeneutic model provides the clinician with a model of a patient's illness as a syndrome of meaning. As a clinical model, its purpose is to enable the physician to elicit and analyze the meaning illness has for a patient and to consciously and successfully translate across medical subcultures. Unlike the biomedical model, which conceives disease as a biochemical or physiological abnormality, the cultural hermeneutic model conceives illness as a meaningful experience of an individual. Thus while the data made relevant by biomedical models are clinical data that reflect underlying physiological disorder, the primary data made relevant by the cultural model are those that yield special insight into the semantics of sickness. (1981:178-79)

The biomedical model of clinical diagnosis operates on a number of

assumptions concerning the sequence of clinical events. First, it assumes that the patient initiates the clinical encounter by "presenting" with one or more symptoms. Second, after listening to and observing the patient's symptoms, the doctor will elicit signs of some underlying disorder. Finally, the signs that the clinician elicits will have some relationship to an underlying pathological or chemical condition.

However, these assumptions are often faulty as the sequence of clinical events does not always follow this neat pattern. Concerning the first assumption, patients do not always initiate the clinical encounter by presenting with symptoms. This often occurs in routine physical examinations when a number of laboratory tests might reveal abnormalities in pathological or biochemical functioning. Such is the case for high blood pressure, diabetes, and anemia. In this situation, the physician has elicited objective signs of a disease and has created a biomedical reality. The patient is suddenly confronted with a state of ill- health that was up until that moment, nonexistent. After receiving a diagnosis, the patient may react in one of two ways. First, he or she may create an illness reality resulting in an altered awareness of the body. The patient experiences an altered state of health and creates a set of symptoms corresponding to the clinical signs of disease. For example, the diagnosis of diabetes might bring to consciousness the fact that a person had indeed been feeling tired and run down, yet until that time, these experiences were not constructed as symptoms of illness. The patient has now created a new illness reality in order to bring meaning to the biomedical creation of disease.

A second alternative exists when, in the absence of symptoms, a person refuses to accept the disease reality. This situation often occurs with diseases such as high blood pressure where doctors and patients do not share clinical realities precisely because the patient does not create an illness reality. It is common for people diagnosed as being hypertensive to not feel ill. Because of the absence of symptoms, an individual may not choose to believe that she or he has a disease. Instead, they choose not to be ill and thus, may not comply with their doctor's treatment plan. In this study, one woman diagnosed with an early stage cancer confided that she did not really believe that she ever had cancer because she did not feel sick. She believed that the doctor had made a mistake and that she should not have had a mastectomy.

The second assumption; that the doctor, after listening to and observing the patient's symptoms, elicits signs of some underlying disorder, is often faulty as it is frequently difficult if not impossible for the doctor to discover signs of disease. This results in the physician failing to establish a disease entity that corresponds to the illness experience of the patient. The clinician fails to give clinical legitimacy to the subjective symptoms of the patient. The physician may attempt to solve this problem by acting in one of two ways. First, the clinician may refer the patient up the medical hierarchy to one or more specialists or order an array of diagnostic laboratory tests. Second, the clinician may assume that because he or she can find no pathological basis for the patient's complaints, that that patient's illness reality must be ill-founded. This often results in the patient's complaint being classified as psychosomatic in origin.

The third assumption; that signs elicited by the clinician will have some relationship to an underlying pathological or chemical condition, is faulty in that it is often difficult for the clinician to determine whether or not elicited signs refer to some underlying abnormality. For example when conducting a routine breast examination a physician may find some slight nodularity and is unsure of the meaning of this sign. Does it represent an abnormal change or does it refer to a range of normal breast physiology? A variation of this faulty assumption occurs when the sign itself clearly represents an abnormality but the physician is not sure what kind of abnormality it signifies, what other signs it should be grouped with, and how to classify it into a disease category. Again we can take an example from the diagnosis of breast conditions where a dominant lump is believed to be a sign of an abnormal change; however, the kind of abnormality, and its meaning, is often ambiguous.

Because these three assumptions are often not met, clinicians find themselves enmeshed in situations where the medical model guiding their thought and action is no longer appropriate. It is within these contexts that clinicians must face the inherent uncertainties of medical practice. Physicians experience contexts of uncertainty and ambiguity as risky situations and it is within these contexts that risk becomes diagnosed, managed and treated like the unpredictable disease it represents.

4.3 THE MEANING OF SIGNS AND SYMPTOMS IN THE DIAGNOSIS OF BREAST LUMPS:

The process of the clinical diagnosis of breast conditions illustrates the above dilemmas. When a clinician performs a breast

examination and is uncertain about the meanings of physical findings, the most common procedure is to refer the woman on to a surgeon. The surgeon is then responsible for interpreting the meaning of suspicious changes. Surgeons generally begin their clinical evaluation by taking a patient history and conducting an examination of the breasts. Based upon interpretations derived from these two procedures, surgeons will then decide whether additional screening and diagnostic procedures are required. These procedures might include pathologic and radiologic evaluations. A diagnosis is then made based upon interpretations of both clinical and laboratory signs. In bringing meaning to a series of signs, surgeons must draw upon the expertise of a number of different scientific and technological specialists. As discussed in Chapter 3, the meanings of various pathological changes occurring within the breast are not clearly understood and are often ambiguous in that these changes can come to take on one or more meanings depending upon the philosophical orientation of the observer. Thus, surgeons are often faced with the task of translating and integrating esoteric and experimental knowledge into practical clinical knowledge. This makes the task of diagnosis particularly problematic for the surgeon. Within the scientific realm, ambiguity poses no immediate problems and in fact, can be a positive motivator for the quest for new knowledge and new understandings (Murphy 1982). The clinician however, is faced with the task of translating these meanings so that he or she can act upon them. In other words, the task of the clinician is to remove ambiguity by creating categories that will give order and sense to the signs. But, attempts to remove ambiguity often leave clinicians in a state of uncertainty concerning diagnosis, management, and prognosis. And this

is a difficult dilemma within which the surgeons find themselves more commonly enmeshed. Two surgeons illustrated this dilemma by explaining:

> In terms of early diagnosis the only differences are the tools. In the old days you had nothing but your hands and your eyes and your senses. Now you've got mammograms and sonograms and thermograms. I don't know if what we're finding is the same thing as it was when we gathered our early knowledge.
>
> It's very unforgiving if you miss a cancer. I keep telling myself that my fingers will tell me just so much and mammography will tell me just so much and the combination of mammography and physical examination will tell me more than one or the other alone but even then, mammography and physical examination both can come to the wrong conclusion.

Clinicians are caught in a dilemma in that their very attempts to reduce uncertainty through the use of multiple diagnostic technologies, can ironically act to increase uncertainty. And even when diagnostic results are consistent, there is still the chance of being wrong, of missing a hidden cancer or of failing to predict the development of a future cancer. This section will explore how surgeons experience this uncertainty within four phases of the diagnostic process: systems of referral, taking a patient history, the clinical examination, and the use of diagnostic techniques.

4.3a Referral to a Surgeon:

A woman may be referred to a surgeon for a number of different reasons. Referral may depend upon signs elicited by another clinician, symptoms experienced by a woman or a combination of both. Most women are referred to surgeons by general practitioners, internists or gynecologists and many referrals to the university hospital were from community health centers, family planning clinics, and women's health clinics. Because the diagnosis of breast cancer is in the final

analysis, a microscopic one and because the interpretation of a physical examination is difficult, the responsibility for diagnosis gets passed up the hierarchy to a specialist who is assumed to be better equiped to deal with this uncertainty. As one surgeon pointed out:

> I notice that many of the internists bail out so to speak as soon as they feel something that doesn't seem just right. And they shift the responsibility as to diagnosis and treatment to someone else.

Another surgeon explained:

> 85% of my practice has been this breast trouble,...its about 85% breast headaches. I get a lot of referrals from mostly the gynecologists and internist when they discover a lumpy breast or a breast that is difficult to follow.

The general practitioner is faced with several problems which he or she solves by referring a woman on to a surgeon. First, as medical students, they receive little training in how to conduct breast examinations. Second, internists and general practitioners conduct fewer breast exams than do gynecologists and thus have less opportunity to become familiar with variations of breast changes. And third, the proper management of breast problems is generally accepted as falling within the speciality of surgery. This trend is due in part, to the traditional mode of treating breast cancer with surgery. However, there are many kinds of breast conditions that might be better managed by other medical practitioners. One gynecologist explained:

> You've got to look at the interesting history of why surgeons are doing breast biopsies and not gynecologists. It's the same reason why general surgeons in a big city don't do hysterectomies and gynecologists do. It's a concept of economic turf. I don't know how and when it got to be that ob-gyns gave up the turf of breast operations to general surgeons but it was probably parallel to the time that education about breast disease began to falter in terms of ob-gyn training programs. So, there is no formal training in ob-gyn residencies at a good place like the university hospital. No education really about it in medical school. It's like

nutrition. It just doesn't exist. It's strange for us people who see all the breasts not to know what to do. That's a problem!

If general practitioners do not refer, they may face legal consequences. Another gynecologist explained the problems he faces in failing to diagnose breast cancer:

> It hasn't happened to us although it is a common problem and one of the leading causes of liability claims in gynecology. So it is an issue, I don't know what the correct answer is to protecting against that other than good careful examinations. I think that gynecologists and other specialists have been improperly and unduly sued or criticized for failure to diagnose when the problem is not in the ineptness in the examiner, it's the course of the disease and the variability of the disease.

Thus, for a number or reasons, uncertainty gets referred up the medical hierarchy to be dealt with by the surgeon.

Finally, a woman can arrive at a surgeon's office through self-referral. Women often become aware of the health hazard of breast cancer through a friend or a media event and thus seek the advice of a surgeon either because they have found a lump themselves or are concerned about their risk of getting breast cancer. While most surgeons in the private hospital reported that only a small number of women were self-referred, they said that most self-referred women tended to see the surgeon for concerns other than the discovery of a dominant lump. One private surgeon explained:

> Now, because of all the publicity and particularly what the Cancer Society does, every woman is scared that she has got breast cancer and she's going to die within a week of it. So the number of women who go to the doctor is just fantastic. So many of them just walk in, they just come in off the street. Because it is so well advertised every woman is practically concerned about her breasts every day of the week. So they just go to doctors, they can't escape it.

A greater number of women were reported to be self-referred at the

university hospital. This is in part due to its greater visibility and the existence of its Breast Screening Clinic. A nurse explained:

> About 40% would be self-referred or friend referred. A lot of women just hear about it [the Breast Screening Clinic] from friends. Usually they have a perception of a breast problem. They think there's a problem although sometimes you get women who come in just because they're high risk and they know they want to be followed.

In sum then, women are usually referred to a surgeon without a diagnosis. Thus, it is the surgeon's task to give meaning to a series of symptoms and signs and then to act upon the diagnosis.

4.3b Meaning of Signs and Symptoms Elicited in Patient Histories:

The surgeon begins the diagnostic process by taking a patient history with the aim of eliciting three kinds of information; the patient's level of concern, current and past symptoms, and risk factors for breast cancer. All three types of information allow the surgeon to predict whether the woman's condition might be benign or malignant and to begin to create a number of possible diagnostic categories.

All surgeons explained that the first thing they try to do in the initial encounter with a patient is allay her concerns and fears. They gave two main reasons why they thought that this was important. First, surgeons realize that the discovery of a breast lump causes a woman much emotional distress and they believed that it is important to address these concerns from the start. Thus, many of the surgeons in private practice said that they attempt to see a woman as soon as possible. Two explained:

> The first thing she does is calls. She's freaked out. So I consider it an emergency. I try to see her the same day.

> I see most of them the same day that they are seen in the primary care doctor's office or the same day they have called. They come in, are sitting there wringing their hands and maybe crying and maybe just scared to death. I consider it an urgent problem.

It is more difficult for surgeons working at the university hospital to see a patient immediately. However, if the woman is referred privately or with a diagnosis of cancer, every effort is made to schedule an appointment within the following two to four days. The surgeons working at the university hospital have commitments to teaching and research in addition to their surgical practice. Thus, women are often seen first by clinic nurses who are faced with the task of reassuring the patient and taking a history.

Apart from a personal concern for the emotional well-being of their patients, assessing the woman's level of concern also aids the surgeon in deciding on appropriate diagnostic and management procedures. Because the diagnosis of breast conditions is an uncertain act, there is always the very real chance that the clinician will be wrong. This puts the surgeon in the uncomfortable position of making a decision that is not always correct. By addressing a woman's emotional concerns at the beginning of the clinical encounter, the surgeon can encourage her to take some responsibility for decision making. One surgeon explained:

> The first thing you have to recognize is that on the basis of a physical examination alone, you know, you can only make an educated guess which has maybe an 80% accuracy. So you're always left with the concept that you're wrong 20% of the time....It depends on how they [women] respond in the conversation as to what one does. There are many women who are very satisfied with the doctors just examining them. If they're young, if they're in the low risk group and their likelihood of having breast cancer is very low, if they don't want anything else done, I don't push them.

Thus, by addressing a woman's fears and concerns, surgeons aim at establishing a caring relationship with their patients. Hopefully, this will enable them to more easily carry out diagnostic and

management procedures as well as enable them to share the responsibility of choosing these procedures with patients.

The second step for the surgeon in the history taking process is to elicit past and present symptoms. These might include breast pain, a lump, or nipple discharge. Surgeons also include past biopsies and mammograms under the category of symptoms. The interpretation of current or past symptoms plays an important role in framing the context of a physical exam as the interpretation of symptoms allows the clinician to predict what kinds of signs he or she might discover and what kinds of meanings these signs might have. One surgeon explained:

> I go into their previous symptoms, whether they have had any previous cysts aspirated, any previous biopsies and present symptoms of course, what it is that brought them here. They found a lump in their breast or their gynecologists found a lump in their breast or they got pain or tenderness or various other complaints or symptoms that they have. And then finally, when I get that all together, I put down what I think it might be. And from there I carry out a routine examination.

The meaning of symptoms varies and while diagnosis is not made on the interpretation of symptoms alone, they do help the clinician to interpret the meaning of clinical signs. For example, symptoms such as a report of a past biopsy that was atypical, or a bloody discharge, or dominant lump is very different from symptoms of pain and tenderness occurring around the menstrual period. The former symptoms are likely to be interpreted as warning signals by the clinician while the latter symptoms are more likely to suggest that all is normal. Ironically, while a symptom of pain is often a cause of concern for women, it is frequently interpreted by surgeons to mean that the chances of finding a malignancy during the physical exam, will be low. One surgeon explained:

With a woman who has a lot of soreness, especially premenstrually

> or throughout her cycle, you're going to be far more concerned about it being fibrocystic disease than cancer. Nothing eliminates the possibility of malignancy but that decreases the possibility. I presume that that's not going to prejudice anything but that it will aid me with coming up with the information. And then I do an examination.

Finally, the surgeon elicits any risk factors for breast cancer. Here, clinicians draw upon epidemiological knowledge about major risk factors. These include a woman's age, menstrual history, number of children, age of the woman at the birth of her first child, breast feeding history, hormonal use, and family history for breast cancer (Schwartz 1982). The discovery of risk factors is crucial in helping the clinician select appropriate diagnostic and follow-up procedures. As I will show, in the clinical language of risk, risk factors are often talked about as if they were clinical signs. That is, risk is talked about as if it were a clinical entity, not a statistical concept. While the translation of risk into a sign or a clinical entity will be discussed at greater length in chapter 6, the relevant point to be made here is that the number and kind of risk factors that a woman "has" plays a important role in clinical diagnosis and management. The following comment by a surgeon illustrates this point:

> Well, I examine her and make sure that I don't feel any distinct mass in her breast, get a mammogram, make sure that they're negative and that the woman gets followed. But it depends upon family history, it depends on some of their risk factors....Under the age of 30, I'm a little less aggressive in terms of taking her right to the biopsy.

In sum, the information gathered by the clinician during the history taking process is crucial in helping to bring meaning to the physical examination and in deciding whether or not additional diagnostic measures are needed. Thus, by the time the clinician

conducts a breast exam, he or she has begun to formulate a number of hypotheses about how the clinical findings might be interpreted.

4.3c The Clinical Exam:

When conducting a physical examination of the breast, the clinician relies on two senses, seeing and feeling. The art of clinical examination lies in the skill of knowing how to see and feel and knowing how to interpret what has been seen or felt. Most surgeons will agree on how a physical examination of the breast should be conducted and interpreted. While a breast exam "should" be an objective clinical procedure, in reality the clinical act is one that rests with the subjective skills of the clinician. Often the surgeon experiences uncertainty both in terms of knowing what is seen and felt and understanding what is seen and felt. This uncertainty is shaped in part by the ambiguity in the meaning of physiological changes within scientific modes of thought and in the subjective nature of the clinician's sense perceptions. Thus, in addition to information elicited in the patient history, the clinician adds information that she or he gains through the sense perceptions.

4.3c.1 Problems of Seeing:

The first act of a clinical examination is that of observation. Through this act, the practitioner attempts to "see" what might lie below the surface, what visible signs might lend meaning to the invisible structures that he or she will then feel. Until recently, the diagnosis of breast cancer took place at a stage when the disease was well manifest, at a point where the invisible processes within the body had become expressed on the surface. These signs that can be seen, include discharge from or inversion of the nipple, scaley skin

around the nipple, dimpling or puckering of breast skin, swelling or discoloration, and alteration in size or shape of the breast. In general, visible signs speak to clinicians with clarity. While they can not be said to signify cancer, they do signify a change that must be investigated further. Thus, while the practitioner might be uncertain in <u>understanding</u> what is seen, there is little uncertainty in <u>knowing</u> that, what is seen, is not normal. One surgeon stated:

> A patient that I just saw today has an obvious pulling lesion in the upper outer quadrant of her left breast that is so obvious. This lady has as got an obvious lesion that I can see. There was dimpling and pulling of her skin as she leaned forward. That to me almost makes the diagnosis. I don't need a zeromammogram to tell me that she needs a biopsy. You see, she's got cancer of the breast and certainly needs a biopsy.

The perception of a visible sign lends greater certainty to knowing what will be felt but when no visible signs can be seen, the technology of mammography is used to see what is beneath the visible surface. One older surgeon lamented the fact that because of these newer technologies, many younger practitioners do not make good use of their own visual senses. He explained:

> The first thing that you do, as in almost every examination, is to talk to the patient to get an idea from the history. Then in the physical examination, you look. There are none so blind in this world that won't evenlook! I thought that everybody examined the breast by looking. And everybody doesn't. I have them [women] put their arms out and the arms go up and you go through various manoevres so that the breast mass moves on the chest wall. I see the lesion before I touch it.

Seeing a sign of disease lends greater certainty to what will be felt while the lack of a visible sign enlarges the clinical space of uncertainty. Cancer in its early stages, is an invisible disease. It lays hidden and silent beneath the surface. It is an inward disease and only reveals itself to the visible eye when it has spread its

reaches throughout the organ or entire body. Currently within clinical medicine and public health, the battle against breast cancer is directed towards early diagnosis thus requiring its detection before the disease becomes expressed on the visible surface. Emphasis then, has been shifted from that of seeing what lies visibly on the surface to searching for what lies invisibly beneath the surface. This shift has introduced many dilemmas for the practitioner in terms of being able to know and understand what is felt during the physical examination.

4.3c.2 Problems in Feeling:

The art of a physical examination of the breast is one fraught with uncertainty. There are two dimensions to this uncertainty. The first concerns uncertainty in knowing what is felt. Here I am referring to the clinician's ability to know whether or not what is felt is normal or abnormal. The second dimension concerns understanding what is felt. Here I am referring to the clinician's ability to interpret what a change means.

The first dimension, knowing what is felt, is shaped primarily by the physician's skill in palpation and his or her assumptions about what perceptions should be interpreted as normal or abnormal. For example, clinicians skilled in the art of palpation may consider nodularity to be within a range of normal while those less skilled may be more likely to consider or "know" nodularity as a sign of disease. This does not imply that the clinician will necessarily understand what these abnormal changes mean.

The second dimension, understanding what is felt, is shaped by the state of knowledge about the meaning of breast changes as embodied in

scientific knowledge. Clinical uncertainty within this dimension is often a result of ambiguity inherent in the scientific understandings of the meaning of breast changes. The clinical transition from knowing what is felt to understanding the meaning and significance of what is felt is often problematic. And it is during the physical examination of breasts that the clinician begins to face the dilemmas of integrating knowing what is felt with understanding what is felt.

Knowing What is Felt:

Knowing what is felt depends first upon the surgeon's experience and skill and second, upon his or her assumptions of what "normal" should feel like. In the first instance, surgeons realize that no matter how experienced they are, there is always a chance that they will either fail to "feel" an abnormal change or that they will not "know" that what they have felt is abnormal. All surgeons I interviewed reported that there was always a chance of being wrong or missing something during a physical exam. Two surgeons explained:

> Well, the first thing you have to recognize is that on the basis of physical examination alone, you can only make an educated guess which has maybe an 80% accuracy. So you're always left with the concept that you're wrong 20% of the time.

> Well, you always get fooled. No one's a hundred percent sure and you never know. But you can get to have a pretty good feel, pretty good idea.

Because of this uncertainty, surgeons rely upon other modes of knowing. For example, one surgeon stated:

> I do not feel super confident that I'm sharp enough, that I'm cool enough that if there's a little breast cancer there, I'm going to find it and I'm going to know. And so, I count on the patient's help; self examinations. I make little drawings and maps in my own notes to compare for future examination and hope that if something appears it will be different enough to let me know. But knowing that my error rate will be in the order of 20%.

Older clinicians, those with more experience tended to be more comfortable with the uncertainty about what they can and cannot feel. Put another way, they tended to put more trust in their subjective senses. As one of the older surgeons explained:

> Well, there is a feel, just an instinct when you know, you've felt a lot of breast lumps. There are things that I feel confident about that are movable, rubbery, they're symmetric. Now I know very well what I'm feeling, palpating is the surface. And you can not assume that something is homogeneous all the way cause there could be nests of tumor. ...I put a lot of credence to my fingers. And I have not as yet become aware that I've followed somebody that I would look back and with horror say, "My God! This lady has cancer now and she had it when I saw her 3 months ago!"

The second dimension of uncertainty in knowing what is felt concerns the clinician's assumptions of "normality". For example, the physical conditions that physicians are most uncertain about in terms of knowing what they are feeling are those of general lumpiness. While clinical criteria exist for classification into stages of lumpiness in terms of density and nodularity, it is ultimately up to the clinician to "feel" the differences between these stages. Thus, the classification of degrees of lumpiness rest in the subjective evaluation of the physician. Furthermore, breasts are not all homogeneous and clinicians must make some distinction between when the range of normal becomes abnormal. Thus, while it is fairly clear what "normal" should feel like and what "abnormal" should feel like, it is the grey area in between that gives rise to the most uncertainty. Three surgeons explained this problem:

> A dominant lump, a cancer is usually easy, a cyst is usually easy, a fibroadenoma is usually easy. But if there is a lot of stuff in between...you know, it feels kinda lumpy and I don't know what I'm feeling. I don't really feel a dominant lump yet it doesn't feel the same as the other side. I don't know what I'm feeling. Its something there, its probably fibrocystic disease, but its the in between, it's the grey area...

> Multiple lumps are always a little unnerving because you know that the lumps aren't all cancer but you know that there could be one hanging around the others and you know, you can't biopsy everything that feels lumpy.
>
> My god, some women come in and they have breasts that feel like any given part of their breast could be a cancer! Very firm, very nodular, very difficult to examine. Very variable feeling breasts on both sides and multiple areas and you don't know what to do!

It is precisely this same dilemma facing surgeons that leads general practitioners, gynecologists, and nurses to refer women up the medical hierarchy to surgeons. When asked what kinds of women were difficult to examine a gynecologist replied:

> The only ones that are easy are women with soft breasts. They're not fibrocystic or lumpy in consistency so that one can palpate throughout the breast tissue and feel confident that there is no thickening or mass. And that's maybe 50% of the women we see. The others are difficult to examine in the sense that they have a large volume of breast tissue or the breasts are fibrocystic meaning firm, lumpy inconsistency, so that if there were to be a small mass within that breast tissue, its usually impossible to palpate it clinically. And that's a frustrating group of patients where the physical examination is not reliable to diagnose early disease...So, in 50% of the population, the physical exam itself is not adequate to diagnose early disease.

Uncertainty in knowing what is felt during a clinical exam often results in the reliance on additional diagnostic tools. However, even when the clinician can determine just what it is he or she feels, there is often much uncertainty in understanding what the clinical findings mean.

Understanding What is Felt:

Understanding the meaning of what is felt is important in helping the clinician to determine first, whether additional diagnostic tests are needed and second, the kind of approach he or she will take in the clinical management of the patient. In general, clinicians understand

a dominate lump or area of thickening to be a sign of abnormality indicating the need for further diagnostic measures. However, while the discovery of a dominant lump or thickening is interpreted as abnormal, the clinical meaning of abnormal often remains uncertain. For example, this becomes particularly problematic with conditions of general lumpiness combined with a number of risk factors. Here, the clinician is not only uncertain about his or her ability to detect (or know) an underlying cancer but also about the meaning of these breast changes.

This uncertainty about the meaning of breast changes can be traced to the ambiguity in meanings at the level of medical science. As I have discussed in chapter 3, there is much controversy over the meaning of benign breast conditions in the scientific literature. I have argued that benign breast conditions can be understood as being normal and abnormal at the same time. This inherent ambiguity stems from the lack of knowledge about the natural history of breast cancer, the lack of known causes, medicine's inability to prevent the disease, and the high prevalence of benign breast conditions in Western society. For example, a pathologist whose research focuses upon the meanings of pre-malignant conditions and minimal cancers explained that benign conditions can be understood both as normal and as a disease process.

> I think of benign conditions as different expressions of some underlying process. That is, various kinds of prolific lesions that we call fibrocystic disease for instance, probably all lead back to some underlying etiologic condition, some factor....I think it's a disease process. Its just that it is so prevalent in our particular society that we don't recognize it as a disease process.

Within the field of radiology there is also ambiguity as to the meaning of benign changes. One radiologist explained:

> There was this debate about what fibrocystic disease was. I don't know the answer to that. I've always felt that anything that was so common shouldn't really be dignified by calling it a disease. I don't know whether its a disease or not. But you know, when you begin to talk to the pathologist...you begin to wonder what really is going on here. The proliferative variety, I think are the precursors or at least very early stages of malignancy. So, that's a disease. I don't know the answer, I don't know that anybody knows the answer.

For medical scientists, benign changes can often be understood as being both normal and abnormal at the same time. There is as yet no clear agreed upon understanding of what some signs mean. The central dilemma of translating ambiguous scientific knowledge into clinical practice arises at a number of levels in the diagnosis of breast conditions, particularly with those conditions about which the clinician is fairly certain do not represent cancer but at the same time represent an abnormal condition . Consequently, the clinician is faced with uncertainty about whether what he or she feels could either hide a current cancer or become cancer in the future. The key question for the medical practitioner concerns the clinical meaning of benign conditions. We can explore this dilemma by asking how clinicians translate scientific knowledge about benign breast conditions into clinical practice. Under what conditions do they understand it as representing a disease condition or a normal change? It is useful to begin by examining the clinical language used to speak about the diagnosis of benign conditions on the basis of a physical exam only. In other words, what are the the clinical meanings of felt lumps?

First, much clinical uncertainty in understanding the meaning of lumps stems from the changing nature of medical knowledge in general. Many of the surgeons interviewed were aware of the shifting nature of medical knowledge. For example, one of the older surgeons explained:

> In my lifetime the truth has been around three times! When I got started the absolute truth was known...I learned all that very well. The problem is there's no word of truth in it! The entire field has changed and what's happened now as a result of our intense efforts to make the early diagnosis, we are seeing a spectrum of illness that most people don't really have a natural history of. I don't know if what we are finding is really the same thing as when we gathered our early knowledge about breast cancer. See, nobody knows what the real natural history of it is.

In addition to the changing nature of medical knowledge, much remains unknown within the domain of medical research about the meaning of benign conditions. Because these conditions are so prevalent and because they are also associated with breast cancer, most surgeons held contradictory understandings of benign breast conditions and spoke of them as <u>both</u> normal and abnormal. A young surgeon explained:

> Since I don't know the pathogensis of fibrocystic disease, I don't know if it's a disease. I honestly don't know. I can't say. I consider it, when speaking with women, as a natural phenomena because it is so prevalent. I can't tell you how I see it in the continuum of things.

Another surgeon explained:

> I don't know, it's (benign changes) one type of breast tissue. Disease may not be the correct terminology because it has connotations to patients that create excessive worry. There are some reports that show that women who have that type of breast tissue, what ever name you use, we call it mammary dysplasia because that's a radiographic term for the same process, show an increased incidence of breast cancer. There are other studies that don't confirm that . Frankly, the consensus would be that we have to accept that the patient has a higher risk to develop breast cancer but at the same time she does not have to lead a life in total fear that she is gonna have breast cancer any more than the average woman. I don't think we should single out the fibrocystic breast for undue alarm but they need to be followed closely, do self exams, get regular exams, and they need a higher index of suspicion entities. Then logically, we must treat them as such.

Because there is controversy among medical researchers as to whether benign changes do in fact represent a current or future disease process and because there exists no known method of treatment or

prevention of benign breast changes short of physically removing them, clinicians understand these conditions as; as being normal; as hiding a current cancer; as disease states in and of themselves; and as signs of future diseases. This clinical ambiguity in meaning is illustrated by the use of the term disease to talk about normal benign changes. Within clinical practice, there is little room for ambiguity and thus, all conditions become talked about in the language of disease. What is normal becomes talked about as a normal disease. The following quotes by surgeons illustrate this:

> I've always felt that this was not a disease. The largest percentage of people who have benign disease are not likely to get cancer.
>
> I think what we call fibrocystic disease in our society is just normal. I mean if the incidence of the disease is 70% in our population, which is a conservative number, then how can you say it's abnormal if women have fibrocystic disease, if 70% of the woman have it? It doesn't make sense
>
> Most women have what's called fibrous dysplasia or mammary dysplasia or fibrocystic disease, whatever "that" is, that huge waste basket of benign conditions. One really wonders whether its fair to call anything a disease if its present in more than half the people that are just walking around and seem to be reasonably healthy.

Thus, surgeons are faced with much uncertainty in terms of both knowing what is felt and in understanding what is felt. When faced with these dilemmas, practitioners often take further diagnostic actions to reduce this ambiguity and increase clinical certainty. At this point the clinician shifts from a mode based upon his or her subjective perceptions and ways of knowing to one based upon objective technologies and scientific knowing and understanding. The clinician is now faced with integrating these two modes of experience, the subjective clinical mode and the objective, technological, scientific

mode and while further diagnostic tests can act to reduce ambiguity they can also act to increase ambiguity and clinical uncertainty.

4.4 DIAGNOSTIC TECHNIQUES: MAMMOGRAMS, BIOPSY and FINE NEEDLE ASPIRATION:

Surgeons have a variety of diagnostic tools available to them that can be used to increase their certainty about the meaning of clinical findings. The three methods most commonly used by practitioners interviewed in this study were mammography, biopsy, and fine needle aspirates. The use of these medical techniques increases the range of clinical perception thus resulting in additional information and hopefully in greater certainty in the diagnostic process. Unlike information obtained from the patient history and physical exam, this form of perception produces indirect inforamtion about the body. Here the observer observes not the body itself but a symbolic representation of the bodily parts (King 1982:85). As with direct methods of observation, what is observed must be interpreted and the observer must bring meaning to the phenomenon.

> Yet the different methods, direct as well as indirect, have certain features in common: sensory presentations that require interpretation. The dermatologist sees changes in color, contour, texture, and general appearance of the skin; the ophthalmologist studies analogous changes in the eye; the auscultator notes changes in the breath sounds transmitted through the chest wall; the radiologist sees congeries of shadows; the pathologist notes patterns and details of colored masses. The difficulty lies not in seeing or hearing, but in understanding, i.e., in drawing conclusions from what is seen or heard (King 1982:85).

Ironically, while the goal of diagnostic technology is to produce knowledge which will enable the clinician to reach a more certain diagnosis, these technologies can lead to greater clinical uncertainty. This is largely due to three problems that the clinician encounters

with the use of diagnostic technologies. First, the clinician is often faced with the difficult task of translating inconclusive laboratory meanings of test results into clinical practice. Second, even when the meaning of test results are clinically clear, the clinician is often uncertain about the accuracy or validity of a diagnostic test. And third, the proliferation and greater dependence upon indirect diagnostic technology often undermines the clinician's own confidence in his or her understanding of the meaning of signs elicited through direct observation (e.g., listening, observing, feeling).

The first problem, that of the translation of test results into clinical practice, often leads to much uncertainty in that data produced by diagnostic technologies must undergo two levels of interpretation. First, the test results must be interpreted by a medical scientist. Second, these interpretations must be translated by the practitioner in such a way as to have clinical relevance. Thus, with indirect methods of observation, the complexities of interpretation increase and often result in greater uncertainty concerning the clinical significance of a given condition. To illustrate this dilemma, a pathologist explained some of the problems he encounters in translating his pathological findings so that they make clinical sense:

> I'm trying to use customary pathologic terminology to describe the histology of the lesion. But the important thing is what does that mean? And there are two things that are important. One is to establish what it actually means and the other, is to understand what it means for the clinician. That is part of our translation. Sometimes we translate items, for example lobular carcinoma in situ. What is heard at the other end is only carcinoma. And so, how I handle that is that I tend to repeat myself in the report. I will describe the lesion for my own purposes and then I'll provide a diagnosis. And then in a note, as many of my colleagues don't read the description, I comment about what we know about the lesion, what it means, what is

possible to expect, what's not possible. And I modify this in terms of what I think they might do.

As was pointed out in Chapter 2, the diagnosis of an in situ carcinoma is a microscopic one and these conditions are most often discovered quite by accident. The meaning of lobular carcinoma in situ is ambiguous because it is understood to be both a cancer and not a cancer at the same time. As a result, there exists much controversy concerning the clinical meaning of a pathological diagnosis of in situ carcinoma. In the above quote, the pathologist stated that he often attempts to comment about the clinical significance of pathological interpretations. While pathologists often make comments concerning treatment, it is the clinician who in the end, is responsible for selecting and carrying out treatment and management. The following pathology report (not written by the above pathologist) illustrates one way in which pathological findings about lobular carcinoma in situ might be communicated to the clinician. Note here that the clinician is left with the task of bringing clinical certainty to an ambiguous pathological condition.

GROSS DESCRIPTION: Received in formalin and labeled with name only are two irregular masses of tissue measuring 2.8 x2.0 x 1.6 cm, and 2.5 x1.3 x1.3 cm. The tissue appears to be fibrofatty. Cut surface reveals small cystic lesions. No obvious calcifications or hemorrhage are seen. The tissue is totally embedded in cassettes A through F.

Diagnosis:
1. Microscopic focus of lobular carcinoma in situ. (excisional biopsy of left breast mass)
2. Mammary dysplasia. (excisional biopsy of left breast mass)

NOTE: The treatment of lobular carcinoma in situ is controversial. Haagensen, et al, recommend systematic follow-up. Rosen et al, recommend mastectomy.

Here we find that the clinician is faced with translating ambiguous scientific knowledge into clinical knowledge and action. More often than not, in cases such as the above, the pathological diagnosis results in greater clinical uncertainty concerning what type of clinical action should be taken. The following surgeon explains how he feels when faced with these dilemmas:

> Whether these minimal breast cancers actually represent cancer, is really a pathologist's definition at this time and I am not a hundred percent convinced that there is a cause and effect relationship between these in situ tumors, so called cancers and ultimately the development of advanced cancer. So, I don't know....I solicit advice from people at the clinic and they solicit mine.

A second way that clinical uncertainty is introduced by diagnostic technologies concerns the problem of validity (reproducibility or precision), and reliability (accuracy), of the diagnostic test. Many surgeons expressed concern over both the validity and reliability of fine needle biopsies. Several surgeons explained:

> There's an error rate of needle biopsy. I've seen 5 law cases where somebody put a needle in and got a negative and 6 months later the patients have a breast mass that everybody diagnoses as cancer. Her nodes are positive and she sues the doctors. So, the question is, you have what is the accuracy of your diagnostic technique?

> I haven't gotten too enthusiastic about aspiration cytology. For one, its fairly expensive and two, I'm a little suspicious that I might get the wrong answer and be led astray.

Third, diagnostic technologies can have the effect of making clinicians less certain about their diagnostic abilities through direct observation and physical examination. One older surgeon emphatically explained how the proliferation of new diagnostic technologies was

undermining the importance of physical examinations.

> I hate tests which are taught to medical students, interns and residents, that they're going to accept because it will absolve them of learning how to take care of patients and examine them. I think that is a very dumb, a very chronic and a very insidious element in our medical education. I think it's stupid!....I think the blind dependency on a test is to be deplored. I personally don't like the needle biopsy 'cause I think people tend to trust it and tend to use it instead of using their senses.

Reiser summarizes this last dilemma by arguing that:

> The historical experience of medicine thus reveals diagnostic technology to be a double-edge sword. Its use can enlarge the doctor's knowledge of disease, but it also can erode his confidence in his ability to make independent judgments. The doctor can rely too much upon machines and technical experts but not enough on techniques of gathering data founded upon his own abilities and experiences. If the doctor develops a distrust for his non-technical judgments, he risks becoming merely an intermediary between the patient and the medical judgments rendered by technical experts and machines (Reiser 1978:172).

Surgeons are caught in a bind of sorts. On the one hand, diagnostic technologies are used to bring greater certainty to clinical understanding and action. But at the same time, their very use often results in greater clinical uncertainty in that the clinician is faced with bringing clinical meaning to often ambiguous laboratory findings, the validity and reliability of such tests is often questionable, and diagnostic technologies serve to undermine the practitioner's confidence in his or her own clinical abilities. These dilemmas will be discussed in greater depth by exploring the clinical use of specific diagnostic technologies, mammograms, biopsy, and fine needle aspirates.

4.4a Mammography:

Mammographic x-ray is used primarily as a screening technology to detect lesions too small to be felt but also for diagnostic purposes to give a clearer picture of the extent of a visible lesion. Mammography extends the physician's ability to see beyond what is visible to the

eye and to detect what cannot be felt with the fingers. Reiser (1978) argues that, "The development of x-ray technology obliterated the distinction between the outer and inner spaces of the body as both were now susceptible to visual examination" (p.62). The use of x-rays also makes it possible for a group of clinicians to evaluate a condition without requiring the physical presence of the patient. Thus, mammography provides the practitioner with additional aids with which to enhance and objectify clinical diagnosis. However, the use of mammography can also introduce a number of problems into the clinical understanding and management of breast conditions. These problems stem from the radiologist's interpretation of breast changes and from the clinician's interpretation of the mammographic report. When the mammogram has been interpreted by the radiologist as clearly representing an abnormal area that is possibly malignant and when the practitioner reaches a similar suspicion during the physical examination, a biopsy will be recommended to confirm the suspected diagnosis. In this case, there is not much clinical uncertainty about what changes mean and about what should be done. The meaning of mammographic signs and clinical signs is unambiguous. However, the clinical situation becomes less certain when the meaning of mammographic signs for the radiologist, are less clear. That is, when the shadows could be interpreted as either normal or abnormal depending upon a number of different factors.

We can explore this problem, first from the point of view of the radiologist. While clinicians often make use of mammography in order to attain a more objective reading of an underlying change, such objectivity is in reality, an impossibility. The radiologist's

interpretation of mammograms is fraught with the same problems the clinician faces when conducting a physical exam. Interpretation is influenced by the experience of the radiologist, the philosophical orientations as to what should be interpreted as normal and abnormal, and by the state of the technology itself. One radiologist explained:

> This is not a perfect science. There are errors involved. Some cancers just don't show up and sometimes they look as though they're benign and some benign things are malignant and it's, it's not quite that simple. Our purpose is to get the best possible diagnostic mammograms. And that requires a great deal of attention to the technical aspects of the examination. We have very good technologists who do that. And secondly, it requires our experience and expertise in looking at these images and saying, "That's an area I'm concerned about or that's not one I'm concerned about." A great deal of it is subjective. It's much more an art than a science I think. The interpretation of mammograms are based on experience. You know, you can just look at something and say, "I just don't like the looks of that. I can't really explain precisely why but I'm not happy with that." So, you need a combination of technically good images and an interested interpreter who has had some experience.

A mammographic image can be interpreted by the radiologist as being more or less suspicious depending on a number of influencing factors. For example, one radiologist explained that the most difficult kinds of images to interpret were those of benign disease. For these conditions, he relied on other information.

> I think the flagrant cancers are the easiest and benign disease is the most difficult....We make determinations all the time on the basis of risk. Here is an illustration of what we do. This is the path. report and this is our mammography report. Now on the back of the mammograms we have this information which is designed to let me know whether I'm dealing with a woman who's at high risk. It tells me if she's nullaparious, whether they're pre or post menopausal, whether they've had previous mammograms, what their family histories are like, if they've had previous breast surgery, what their current complaint is, et cetera, et cetera. All of these things are designed to let me know if this woman falls into a high risk category or not and what are the clinical, physical, findings, because you can't interpret these in a vacuum. And then if I see something that I'm not comfortable with and say," This woman is 33 years old and she's had a mother and a sister with breast cancer and she's had a previous biopsy and she's nullaparious," I would be much more inclined to recommend

biopsy for that woman than I would for one who is the same age, has had six children, no family history, and fatty breasts.

This rather lengthy quote illustrates how the radiologists takes into account many different kinds of information in the interpretation of a mammographic image. Finally, radiologists know that there is always the possibility that their interpretations will be wrong. And they attempt to convey this possibility to the clinician. A radiologist explained:

> Here we are with a responsibility to try to find early breast cancer and we may do a mammogram on a woman that we interpret as negative and at the same time her physical examination is negative and three months later she has a lump and it's removed and its cancer. The question is, were we in error in not finding it? Well, we attempt to protect ourselves by including as part of our report, a caveat that says zeromammography cannot exclude breast cancer and should not deter the further evaluation of positive physical findings. Most people put their statistics on their report. They say, "Statistically at this institution, we have 22% false positives and 9% false negatives and you should bear this in mind in the interpretation of the report." I think most surgeons know these numbers, we've certainly published ours and made them clear to everybody.

In sum, much clinical uncertainty in the diagnosis and management of patients stems from uncertainty and ambiguity in radiologic interpretations. More often than not, these uncertainties increase the chances that a surgical biopsy will be conducted in attempts to bring certainty to clinical understanding and management. Three surgeons explained:

> I use zeromammography, but I don't fully trust that. That's not God's gift to us either. I had three patients come in with negative zeromammograms, with lumps that didn't show up on the zeromammogram, and they have had cancer with an absolutely negative zeromammogram! And, I have had a hell of a lot of patients with a very suspicious shadow that I was pushed to go in and do a blind biopsy in spite of my impression that its nothing. And it turns out to be much to do about nothing. And then I had one patient who had a routine scan, some calcifications, and she did indeed have a cancer but no palpable lump. So I think there's a place for it but I think the blind dependency on a test is to be deplored.

> Suppose you can't feel anything. You take a mammogram and incindentally the radiologist wants to cover himself, reports something that's suspicious and suppose you don't take it out? Then where are you? Then where are you if it is really something significant?
>
> The problem comes in with a vague like mass. Should the person have a biopsy? You know, my aspirate is 95%, my mammogram is 85%, but I can't give a 100% guarantee. For complete peace of mind and 100% guarantee, a biopsy is needed.

These quotes illustrate that although mammography extends the clinical perception of the body, it does not necessarily lend clinical certainty to diagnosis and management. In the final analysis, the diagnosis of breast conditions is a microscopic one, dependent upon biopsy. Ironically, the very search for certainty through the use of a non-invasive technology such as mammography, often results in greater uncertainty thus leading to surgical intervention. The dilemmas faced by the surgeon in the interpretation and management of breast conditions are often resolved by removing the condition which gives rise to ambiguity and uncertainty. In this respect, biopsy can be understood both in terms of diagnosis and as cure.

4.4b Diagnosis by Microscopic Analysis:

Microscopic analysis is a major method of eliciting indirect knowledge about the body. As with the clinical and radiologic examination, the art of pathology is one of interpretation. The skill of the pathologist lies in his or her ability to interpret the meanings of various pathological patterns and then to draw inferences from these patterns to larger relationships of the whole body.

> A microscopic slide is entirely comparable to the x-ray film. The trained physician who studies the patterns, shades, and colors under the microscope is making indirect observations of a part of the body. The various colors and shadings, lines and dots, do not exist as such in the body, but they have a correspondence to what does exist, a correspondence that can be inferred and given

meaning by suitable interpretation. (Reiser 1978).

Microscopic analysis of breast tissue is considered to be the only technique that can provide a definitive diagnosis. Once a specimen of breast tissue is surgically removed, it is sent to a pathologist for diagnosis. Inferences drawn from pathological analysis are often clear as the signs of most forms of breast cancer and many benign conditions speak clearly to the pathologist. In these situations, the practitioner has little problem translating pathological findings to have clinical relevance.

However, clincial certainty about the meaning of a pathological change is not always to be had. This has become more problematic as technological advances have allowed for finer discrimination of tissue changes. Although finer changes can be detected, the scientific and clinical understanding about the meaning of these changes and their realtionship to a disease entity has lagged behind. The result is that it has become unclear where the line between normal and abnormal should be drawn. Thus, although microscopic analysis produces supposedly objective, indirect ways of perceiving the body, understanding the clinical significance about what is detected under the microscope is often difficult.

Surgeons described three major problems encountered when utilizing biopsies to increase clinical certainty. First, it is often difficult for the surgeon to decide when and what to biopsy. Second, many surgeons do not trust the needle biopsy to give them an accurate reading of the tissue. And third, many found it difficult to interpret pathological findings into clinical practice.

4.4c When and What to Biopsy:

When to perform a biopsy is perhaps one of the most problematic dilemmas for clinicians. There are two reasons for doing this. The first is to gain a more definitive diagnosis and the second is to remove the clinical sign, the physical condition that gives rise to clinical uncertainty. There is general agreement that any dominant mass should be removed. However, it is not always easy to define "how dominant" a mass should be to indicate a biopsy. The physicians interviewed were very concerned about the problems of conducting unnecessary biopsies but they felt that the risks of doing nothing in the face of uncertainty were too high. The decision not to do a biopsy presents a risk to both the doctor and the woman in that should a lump turn out to be cancer, the doctor is legally at risk whereas the woman's life is at risk. There is, however, no legal risk to the doctor for having performed an unnecessary biopsy. One gynecologist explained his feelings about unnecessary biopsies:

> I think the most common cause for biopsy in terms of pathological evaluation turns out to be fibrocystic breasts. So it would be nice to reduce the pool of people who have biopsies that turn out to be nothing. But it's my medical attitude that any solid lump should be removed, period! Despite fine needle, mammogram, et cetera, so, I'm not likely to get into trouble. I know there is no legal ramifications of referring someone who gets an unnecessary biopsy, 'cause I didn't do the biopsy, just referred.

For surgeons, it is safer or less risky to perform a biopsy even when they may be fairly sure that the lump is not malignant. A surgeon explained the way he approaches this problem:

> If she has a dominant lump I remove it. I tell all women that one way or the other they have to get rid of it. I'm compulsive...I get rid of all lumps. I don't sit and watch lumps. And a lot of people do. I get sent a lot of cases where somebody's been following a lump for 6 months, quote a "cyst". It's cancer. A lot of people think they can tell a cyst from lumps. I don't think I can. I have to get rid of it. I cut my risk down.

Thus, the surgeon cuts down his or her own risk by cutting out a lump. Certainty is brought about by removing the physical condition that gives rise to the clinical uncertainty. The following quotes serve further to illustrate this dilemma:

> I tend to be rather aggressive about doing biopsies and sometimes I get a little guilty about that. And then, you know, you have a situation where I feel a little bit guilty and then have it pop up to be pathologic! Here I am telling the patient, "Ah, it looks good, we're doing it [biopsy] to eliminate that little 1 or 2% worry in the back of my mind." And then to have to say, "Look, you know, there was....there were elements of malignancy here." Or in some cases, blatant invasive malignancy! I mean we are legally at risk, emotionally at risk, and physically, the patient is at risk.

> You're only free within the environment in which you find yourself. Both the patient and the doctor now are trapped in a different environment than they were before when all this possibility existed [referring to pathological diagnosis]. And there is no way that one can examine a patient unless you take something out and look at it under the microscope. Both the doctor and the patient feel more comfortable doing something. If you don't you might hit somebody who has really bad trouble and if you leave it alone, if you don't do anything about it you're in legal problems.

What other kinds of actions could surgeons take to cut down on their risk in the face of uncertainty? One such answer would be for surgeons to acknowledge and share their uncertainties with their patients and thus, share the responsibility for decision making. Several surgeons said that when they felt that a biopsy was not warranted but they could not be sure, that they shared this uncertainty with the patient and then let her make up her mind about what should be done. Two surgeons expressed this more conservative approach to biopsying. Both of these surgeons were older, had specialized in breast conditions, were more confident about their ability to conduct a good physical examination, and believed that they had good compliance

with patient follow-up. One explained:

> Now not infrequently I end up by not operating or biopsying. I just say that I don't think that biopsy is warranted. But almost always when I get to that point, I ain't going to stick my neck out and say that biopsy isn't necessary. I feel that it's my obligation to myself and to the patient to see them again, maybe once every three or six months for a reasonable length of time and make sure that I'm not missing something.

And another surgeon felt more strongly:

> Unnecessary biopsies I don't understand. I've seen women come in because they're fibrocystic. Now fibrocystic lumps come and go and come and go and if that patient goes to a surgeon who lops out every lump before it has a chance to regress, she will present,...as I have seen some patients at age 38 or 42, who have had 17 biopsies. And they come in with their 18th breast lump. Now I don't know what the heck is going on because their breasts look like hand grenades went off! They have scars on the outside and they're scarring on the inside, undersurface. I just don't know what I'm palpating anymore. I think it's terrible.

With this last quote, it is interesting to note that while unnecessary biopsies may cut down on a clinician's risk by reducing current clinical uncertainty, they can at the same time act to increase future risk and uncertainty. This last surgeon explains that with women with multiple biopsies, it is difficult for him to know what he is palpating. A biopsy often leaves a scar and scar tissue can act to hide a future cancer.

Not only is it a problem for clinicians to know when to biopsy, but also to know what to biopsy. In the case of a dominant lump or a clear mammographic finding, there is no question about what to biopsy. However, in the case of general lumpiness, knowing what to biopsy becomes more problematic. One surgeon explained:

> Well, multiple lumps are always a little unnerving because you know that they all aren't cancer but you know that there could be one, sort of hanging around in among the others. And you know you can't biopsy everything that feels lumpy. So the question is if I'm going to biopsy, what do I biopsy? And usually when you ask yourself that question, you end up not biopsying at all.

And finally another surgeon explained:

> It is when her breasts are very firm and rubbery and its so lumpy that you just wouldn't know where to biopsy. You know, her breast is just all that way....The ones who come in here with a lot of lumps here and there are for the most part going to be benign because breast cancer doesn't present that way very often. But they're worrisome because you just got to prove it, you know.

Thus, in the initial stages of deciding whether or not to continue further along the diagnostic path, clinicians are faced with much uncertainty about what and when to biopsy.

4.4d Needle Biopsies:

The most common method of obtaining a microscopic diagnosis is by surgically removing breast tissue through a surgical biopsy. However, a needle biopsy is a procedure whereby tissue can be obtained quickly without the need for a surgical procedure. In this research, I found that needle biopsies generated the most controversy of all screening and diagnostic procedures. Many of the surgeons used this procedure selectively as they felt that it could not be fully trusted to give accurate results. One surgeon explained:

> I use it selectively. With this lady this morning, her lump is really very small and I would be afraid that I would ruin the specimen if I tried to aspirate besides having it be difficult to be sure you're getting into it. If it's negative, then it doesn't help me at all. If it's positive, I wouldn't depend on it 100%. I would still want to take it out but it helps me prepare the patient more.

Another surgeon explained his reservations:

> I'll tell you my feeling about it. I've always been less than sure about it because number one, if it's malignant, you got to know that and I know of no one who's going to do a mastectomy on the basis of the aspiration cytology without histologic confirmation. Secondly, if it's benign, then you worry, "Did you have a sampling error?" And all that it is going to do is take one mistake where you shrug it off for 6 months because you have a benign cytology and then you have a malignancy that's continuing to grow and whether you've really done the patient harm or not...certainly legally you're in a hell of a bind!

A surgeon who was in private practice said that he felt that too many needle biopsies were being conducted at the university hospital and that women were being subjected to an unnecessary and uncomfortable procedure.

> Well, when I see people in consultation, it comes down almost always to do they need some kind of a surgical procedure or don't they? I see a lot of women with fibrocystic changes in their breast. I've followed many patients,..I've been in practice for 25 years now and many patients I have followed for 15 and 20 years. Every three or four months I map their lumps and I've never biopsied. But when I get suspicious, when I'm not sure what I'm following, I think they need a biopsy...The thought that I'm going to depend on a needle going into this thing and getting a few cells and then I'm going to depend on that,...and if it comes out benign, I mean it didn't show any evidence of cancer, that is definitive, I think that's dumb. I don't trust the random needling of a suspicious lesion. If its positive then that's terrific, that's all right but what are you going to do if it's negative? And I have had a number of patients come to me that I wouldn't have been close to thinking it was suspicious and needed some investigation and they've been to (the university hospital)...and they're getting stuck! I look at some of these patients and I think that the decision to do that on somebody that I am not that worried about. It's kinda of a judgement that I don't understand.

Another young surgeon was outspoken about what he thought of needle biopsies:

> I never do that. I have no faith in it. I wouldn't trust it on my mother or my sister and therefore I wouldn't trust in on a patient. I think it's nonsense. The yield is not going to produce confidence on the part of me. It is a worthless test. I would never do it. I don't care what is done anywhere else in the world. The only way you can confirm the validity of a fine needle aspirate is a biopsy. So, the patients wind up having two procedures and its worthless.

Other surgeons stated that they felt that needle aspirations were of some use as diagnostic procedures. One surgeon explained:

> I make a decision as to whether I think a fine needle aspirate should be done and if I do, I go ahead and do it right then and send it to cytology...And then I make the decision about mammograms, and then I make a decision as to whether a biopsy is going to be needed or not. The biggest value of the fine needle aspiration is that if you get back fluid and the mass goes away, then the problem stops. It answers the third question which is

> that the biopsy is not really needed...If it's a solid lesion, then it answers the question in my mind that you're going to need to pursue the diagnosis further and I do send it for cytology. If it's a malignancy cytology, then the diagnosis is made. If it's a negative cytology in the sense that it shows no cancer, then it just tells me that the patient's going to need a biopsy. I think any solid lesion, any solid lesion in a woman that is a distinct three dimensional mass, I don't care what the fine needle biopsy shows unless it shows cancer. If it shows cancer then that says that I don't have to do a biopsy. I can go right in and talk about treatment. My goal is to prove to the patient that she does not have cancer. Which is a different way of approaching it than to prove that she does have a cancer.

Other surgeons explained that the use of a needle biopsy was important as it provided additional information concerning the need for further diagnostic procedures as well and information for treatment and patient management. Several surgeons explained that it was a procedure that they could do immediately in their offices. One explained:

> I have been using the fine needle more and more in the last 6 months or so and it's just something I can do here in the office very easily and it doesn't cost a patient very...it doesn't cost her anything and I think it gives me an indication as to how to approach the biopsy number one. And number two, how to approach the patient in terms of trying to quell their fears or in terms of reinforcing that they might have a cancer. I mean, it tells me information that I need to use in treating and dealing with the patient.

One of the nurses who worked at the breast screening clinic at the university hospital explained that they used needle biopsies because they were relatively cheap, easy to perform and it allowed them to continue to conduct a high number of cytological screening procedures, thereby cutting down on their risk of missing a cancer.

> We deal with lots of patients every day and we deal with a lot of benign and cancer things and its takes a lot of effort to do correctly. Basically in the overall surgical community, you're doing 5 benign biopsies for every cancer, which is the way it really should be because if you do less then you'll start to miss more. But biopsies are very expensive and it's very difficult to decide (whether or not to do one). That's why we like needle aspiration cause it's relatively cheap and relatively easy. But it still takes a degree of skill and having a good cytopathologist...But the needle aspiration is excellent. I think

its very important. You have to pursue everything because cancer is out there. It's there and you have to find it. If you wait till it's obvious, then you've lost, you've lost the game and that's it.

For the most part, the preferred method of diagnosis was surgical biopsy. Surgeons reported that needle biopsies were good for providing additional information about what a surgical biopsy might show and to alleviate the concerns of patients when a benign condition was suspected. However, needle biopsies can provide a somewhat less invasive biopsy procedure that can be used by practitioners other than surgeons. One gynecologist explained:

> Fine needle aspirates have been around a long time...In a good interpretive setting, they have a false negative rate...anywhere between 1 to 5%. So, you're not likely to miss a cancer unless it's a very small cancer or you didn't do the tests right or you don't have a good pathologist. If I have a patient who has a breast lump, one of my ways of proceeding is doing a fine needle aspirate in the office without anesthesia and I do it with a 22 gauge needle. It's then processed as a pap smear. It's helpful in that if the mass is cystic and it completely goes away, the patient walks out of the office extremely relieved and the problem is resolved. If it turns out to be not a cyst and there are actual cells there, then it's spread on a slide and processed and sent to the lab. If it comes back suggestive of cancer, then I think the patient needs to have a biopsy...You have to know what the tool is and when it's useful. It's a good screening test. It's nice to send someone to a breast surgeon, like call up John Smith and say, "John, I saw a woman today. She had a one centimeter mass and did a fine needle aspirate. It's cancer." He can then know to see her that day, that it's urgent. He knows how to approach her for biopsy. So it is only an adjunctive test. But it's a helpful test. That's how I use it.

Finally, some surgeons may use needle biopsy to attempt to allay their own uncertainties in situations where a woman's breast is very difficult to examine and where it is difficult for the surgeon to decide exactly what it is he or she is feeling.

> It's the grey area in between. You know, it feels kinda lumpy and I don't know what I'm feeling. I don't really feel a dominant lump yet it doesn't feel the same as the other side and the same thing bothers women. I don't know what I'm feeling....That's where I think these...the fine needle aspirate helps me the most....It's

the grey area...I try to make up my mind, would I biopsy that or would I not biopsy that? Or wouldn't I biopsy that but I can stick a needle in and if that comes out negative, then I sleep better. I sleep better.

4.4e Clinical Interpretation of Biopsy Results:

Once the surgeon has conducted a biopsy, most often his or her uncertainties will be put to rest once he or she receives the pathology report. If the diagnosis is malignant then the surgeon must begin to negotiate a treatment program with the woman. If the diagnosis is benign, then the surgeon must interpret the meaning of a benign diagnosis and negotiate a management program for the women. Sometimes, however, the diagnosis will represent an area of much controversy and uncertainty. Surgeons are cognizant of the fact that there is a certain amount of subjective influence when pathologists interpret biopsy samples. One surgeon explained:

You have to know your pathologist. You have to know if he's conservative about..you know...or if is he's heavy on the call.

[MEANING?]

He calls them positive when another guy would call them negative. In other words, his thermostat is set differently. He tends to over call. You have to know if your pathologist tends to over call or under call. You know, having been in the business, having watched some of these pathologists around ...There's a pathologist that I...where ever I'm doing the case, I'll steal the slide and take it to this one pathologist because as far as I'm concerned in 25 years, he's had no backfires. He hasn't made a mistake. And I've seen some other ones with plenty of mistakes.

[OH REALLY? IN TERMS OF BOTH OVER CALLING AND UNDER CALLING?]

Rarely, over...well, there's one doctor in town that's doing a research program as you know, that tends to over call lobular. Because a lot of people don't call lobular carcinoma in situ a cancer. Haagensen doesn't for instance. Now you take his slides around and half of the the stuff he's called lobular carcinoma in situ, the other guys won't. So you know, if you're not going to do anything about it, you're not going to do a mastectomy, it doesn't make any difference. You can over call any day in the week.

Another surgeon expressed similar feelings as he explained:

> The question is, how much treatment is necessary for an early cancer? The answer is at this point, no one really knows. We do know that if you treat the total breast, with carcinoma in situ, that your chances of curing that patient are going to be about 99%. Ok, that is essentially the pathological error in making the distinction between a truly invasive cancer and a truly carcinoma in situ. The pathologists are not infallible. There can be one break in the membrane that makes an invasive cancer that was missed on one slice or was blurred by the way the tissue was sliced. And that's an invasive cancer and that's not in the same group as carcinoma in situ.

Finally, one surgeon explained that he was sympathetic to the pathologist's dilemma:

> What has happened is we have suddenly given to the pathologist a spectrum of the disease they have no knowledge of.

Uncertainty concerning the meaning of clinical, radiological, and pathological findings brings the surgeon face to face with many dilemmas of patient treatment, management, and prognosis. These uncertainties give rise to the clinical management of risk, both risk as understood to reside within patients and the clinician's own personal risk of being wrong. The language of risk is central when clinician's talk about treatment, management, and diagnosis and embodies within it, all the ambiguities and uncertainties of clinical thought and practice. Clinicians begin to face their own uncertainties when they first communicate to their patients, a diagnosis. And it is the interaction between the clinician and the patient where the risk and uncertainty must be confronted.

4.5 PATIENT MANAGEMENT:

As we have seen, the clinical management of women with benign and malignant breast conditions is often conducted within a context of uncertainty concerning the meanings of such conditions. Because of

this, the surgeon cannot know if a woman with a benign condition will go on to develop a cancer. Neither can the surgeon know with any accuracy, the "best" treatment for a woman diagnosed with a malignant condition. Thus, the clinician is faced with the task of managing and treating both what is known and what cannot be known. The clinician is responsible for not only for managing and treating a physical condition but also for managing and treating risk; a woman's risk of developing cancer, the clinician's risk of wrongly diagnosing and being unable to predict the outcome of a given condition. When moving from diagnosis to management and treatment, clinicians continue to be faced with uncertainty. Here, I want to explore the types of uncertainties that clinicians encounter in the management and treatment of benign conditions.

A surgeon may choose one or more management options. First, if the surgeon decides that a condition does not represent any risk to a woman's health, he or she may simply do nothing. Second, the surgeon may decided that the condition represents some risk but not enough to warrent a biopsy. In this case, the surgeon may decide that the woman should be followed. Third, the clinician can recommend a number of less invasive intervention procedures such as vitamin E therapy, removing caffeine products from a woman's diet, prescribing diuretics and in some cases, hormone treatment. Fourth, the surgeon may decide that the condition represents enough risk to be biopsied or removed. In this situation, a biopsy represents both a diagnostic as well as a treatment procedure. Finally, in extreme cases, a surgeon may recommend that a woman consider a prophylactic mastectomy. This last management procedure consists of the clinical act of removing risk by

physically removing the breast. Here, mastectomy is a treatment for risk of breast cancer, not for the disease itself. The treatment of risk by mastectomy will be discussed in detail in chapter 6.

4.5a Conveying a Diagnosis:

As I will discuss in the next chapter, women expressed much distress concerning the ways in which they were given their diagnosis. Both women who received benign and those who received malignant diagnoses felt that for the most part, their doctors did not address their personal concerns. Most benign biopsy results were given to women over the phone by the nurses or receptionist. While several surgeons explained how they experienced having to tell a woman that her biopsy results were malignant, only one surgeon explained how he gave women a diagnosis of a benign condition and said that he tried to emphasize that the diagnosis did not mean that the patient would get cancer. In fact, he said that he tried to emphasize the normalcy of the condition:

> I tell my patients, "By definition you have fibrocystic disease of the breast." And I tell them, "That sounds terrible! That sounds like cystic fibrosis and that sounds horrible!" It is so common as to warrent questioning whether it should be called a disease or whether it is simply among the range of normal. And I tell them, "What that really means is that you have breasts that will make lumps from time to time and it will make the discovering of the breast ca..., of more serious conditions, more difficult, 'cause your breasts are harder and lumpier. You're going to have pain in them that will create anxiety in you even though the pain isn't a terribly worrisome symptom. It will focus your attention on your breasts and so it is bad for those reasons and not because it means you have a greater chance of getting cancer.

This surgeon reported being sensitive to the mixed messages that women are given when they receive a diagnosis of fibrocystic disease and explained that he attempts to allay these fears. Yet, as will become clear in chapter 5, the very act of being labeled with a disease causes a great amount of distress in women. The act of giving a

disease name to a condition and at the same time considering it normal puts both a woman and a clinician in the dilemma of understanding and treating the condition which is neither a disease nor an illness but at the same time is not a state of health.

One surgeon believed that giving a woman a diagnosis of benign was an easy thing to do as it allayed her fears of cancer. As we will see in Chapter 5, this is not always the case. Often, because of the mixed meanings of benign conditions, women will not believe that a benign diagnosis gives them a clean bill of health.

> It's not a difficult thing to do to assure a woman that she does not have breast cancer. That's what they want to hear and so, you know, if there is a specific complaint like pain or lumpiness here or there, you can assure them that if they feel this way, that this is a quite common natural phenomena, part of being a woman. In many instances it does not represent anything to worry about. And I ask them to continue to do self examination and if anything changes, to let me know and if not, I'll see them in a year to see that everything's still OK.

Many of the surgeons reported that they found it difficult to inform a woman that her biopsy results had turned out to be malignant. A young surgeon explained:

> I find myself, and it's a matter of my own personality, tending to give favorable news. You know, to allay anxiety until we have the biopsy result. And I do that even during the biopsy when I take something out and say, "Oh shit, that looks like a cancer." And I'll tell them, "Ah, you know, you can't tell, come back to the office tomorrow and I'll have all the microscopic reports at that point.... You know, talk to you tomorrow." Nobody ever taught me,... you know. That is still a very very uncomfortable situation for me and it's terrible for the patient...I tell them, I don't know the future, nobody knows the future. If they believe in God, God knows the future and I'm sure as hell not God. And so I tell them, "What we know now, as of this moment after the biopsy is that you have a majority chance of being cured of this tumor.

An older surgeon explained that he did not find it difficult to give a woman a diagnosis of cancer:

> Once you have the diagnosis, you really have to use the word cancer in order to make the...a reasonable decision. And yes, it

> is the job of the clinician, usually the surgeon who has done the biopsy to say, "Well, this is what we found." It's usually not that hard I wouldn't say. It's jarring but its, in a way it's gentler than the other thing when they woke up from the general anesthesia and the breast was gone.

Here, the surgeon speaks from his past experiences of one step procedures inwhich the breast was removed at the same time of the biopsy. Finally, two surgeons explained how they think women react when they receive a diagnosis of cancer.

> I've always been very impressed with how much courage women have,...patients have. How well they tolerate being told. Now they may break down later you know. Maybe it doesn't hit them right at the time but most of them that come for a biopsy have thought of this and this is what they've been scared about. I just tell them, "I'm sorry but you know, It's what we hoped it wasn't." I try not to use the word cancer. And then I give them as much hope as I can. "It's a little thing." Anything that's good about it. I try to tell them the good features. And then I try to say, "We don't have the full story until we do some more studies." But ah, the majority of them of course get a little weepy.

> When I talk to patients, I give much more information to the patients than that pamphlet does (referring to the pamphlet published by the State of California). Now what the patient remembers, is another factor. And they probably don't remember...I realize that after the words cancer, operation, mastectomy, the hearing goes off. And there are studies to prove all this. They're thinking, while you're sitting there talking about the risks of the operation, they're sitting there thinking about who's going to take care of the dog for the next 10 days, who's going to pay the bills, you know, all the other factors involved with anyone going into the hospital.

As I will show in the next chapter, for women, the receiving of a diagnosis whether it be benign or malignant, is a transition point from one state of health into another. The time between a biopsy and receiving the results is one fraught with much anxiety. It can in one sense be understood as a liminal phase between states of health. For the clinician, the process of giving a diagnosis represents a transition from the clinical act of diagnosing to the second phase of

patient treatment and management. While much attention is given to clinical phases of diagnosis, treatment, and prognosis, little attention has been given to the transitions between these phases. For patients, these transitions are the points at which the doctor has the most control. There may be no easy way to relay a diagnosis of cancer; however, as I will show, women with both benign and malignant conditions experienced this transition phase as one of the most difficult. Clinicians need to be better equipped to deal with these uncomfortable situations.

4.5b Patient Management Decisions:

Once a clinician has reached a diagnosis and has conveyed this to the woman, he or she must decide upon some sort of treatment or management procedure. When a surgeon is fairly certain that the condition is completely benign and does not represent much risk of breast cancer, no management procedure will be undertaken. However, often the surgeon can not be sure that the condition is one of low risk and must decide just what kind of management procedure will be the safest and most acceptable. There exists a great deal of confusion as to the best types of procedures for benign conditions and often a procedure is chosen based upon they type or extent of benign disease a woman has or how much at risk she is thought to be. For example, one surgeon explained:

> I think this is probably the area of greatest confusion. It really is...She has seen her gynecologist and maybe a general surgeon. Maybe she's had a biopsy and or a mammogram which shows this data which puts her in quote, increased or at increased risk. There's all the risk factors and you know them so lets say she's now been told and she's at increased risk for developing cancer or that she has a biopsy that shows atypical cells. That's the common thing. Now, well, what does she do? She's told by one doctor, "Don't do anything, we'll follow you along." She's told by another doctor, "You've got to have surgery." She's told by

another doctor, "Gee, maybe you should have this kind of surgery. And another doctor says, "No, you should have that kind of surgery." And it becomes a real confusing area.

Thus, uncertainty and ambiguity in the clinical understanding of benign conditions leads to uncertainty in management. And management of benign conditions is treated by doctors largely as management of risk rather than as the management of a physical condition itself. The danger of benign conditions lies in their relationship to breast cancer. As I have explained, benign conditions can act to hide a current cancer or can progress into a future cancer. Doctors's management of benign conditions centers upon reducing the condition so that hidden cancers can be more readily detected and so that the risks of a future breast cancer can be reduced. However, there is little that surgeons can do to reduce the amount of benign disease short of physically removing it. Thus, in many cases, the surgeon will recommend close follow up of a woman. In this manner, the surgeon can keep a close surveillance over a woman's breasts and become familiar with any changes which might signify cancer. The following surgeons explained their reasons for close medical surveillance of their patients:

> There are certain patients of course that you get a little more worried about and you just have to frankly express that you're a little more worried about them and they just have to resign themselves to a routine of close follow up and biopsy when necessary, mammograms when indicated.

> I've followed many patients...I've been in practice for 25 years now and many patients I have followed for 15, 20 years. Every three or four months and map their lumps and I've never biopsied. When I get suspicious, when I'm not sure what I'm following, I think they need a biopsy....I don't believe that there is any way that we got as yet that puts us all, the surgeons, in a totally safe attitude. The closest that I know of is the attitude that I learned from Dr. Black. You follow your patients carefully in a concerned way, and I see most of these people, they come in every three or four months and it's incredible how lumps will change.

Finally, one surgeon explained that he follows many of his patients diagnosed with minimal cancers. Recall from chapter 3 that there exists much controversy over the meaning of these conditions and their management.

> I've got about 35 women I'm watching now. All the way from ductal in situ to lobular in situs. And I only had one turned out to have a metastatic cancer and I think she got it from a lump. I follow 'em forever. 5, 10, 15 years, some of 'em. If they're high risk, I have them come in 3 times a year, medium risk, twice a year. Other than that, once a year. I don't see them any less than that. I see most of them twice a year.

The points to be made here are that surgeons, because they can not be certain that a benign condition is truly benign or will remain benign, are at risk for failing to discover a hidden or future cancer. There is no way to prevent breast cancer short of removing the breast and thus, surgeons maintain close medical surveillance over physical conditions about which they are uncertain. Some clinicians explained that they do attempt to give women some advice on things they can do to possibly reduce the amount of benign disease. At the time of this research, several clinical studies were being conducted to investigate the effects of caffeine and vitamin E on benign breast conditions (Ernster et al. 1982, Minton et al., 1979, Minton et al., 1981). The objective clinical findings showed that the reduction of caffeine and the addition of vitamin E had no statistically significant effect on the condition. Nonetheless, some surgeons recommended these therapies to women. While these therapies represent two of the possible ways that women might be able to reduce their amount of benign breast disease, it has not been shown that they will reduce the risk of breast cancer. Therefore, most of the surgeons were not very enthusiastic

about relying on the sole use of these therapies in patient management.

> Most of the time we were not interested in treating benign conditions cause there wasn't very much we knew how to do. Now at least we can tell them some of the theories about it. Maybe take them off of various things like coffee and caffeine and chocolate and give them some vitamins. For a lot of them it does benefit.

A nurse practitioner explained:

> There's not a whole lot you can do about prevention. I say, now look, on general principal, you can keep your caffeine intake down. I don't know if this is going to change anything. You can keep your fat in your diet down. You can check your own breasts. I mean it's not prevention but you can do these things. Basically there's not a lot you can do to prevent it....Most women realize that they can't prevent breast cancer..but the thing is, that most of us don't think we'll get it so most of us are not concerned about preventing it.

Some women are concerned about preventing breast cancer because of their having been diagnosed with a benign condition which brings the possibility of breast cancer that much closer to the women's lived reality.

A key issue to understanding the medical management of benign conditions concerns the way in which surgeons think about these physical changes. In whom or what does the risk of breast cancer lie? While surgeons, on one level, speak of women at risk, at another level, they speak of breasts at risk, tissue at risk. The clinical language of breast health centers primarily upon the organ rather than the person. Again, this will be clearly illustrated in chapter 6 but here it is interesting to examine the language used by surgeons to describe how they talk about benign and malignant disease.

> I have kept a file on all of the benign breast conditions, alphabetically. I fill out a breast sheet which you might be interested in seeing. Here is the form I've adopted. They're all just listed alphabetically as to what their problems were. And so I have a pretty good record of all these cases. There must be about a thousand. Of course you have the whole gamut of the problem as to the type of breast you see and what you do with them and how you follow them and when you decide they ought to be

biopsied and when you know they are cysts or have a pretty good idea they are cysts and aspirate them and so forth.

Other quotes in this chapter and chapter 6 illustrate the language of risk and diseases being located in a particular organ, the breast. What is important here is that surgeons do not just manage women with risk, but more specifically, they manage breasts at risk. Breast cancer is a systemic disease and its cause is most probably multifactorial in nature. However, because there is no way to prevent breast cancer by altering specific factors in a woman's environment, the focus becomes reduced to the site of the disease. If clinicians cannot alter the context which produces the disease, then management is directed towards the physical site where the disease becomes manifest. The result is that clinical uncertainty becomes removed from the wider scientific context, condensed and reduced into risk which is then seen to reside within a specific physical part of the body. Through this process, clinical uncertainty becomes transformed into a disease entity, can be located within the physical body and is now open to manipulation by the clinician. Risk then represents the transformation of clinical uncertainty into a clinical entity. Risk, or clinical uncertainty, can now be clinically managed, brought under close surveillance, or removed all together.

This brings us to the fourth option open to surgeons in patient management; management through biopsy or fine needle aspiration. While needle and surgical biopsies are done primarily to obtain a more definitive diagnosis, they also often result in removing a suspicious lump. They can, therefore, be considered a treatment procedure as well as a diagnostic one. One of the more common treatments for breast

cysts is to aspirate fluid, thereby getting rid of the cyst. Cysts in and of themselves are not dangerous, yet as pointed out in chapter 3, it is thought that a woman who develops multiple cysts is at a higher risk for breast cancer. Cysts can sometimes cause discomfort in a woman and getting rid of the cyst does indeed relieve both the doctor's and woman's fears of cancer. However, cysts will often disappear on their own and having a cyst removed by needle aspiration is not thought to remove the risk of breast cancer. The following surgeons explained their use of fine needle aspiration to treat cysts:

> I examine them and it, it's...if I think it's a cyst or anything benign, I'll stick a needle into it and if it's a cyst, I get rid of it and that's all there is to it. Then I do a follow up examination.

> If there is a dominant lump, an obvious area that's firmer than the other, I explain that I would like to stick a needle in it. We can accomplish two things with that. Number one, if it is a cyst ...and it frequently is...One young lady had three lumps and they were all cysts and I put a needle in it and take out a yellowish, maybe a cloudy, maybe a clear fluid, and that results in total disappearance of the lump. You can now consider that examination to be consistent with fibrocystic disease.

As I have shown, surgeons use fine needle aspiration both as a diagnostic tool and as a treatment procedure. As I have argued, surgeons also conduct biopsies both to obtain a more definitive diagnosis and to remove the physical condition giving rise to the uncertainty. They thereby obtain clinical certainty by removing tissue at risk. While, in theory, some conditions may be more benign than others, in practice, all benign conditions are considered to represent the risk of cancer. One surgeon explained:

> I think that certain changes in the breast are premalignant changes and then there are certain other changes that I think have a very benevolent relationship to cancer. I wouldn't say all are on the road to malignancy by any means...but actually, I think a lot of that is just an intellectual process and I'm not sure that in the individual case,...a lump is a lump is a lump is a lump no

matter how much thought you give it and you probably have to get it out. So, you can be theoretical but in practice you have to pay attention to what is dangerous and what may be dangerous.

Surgeons have been trained to carry out therapeutic procedures which involve removing abnormal or diseased tissue and it is difficult for them to leave in the breast, tissue that is not malignant but at the same time not "normal". The same surgeon quoted above went on to explain:

> You realize that as a surgeon, you've been brain washed a bit ...I derive a certain degree of comfort getting rid of tissue that has already proved itself to be a bad actor. And I've always considered that in a certain number of breasts, such as 30 or 40% of them, with other lesions, carcinoma in situ, or not invasive carcinomas or a full range of significantly premalignant changes that are detected in breasts, I feel that I've done them a favor to get rid of that particular tissue. Of course, it would be even simpler if there was one breast. Some of our activity is made somewhat inconsistent in that we go after one breast and then we let them go along with the other. But we have to make a compromise. I suppose if it could be proved that a woman could end up with very fine looking breasts and the premalignant or the early malignant changes are wiped out by the radiation therapy, and the results are just as good as surgery, well, I think that we'll have to close up shop and have the biopsy as a diagnostic factor, not a therapeutic factor.

Here, the surgeon is not speaking of treating clearly malignant conditions, but rather about those that are non-invasive and premalignant. These conditions are not life threatening in and of themselves; they do not cause the woman any discomfort. However, they do represent a risk of invasive breast cancer and therefore, within the surgical context, need to be treated. In other words, the premalignant condition represents a risk of breast cancer, and the surgeon removes the risk by removing the premalignant condition. However, the surgeon above also explains the dilemma he faces; that although he has treated one breast, there is another and what ever caused the premalignant condition in the one, might also cause a premalignant condition in the

other. Surgeons cannot remove the cause of the condition, they can only remove the condition. The assumptions made by the surgeon are that what ever caused the premalignant condition might also cause breast cancer. Breast cancer might progress through different stages of tissue change and therefore, since there is no way to change the underlying cause, surgeons continue to remove tissue that is different from normal.

As we have seen, there is much controversy over what should be defined as normal and it is not clear that the same factors that cause breast cancer, cause premalignant or benign conditions. However, surgeons remove this uncertainty, or their risk of being wrong and the woman's risk of a possible cancer, by removing the condition itself. Surgeons assume that the condition is the visible manifestation of invisible causes. Surgeons remove not a "disease" but rather a "risk" of a disease. Ironically, surgeons also know that they do not remove all the risk and this requires that they keep close surveillance on their patients so that they will be able to catch the cancer early if it does develop.

4.6 DISCUSSION:

Surgeons are enmeshed within a context of uncertainty concerning the meanings of benign conditions. These uncertainties stem from ambiguities in the scientific understanding of these conditions and from clinical uncertainties associted with the clinician's ability to detect abnormal changes within the breast and with his or her ability to understand the meaning of these abnormal changes. These uncertainties entail clinical risk, and the practice of medicine

entails clinical risk taking. However, the dominant medical model does not allow for uncertainty. Rather, it requires certainty at all costs. Signs must be classified into diagnostic categories and diagnostic categories must identify disease and disease must be removed. Within the dominant clinical model, clinical risk becomes transformed into a clinical entity residing not within clinical practice nor within the clinician, but rather within the patient. Clinicians transform their own risks into the patient's lived risk. Women are seen as carriers of risk, tissue becomes defined as being at risk.

Part of this problem is due to the fact that risk for the clinician, has consequences that the current models of medical thinking and practice are not able to deal with. Clinicians learn how to memorize knowledge. They are expected to decode signs and discover underlying realities of disease. If they cannot or do not do this correctly, then they are seen to be at fault. Risk and uncertainty are inherent in medical knowledge and practice, yet these qualities are denied. Clinicians can be sued if they are wrong. The result is that clinical risk is transferred to the patient. It becomes transformed into a clinical entity, a sign of a disease. Clinical risk can then be removed with the scalpel. Or the tissue at risk can followed so that if it changes and becomes more risky, it can be treated. Clinical risk gives rise to the clinical creation of a new disease entity whereby patients are diagnosed with risk and then treated to remove risk. Clinical uncertainty, then, becomes transformed into the clinical management of risk. To understand this process more fully, I turn now to exploring women's experiences of benign breast disease and being at risk for breast cancer.

CHAPTER 5: RISK, AMBIGUITY, AND THE MEANING OF LUMPS: LAY EXPERIENCES OF BENIGN DISEASE

5.1 INTRODUCTION:

Molly is 27 years old and dying from breast cancer. She shouldn't be. She first noticed a lump in her breast when she was 21 years old. Her girlfriend urged her to see a doctor and she did. Her doctor told her not to worry, that it was probably just a cyst. Five years later, in extreme pain and unable to walk, Molly was diagnosed as having breast cancer.

> I had this little knot and I thought, "I'm sure it's nothing." But she says (Molly's girlfriend) "You should go get that examined...just because its better to be safe than sorry." So we ventured down to this little hospital and this doctor, he gave me an exam and said, "Well, I feel something like the size of a pea and it seems like it's a cyst but I don't think its anything you should be concerned about." And I thought, "Oh really? Well wonderful!" But he didn't explain to me the fact that sometimes you need to keep on these things, like cysts can grow into tumors. So I didn't even think about it at all. In my mind it was OK, it was a cyst. So the years after, every time I went for my physical, I would let the doctor know...I always made mention of the fact that I had this cyst and I always made mention of the fact that I had irregular menstrual cycles just because I figured the more information they received, the better. But maybe because I didn't have a consistent doctor every year, they never thought much of it...Then I was only 21 or 22 and they probably figured, "Oh, no big deal!" Maybe I didn't take it as seriously...especially after I heard it was nothing to be concerned about...I think they weren't conscientious enough and that really bugs me because that is what we pay them for. That's what they go to school for. And even if a patient doesn't come in and say, "Well, give me a biopsy," they should say, "Well, a cyst? And how long have you had this? Well, maybe we should take a biopsy just to see." You know, I don't care how young you are or what. That really makes me angry because I think that maybe this could have been prevented.

Molly had none of the classic risk factors for breast cancer. She is young, black, and has no family history of the disease. Benign breast lumps are common in young women, breast cancer is not. Within

the six months following her diagnosis of breast cancer, Molly underwent a mastectomy, an ovariectomy, radiotherapy, and chemotherapy. She does not know how long she has to live.

Fiona is 44 years old and has been diagnosed with a "serious" benign breast condition. She has had several biopsies that have been diagnosed as mammary dysplasia. Fiona is currently under close medical surveillance and must see her doctor every 3 months. Although she has been told that what she has is serious, she is uncertain as to the implications of her disease. Handing me one of her pathology reports, Fiona explains:

> Dr. Smith said that there are other things, mammary dysplasia for one, which could indicate the possibility of cancer in later years. He talked in Latin it seemed to me and much of what he said I did not understand....I'm still not the hell sure what it is I got...At any rate he has been seeing me now every 3 months. Now he inevitably finds something. He's found a couple of cysts in the left breast which he has aspirated. Now today I was up there and he found one in the right breast which he felt was a little bit more of a lump than it should have been....that more water should have come out of it than did. But he's going to send what little fluid that he did get to the pathologist again and I won't have their report till Wednesday. It has been an ongoing saga now for two years. As I say, he inevitably finds something. I have very lumpy breasts. I have mammary dysplasia. So it's one of those things, nobody's sure if it's a disease or what the devil it is. But anyway, every time he finds something like he did today, he puts me on pins and needles again until he decides what else...I have told myself, Sandy, I have told myself, I will not think about this anymore... But it never goes away. It is always there.

Fiona has many risk factors for breast cancer. She is 44 years of age, never married, has no children, and has been given a diagnosis of mammary dysplasia. While it is clear that Fiona does not have cancer, neither is she considered to be healthy. Rather, she has been diagnosed to be at high risk of developing breast cancer. The result is that Fiona is left feeling not quite ill yet not quite healthy.

This ambiguity concerning her current and future states of health has resulted in the medicalization of her life.

Molly's and Fiona's experiences represent the two extremes of the consequences of the ambiguities and uncertainties about risk and breast cancer. While Molly's experiences are unquestionably the more tragic, one might pause to consider the physical and psychological consequences of Fiona's constant medical surveillance. What Molly and Fiona both share is a lack of control not only over medical knowledge but also over medical uncertainty.

In this chapter, I explore how lay women experience and understand medical uncertainty concerning the diagnosis, management, and prognosis of breast conditions. The focus here is not so much on who has control over knowledge, but rather, who has control over the consequences of what is not known. The creation of knowledge lays bare the limits to that knowledge. Because scientists and clinicians have access to knowing the limits of knowledge they also have potential control over the consequences of the application of incomplete knowledge. However, lay people not only have little access to medical knowledge but also little opportunity to appreciate what is not known. This makes it difficult for lay people to evaluate the extent to which uncertainties expressed by their doctors arise from the doctor's personal lack of knowledge (that is, the knowledge does exist but the doctor is not familiar with it), or a more general lack of knowledge within science and clinical practice. This lack of lay knowledge about what can and cannot be known results in a lack of lay control over the consequences of uncertainty.

The aim of this chapter is to explore how women experience this

ambiguous state between health and illness. A phenomenological approach is most appropriate as it stresses the use of methodologies which are interpretative in nature and gives priority to understanding the lived experience. Such an approach grounds lay explanations of ill-health in people's experience (Kestenbaum 1982). We can refer to this as the lived dimension of health and illness. Lived experiences and explanations of states of health are different from the epidemiological and clinical experiences and explanations for a number of reasons. Kestenbaum (1982) argues that for science, reality is the object itself. However, in everyday experience, reality is the experiencing of the object. This points to a fundamental gap that may exist between a person's experience of a given reality and science's explanation of that same reality (Rosenkrantz 1976). As discussed in Chapter 2, medical anthropologists and sociologists have developed this perspective into explanatory models of clinical and lay perceptions of ill health, the biomedical dimensions being understood as diseases and the lay dimensions as illness. It is within this framework that lay experiences of benign breast conditions will be explored.

In this chapter, I will first explore women's experiences of when they first discovered their lump. The second section explores experiences of diagnosis and the third concerns experiences of management and treatment. In the fourth section, I discuss issues of prognosis and prevention.

5.2 BETWEEN HEALTH AND ILLNESS: THE EXPERIENCE OF DISCOVERY

Much has been written about why women delay seeking medical consultation when they discover a lump in their breasts. However, very little attention has been given towards understanding the experiences

of women who do seek medical consultation. The lack of literature in this area points to underlying assumptions held by many in the area of clinical medicine and public health that a major problem in the early detection of breast cancer is getting women to see their doctors immediately if they discover a lump. However, the problem does not stop there. Major dilemmas arise at the point when a woman seeks medical consultation. In this section I explore some of the dilemmas that women experience when they seek medical consultation about a lump in their breast.

5.2a Experiences of Discovery:

A woman may become aware of breast changes in two general ways: she may find a lump herself or her doctor, upon a routine physical exam, may detect a change. Either way, the initial discovery of a lump is a distressing experience, one that instantly changes a woman's perception of her body and self:

> I was just taking a shower and instantly I felt total, total panic. My heart raced. I thought "Oh my God!" You know, "I'm too young!" I didn't want to think about it...And all day I just carried it around all tight and panicky and I thought about, I thought about the articles I had read that said the worst thing you can do is not confront it, go and see someone. It's that fear that leads to so many deaths...I think that one of the reasons that I felt I had to go in and see somebody was that I was avoiding looking. I wouldn't touch, I wouldn't look. I was ambivalent about having my breasts touched. It was like they were just these two things on my body that were alien beings and I wished I could just get rid of them.

> Well, the shock of feeling something like that, that's totally foreign. You know, the sensation of something that doesn't really...it's not something I felt before and it's not all right that it's there. There was a feeling of fear and panic.

> I went to Woman's Needs Center to get checked up and they found the cyst in my breast. Somebody else was examining me and she (the nurse practitioner) was there also. She didn't like the way that woman was examining me 'cause she said, "No, you have to do it like this. Oh, see! There is something there!" Then she had me touch it and after that I could not touch it. I could not touch

myself at all.

> The first time I discovered that I had a lump in my breast was when I was showering. I had not been in the habit of examining the breasts and I was pregnant too so my breasts were changing a lot anyway...and my first thought was this is going to affect my ability to breast feed the baby.

Some women respond to the experience of finding something abnormal in their breast by refusing to acknowledge it and hoping that it will go away:

> It was a year ago June. I had gone for a pre-employment physical and the doctor pointed out this thickening in my breast which I had not noticed at all...She wanted me to come back 2 weeks after my period and she would check me again. Well, that day I was so distressed by what she said,...That whole thought that something might be wrong was so frightening that I couldn't figure out what to do next and I really realized why some women neglect doing anything cause you are just immobilized by fear. I really felt vulnerable.

5.2b Seeing a Specialist:

Once a woman has made the decision to seek or continue medical consultation concerning her breast condition, the first step is making an appointment with a specialist. As explained in the previous chapter, when obstetricians, gynecologists, internists and other medical practitioners discover a condition about which they are uncertain, they usually refer women on to surgeons specializing in the diagnosis and treatment of breast conditions. As one gynecologist explained, there is really no reason why most preliminary diagnostic procedures can not be carried out by the generalist. However, because the accepted method of treatment for breast cancer has until recently been surgery, treatment of the breast has been and continues to be the domain of surgeons. All women in this study were referred to surgeons for diagnostic work up. Women attending the university hospital were referred to the Breast Screening Clinic which was a part of the

department of surgery and women attending the private hospital were referred to private surgeons. As explained in chapter 2, all women interviewed in this study attended the university hospital.

It is appropriate to describe briefly the setting of the Breast Screening Clinic as the physical place provides an important context in bringing meaning to benign conditions. The Breast Screening Clinic is located in the surgical department of a high-rise clinic building. The building is part of a large medical complex composed of a confusing array of buildings. A busy traffic-choked street divides the towers of concrete and glass as doctors, nurses and other health professionals dressed in white or blue coats walk purposefully from building to building. Young medical students rush to their classes dodging patients in wheelchairs and gurnies. Elevators crowded with children and Deans, the sick and the healthy connect underground parking lots with sterile high tech operating rooms. Each year there is the rape in the parking lot and the assault in the elevator. Finding a toilet or a place to sit and eat is a trying experience. The very experience of attending a clinic at the medical center can be a stressful and unhealthy experience.

When a woman arrives at the medical center, she immediately enters the hierarchical world of those who are diseased and those who cure disease. After she enters the clinic building, she must take the elevator to the appropriate floor. Upon emerging from the elevator she is met with a sign informing her that she is now in the department of surgery. One woman expressed her dismay at attending a Breast Screening Clinic which was part of the department of surgery:

> I was sorta dismayed to see the sign "Breast Screening Clinic" and then all these surgeons' names because obviously they have only

> one answer. Cause if you go to the surgery clinic, you expect surgery. What else can you expect?

Breast screening clinics are held on specific days of the week, the clinic being used for other types of surgical problems on the other days of the week. When a woman arrives, she must notify the receptionist and then she may take a seat in the waiting area. Seats are arranged along the corridors and there is no distinct room serving as a waiting room. The area is light and not unpleasant and many of the chairs are arranged so that one can sit and look through the large windows at the city below. While waiting, women can observe the comings and goings of the surgeons and nurses although the area is totally isolated from the area containing the examining rooms .

Although a specialized clinic dealing only with breast problems is an important service, its location and physical setting distinctly contributes to a woman's experience of diagnosis as being a highly medicalized process. On the positive side, one woman explained that she appreciated the friendliness of the clinic and the amount of information that was given to her:

> I called up and said I had a lump in my breast...They said, "Oh, you can come in tomorrow." And I thought, "Should I be scared or not? Oh, do I need to come in immediately?"...The first time I went in they checked it and she [nurse practitioner] told me just a lot of information...The whole time I went to the clinic, I never had to wait and everybody was real nice...I just felt real informed.

The Breast Screening Clinic employs two nurse practitioners who specialize in breast problems. Their presence plays a vital role in helping to diminish a woman's experience of alienation and lack of control. The nurse practitioners explained to me that their aims were to give women information and to discuss their concerns rather than to

carry out the technical aspects of diagnosis and treatment. One woman explained that she was disappointed with her initial experiences with the Breast Screening Clinic because she had not been able to first see a nurse practitioner:

> I didn't go over for a couple of months because they (the clinic) were pretty filled up. I did finally get over there and was a little surprised that I had an appointment with the...well, I talked to the receptionist because of the referral that I brought over with me. It said, "refer for needle aspiration." She explained to me I wouldn't be seeing the nurse practitioner...She said, "well, since you're here for this possible aspiration, and since you've already been examined, we'll just directly have you see the surgeon." That was a little bit surprising to me but it made a lot of sense. You know, why go through a whole other exam but it was a little less....shall we say, a little less supportive than I expected it. I had a little anxiety going immediately to see the surgeon.

In the initial stages of medical consultation, women want both information and acknowledgement of their psycho-social concerns. The nurse practitioners play a vital role in fulfilling these needs.

There is a good deal of anxiety surrounding the initial discovery of a lump. Women are encouraged through the public health media to notify their doctors as soon as they discover a lump. Yet, sometimes women referred to the Breast Screening Clinic are not scheduled for immediate appointments. An appointment will be delayed if a woman is considered at low risk for the lump being malignant and/or she may be asked to wait until two weeks after her next menstrual period, when her breasts are easier to examine. While most women interviewed were able to schedule appointments immediately, those who were not able to see someone immediately expressed much concern and anxiety. One woman, a student with no other health insurance, explained that after she had discovered her lump, she made an appointment with the student health

service to see a surgeon. Her appointment was cancelled twice and she had to insist upon seeing a surgeon immediately.

> In the meantime, 6 weeks had gone by and I needed that to be resolved. I just couldn't leave it go on. So I made an appointment with a surgeon which was cancelled twice cause the surgeon only comes to student health X number of days a month and he cancelled an appointment cause he was on vacation. I went back to the next appointment and they had made a mistake in the schedule. He wasn't going to be here that day and I just started crying. I said, "I can't stand it anymore! Do something! I shouldn't have to go through this!" So they immediately got me to be seen at the Breast Screening Clinic.

When a woman decides to take action towards resolving her breast problem, she has begun to take control over her own uncertainties and her health. However, if she is unable to see a doctor immediately, she begins to lose this control. For many women, the inability to gain immediate access to medical attention is the first step in giving up control over their own self care.

5.2c Experiences of a Physical Examination:

When a woman sees a medical practitioner concerning her breast problem, one of the first diagnostic procedures carried out is a physical exam. In the previous chapter, I discussed the problems that clinicians face concerning the interpretation of clinical findings. From a woman's point of view, the ambiguities and difficulties of undergoing a physical exam are equally problematic. First, if a woman has detected a lump herself, she looks to the clinician to confirm her findings. The discovery of a lump is experienced by many women as a symptom of some unknown and possible illness. Medical confirmation and interpretation of these symptoms is important as this information helps women to bring meaning to their own experiences. At the same time, however, women fear what the medical interpretation might mean. They

fear that the results of a physical exam will only confirm their fears; that the lump will represent a sign of disease to the clinician. Thus, while women want their symptoms interpreted into clear clinical signs, at the same time, they hope that their symptoms will be be interpreted as normal. They hope their lump will turn out to be nothing serious. One woman explained:

> I went to Planned Parenthood and I waited to see if they would say anything when they did the breast exam. And they didn't say anything. And so I said, "Do you notice anything funny over here?" I wasn't going to say it exactly because I didn't want to even then, I didn't want to admit that there was really something there. So I said, "Around here." And she felt again and she said, "No, I don't feel anything." And then, I felt very relieved. Even though I knew perfectly well that something was there. But because they had told me there wasn't anything, I felt, "Well, they must know, you know, these people do these exams all the time!" In the fall I think, I started thinking, "God only knows what its doing in there!"...I went again and they decided to do the whole routine again and again they didn't say anything and again I pointed it out to them. One woman did an exam and said , "No, there's nothing there." And I said, "I know there is, you know, can someone else do an exam?" So she went and got someone higher up or whatever who came in and did the exam and said there was nothing there. Now it is a pretty tiny thing, or maybe it was at that point. I suppose it might have changed. ...But it seemed so strange because these people were trained!...It wasn't until a year ago, I went in for my annual and the woman did the exam and she said, "Has anyone ever talked to you about your breasts?" And I said, "No." And I said, "Well," I said very flippantly, "Well, I do have this one thing, you know, but I've seen doctors and you know, no problem." And she looked very concerned and she said, "Well, I think you have a more serious problem than that." And she said, "Both your breasts are unusually lumpy for your age. I'm surprised that no one's ever told you that." And I said, "What do you mean unusually?" And she took my hand and said, "Well feel here, you can feel that it's not...you can't feel all the way through. There's a kind of mass forming in your breasts."

This woman has raised several important issues. First, she looked towards the medical profession to legitimate and bring meaning to her own symptoms of a possible illness. When her symptoms were not confirmed, she attempted to dismiss them. However, this was difficult as her symptoms had come to have a lived reality to her. Second,

because initially medical practitioners were unable to confirm her symptoms, she did not feel reassured that she did not have cancer. The thought of having cancer is frightening and thus, she attempted to interpret the lack of medical confirmation as a sign that she must have been all right. Third, when a clinician finally confirmed her own symptoms, she was confronted with having to accept a disease label indicating that something inside of her was not normal. Thus, she was faced with being medically labeled as having abnormally lumpy breasts.

Another woman vented her frustrations concerning her difficulties in having her clinician confirm her own physical findings:

> I was surprised 'cause when doctors had examined my breasts, they hadn't done it as well as I could of, which sorta bothered me cause I thought if they were examining breasts, they would do it really well.

As we have seen in the previous chapter, conducting breast exams and interpreting findings is often difficult from a clinical point of view. However, the public health media and the literature written for women informing them about breast conditions rarely raises this issue. The lay literature implies that the doctor has all the answers and therefore women tend believe that their doctors should be able to perform and interpret a physical exam with little problem. The very lack of information available to laywomen concerning the problems facing the clinician acts further to remove women's control over their own health.

Molly's tragic story presented at the beginning of this chapter is a vivid illustration of women's alienation from knowledge and power. It is useful here, to contrast the following three passages about breast health with Molly's comments. The first statement is taken from

a particularly well-written booklet on breast self-examination (Horowitz and Johnson 1982). The second is taken from an article concerning breast care published in a women's journal, Family Circle (1983) and the third from an article on breast lumps published in another women's journal, Self (1982).

> If you have any questions about how to perform breast self-examination or about what you are feeling when doing the exam, ask your doctor.
>
> Every breast abnormality should be examined by a doctor. Ask him to explain exactly what kind of lump you have. Don't be afraid to ask him to be specific (p:98).
>
> Anytime a lump develops it should be checked by your doctor, since the only ways to know for certain whether it's benign or malignant are aspiration and/or biopsy. Yet when a doctor first examines a pronounced lump, he or she may simply say reassuringly, "It's nothing to worry about--its probably just a cyst," before making sure with aspiration. Is your physician guilty of merely guessing? "Not necessarily", explains Dr. Kister. "Certain characteristics of a growth help a practitioner allay his or her suspicions about it's benign or malignant. The most important factor is whether or not the growth seems to get larger and smaller in connection with the menstrual cycle. Cancerous tumors don't get smaller. They usually grow, although sometimes they may stay the same size. Also, if the lump is movable, it's more likely to be benign. Cancerous growths tend to be fixed" (p:28).

All these quotes can lead women to believe that their doctors should have all the answers about breast conditions. They give no hint of the unresolved issues concerning breast health nor of the problems clinicians face in translating often ambiguous knowledge into practice. Unfortunately, the consequences can result in women dismissing their own symptoms and failing to pursue an uncertain diagnosis.

For example, a few months before she was diagnosed with breast cancer, Molly became pregnant and had an abortion. During and after the pregnancy, Molly's breast rapidly changed, her nipple became

inverted and her breast became hard. She also was suffering from pain in her back, extreme fatigue and a general feeling of ill-health. In short, Molly felt sick. She went to see a gynecologist who then referred her to a surgeon. Molly explained:

> He examined me and said, "Oh no, no no no, there's nothing. I think you just have clogged milk ducts." You know, I thought, "Oh! Whew!"...The nipples were starting to invert and you know, they were very hard. I thought, "Well, this is just not..." And he says, "Oh no, no, they're just clogged milk ducts." I thought, "Oh, Ok, you know, this is a surgeon." I figured he knows what he's talking about! He didn't say, "I think you should have a biopsy" or anything like that. And I didn't know what to ask, you know, and this is probably my fault too. but I didn't think about....I didn't say, "Well, I think we should really have a biopsy or look further. And he says, "Oh, come back and see me." He wanted me to come back and see he again like, in 3...6, weeks...And so you know, I just forgot about it.

I am not interested here in questioning the accuracy of Molly's story but rather with pointing out that even when it became obvious to Molly, that something was drastically wrong with her breast and her body, she still continued to believe that what the doctor had told her was true, that she was all right. Remember that Molly was young, she had just had an abortion and she was naive for the most part about medical issues. Contrast Molly's statements with those of Kate, a woman older and more experienced with the world of medicine. Kate was a newspaper reporter and had covered different types of medical issues.

As with Molly, Kate discovered a lump in her breast while bathing and immediately went to a women's clinic and saw a nurse practitioner. The nurse practitioner referred her to a surgeon who specialized in breast problems. Kate explained:

> It wasn't a typical cancer lump. It was mobile, it was mushy, it wasn't a hard little fixed spot...I had a mammogram which was negative... so I went back to the nurse practitioner and she said, "Well, I don't think it's anything but nonetheless we like to be careful...and it would be a good idea to see somebody who is a specialist." And she recommended a doctor in Oakland who she said

had terrific hands, he was really good in feeling these things out and making decisions about what to do so I went to see him. He was wonderful. Really good, he was a surgeon but apparently does a lot of women with breast problems and he was terrific. He took me through everything step by step from benign breast disease to early diagnosis. He went through all the steps and he explained it would turn out to be nothing at all. Based on the negative mammogram and my family history and a lot of other things, that probably it would be all right. He didn't recommend it, but that I could walk out and forget about it....he seemed to think that probably it wasn't anything and spent a lot of time talking about benign breast disease, about coffee, vitamin E and about a lot of what he thought was my probable future...But I went in for this biopsy, when I went in he was very bouncy and jolly, really a nice guy and he was joking with me cause I was nervous. And as he was doing the procedure, he quit joking. He finished and I sat up and I looked at him and he just looked dreadful. Obviously upset. So I got my clothes on and went into the hall and I said, "You think it's a malignancy don't you?" and he said, "We don't like to see it like this.

I should like to stress several points here. First, Kate saw a surgeon who specialized in breast problems, yet, based upon a physical exam, he believed that the lump was benign. The choice of a biopsy was left up to Kate; the surgeon gave her that choice. Kate herself had a good deal of knowledge about medical issues and felt competent in choosing to undergo a biopsy. What is similar about both Molly and Kate is that both were considered to be at low risk by their clinicians. What is different is that Kate was able to take control over the uncertainty inherent in the physical diagnosis. Kate trusted her doctor enough to take account of the small amount of clinical uncertainty and thus choose to take further diagnostic steps. Molly however, was less aware of the diagnostic uncertainties and continued to want to believe that nothing was seriously wrong.

The point here is not to argue for biopsies under all conditions of uncertainty. As I have pointed out in the previous chapter, unnecessary biopsies are often conducted in order to decrease clinical

risk and can result in scarred breasts, making the detection of a breast cancer even more difficult. Biopsies can raise a woman's chances of dying from breast cancer. Rather, the point is that in order to make informed and responsible decisions, women need to know about medical uncertainty. Lack of knowledge of medical uncertainty raises a woman's risk of over-medicalization on the one hand and of insufficient medical follow up on the other. If women are made knowledgeable of the problems the clinician faces in conducting and interpreting a physical exam, they will be in a better position to take control over choosing whether or not to undergo further diagnostic procedures.

5.2d Experiences of Mammography:

It is routine for doctors to prescribe mammograms for women over the age of 40, also for those who are thought to be at high risk and for women who have difficult breasts to examine. When used appropriately, mammography is highly effective in helping to detect cancers too small to be palpated. However, the use of this technology is not without its problems. As was pointed out in chapter 3, routine mammography for young women is not recommended because it has been estimated that exposure to radiation over long periods of time can increase a woman's risk of developing breast cancer. While much research has been directed towards the medical risks and benefits of mammography, little effort has been directed towards women's experiences of this procedure.

Here, I will discuss women's experiences of mammography with a focus upon issues of uncertainty and control over this screening technology. One of the major problems women experience with the use of mammography is that there is much they do not know about what the

technology can and cannot do. Because mammography involves the use of x-rays, many women fear the effects of radiation. The problem for women lies in being able to identify which kinds of fears are medically justified and which are personally justified.

The risk of exposure depends on many factors. These include the kind of machine used, the types and numbers of x-rays taken, the age at which mammographic screening begins and the benefits of mammographic screening as compared to the risk of not using the technology. Many different types of mammography machines are currently in use, some of which give higher doses of radiation than others. Women are often not aware of this difference and thus make uninformed decisions about where to have mammography done. For example, many of the clinicians at the university hospital expressed concern that women undergoing mammographic screening at the private hospital were being screened with an outdated machine. They felt that women were being exposed to unnecessary doses of radiation. Several clinicians and one radiologist with whom I spoke to about this matter at the private hospital felt that there was no need for this concern. However, the extent to which this information was made available to women undergoing mammography at the private hospital is questionable.

The university hospital had the most recent mammographic technology, machines which deliver low doses of radiation and which were considered by most clinicians to be quite safe. Inspite of this, several women attending the university hospital, confided in me their fears about being exposed to the radiation. For example, one morning, I was in the Breast Screening Clinic following one of the surgeons on his rounds. This surgeon was examining a woman in her early fifties

who had a suspicious lump. The surgeon felt it was important that she have a mammogram and wanted her to have it done that day. The woman began to question him about the risks of radiation and the surgeon explained that the dose was not very high and that she shouldn't be worried. He then left the examining room to ask the receptionist to call and see if the woman could have a mammogram done within the hour.

I stayed in the examining room with the woman while the surgeon was out and the woman explained her concerns. She said that she was afraid of getting breast cancer from the machine, she had heard about the risk of cancer associated with the breast screening trials and wondered why the surgeon couldn't tell what her lump was from his physical exam. The surgeon came back into the examining room and told the woman he had scheduled her for a mammogram, but first the woman was to see the nurse practitioner. When the surgeon left the room, the woman began to cry. As she waited to see the nurse practitioner she said that she didn't understand why she had to have the mammography and that she was very frightened.

Two issues are important here. First, the woman did not understand that the surgeon was very concerned that the lump was indeed malignant and that therefore, the risks of not having a mammography outweighed the risks of having one. Second, the publicity given to the breast screening trials and the risk of breast cancer made the issues seem black and white. The woman did not understand just who was at risk for repeated mammograms and how these women were determined to be at risk. She did not understand that mammographic technology had been perfected so that very low doses of radiation would produce high quality pictures. The surgeon did not have or did not take the time to

address her concerns and thus the woman was left feeling as if she had very little control over the situation.

Once the decision has been made that a woman will have a mammogram, the experience itself can prove to be most unpleasant. A major problem is that if an abnormality shows up on the first mammogram, then additional pictures will be taken. The technician taking the film is not allowed to give any diagnostic information to the patient. However, women know if something is not quite right. The inability for women to obtain immediate information at every point of the screening and diagnostic process is a source of much distress and further leads to a lack of lay control. One woman who was diagnosed with breast cancer explained:

> He didn't really think that anything was wrong 'cause he had done an exam and there was no indication of anything. But they just do mammograms routinely, so I went and there it showed up on the mammogram. I went in and I thought, "OK, that's it." But you have to wait while they develop the film and stuff. So she said (the technician) if they don't get a good shot, they would have to do other views. I thought how many other views could you have! But I found out! She came back and on the left breast, they had to do it again and again and again. And every time, I'd wait, you see, while they went to develop the film. And then they took me to another room with another machine where they could twist you in there even more differently, cause it was way at the base so it was hard to get your body in there far enough to get a really clear picture of it. Well, by that time, I said, "Should I start worrying about this?" Because I suspected they aren't doing this one side over and over and over without being suspicious of something. I asked her and she said they had to get a better picture of this side and didn't really say "Yes, there's something wrong." But they were very concerned about it but they didn't tell me there was something wrong. I knew there was something wrong 'cause you don't do that over and over without there being some reason for it. Well, anyway, then I was finished and they told me it would be a few days before they had the results so I left and came home. I thought, well, if there is anything really wrong, they'll 'phone me or send me one of those cards they send you when something's wrong, to come back. I hadn't been home very long when my doctor phoned me.

This woman was in her early 60's, had very little experience or

knowledge about medical issues, had read little about breast health and did not demand more information during the mammographic procedure. In contrast, the following woman was diagnosed with a benign condition. She is in her mid 20's and was well informed about her rights as a patient and about issues concerning breast health:

> I went for a routine, what I thought was a routine mammogram and the lab technician was great ...They kept taking, instead of say 6 mammograms or 4, she kept going out of the office and coming back and saying, "We're going to take another one" And I just knew something was wrong. The logistics and common sense just stepped right in and said, "Hey wait a minute!" And so I asked the technician, "I'd like to see these when you're all done with them. And she said, "You want to see them?" And I said, "Yeah I'd like to talk to the doctor" and she said, "Oh, ok".. because I'd read somewhere that the patient can not be denied the right to see or talk to a doctor about their condition. But you have to ask because they're not going to say, "Well, would you like to see what we did?"

Finally, a woman diagnosed with a malignant condition explained:

> When they did the mammogram, the first one, the gal that did it, she had a funny look on her face and I remember seeing that and I said, "That doesn't look good does it?" And she said, "I'm not really allowed to tell you." But I said, "I can tell by your face, you don't have to tell me." And she shook her head and nodded her head and agreed with me. And that's all she could do.

Once mammograms have been taken, women often have difficulty understanding the results. When the results are clear cut, a woman receives a diagnosis of malignant or benign. However, very often the results are ambiguous and the clinicians are not certain how they should be interpreted. One woman explained:

> The next time was when I got the mammogram and they saw peculiarities in it, under super-duper magnification, which is obviously a mixed bag. It was bothersome to me. It was more of a question and...some fear, some concern about what this lymph node meant...the mammogram,...looked as if somebody had taken droplets of water and went like that! [flicks her fingers]. Very fine, maybe sprayed an antomizer at it. It was all over the place, some were grouped and some were random. And it was like, "My God, if that's what's happening, I'm going to have lumps of cancer all over!" They never referred to them as calicifications but they reminded me of that in the mammograms I had seen. They didn't

> know what it was. And they were very curious and they wanted to know what it was and so, the suggestion was, "Go home and think about it but don't wait more than a week. I didn't think about it. I thought, "Oh fuck! I'm just going to go do it! [referring to biopsy]" I mean, if that's the level of intensity that he feels about what he sees on there, what choice do I who buy the medical model for the most part, or at least can't discard it totally, what choice do I have?

When faced with confusing mammographic results, what real choices do women have? Part of the problem women face concerns their limited access to detailed information concerning mammography. For the most part, women interviewed had little knowledge concerning how mammography worked or about the interpretation of results. A survey of the kind of literature available to women at the two hospitals studied, showed that little detail is provided concerning mammogram technology and interpretation. A pamphlet put out by the American Cancer Society entitled "Facts on Breast Cancer" gives a short 100 word description of mammography:

> Mammography (x-ray examination of the breast) is a very important diagnostic tool, particularly in symptomatic and high risk women. The newer techniques and equipment, when properly used, have permitted physicians to largely dispel the concern about x-ray exposure from mammography causing breast cancer. The known risk of breast cancer in all women over 50 and in high risk groups between 35-50 is far greater than the theoretical risk for mammography. It is the only method that can find tumors before they can be felt by the most experienced physician"(1978:7).

This short description is typical of most explanations of mammography for lay women. However, it provides no details or "facts" to back up the arguments presented. First of all, mammography is not a diagnostic tool but rather a screening tool. Second, no information is given about what is known about specific risks and specific doses of radiation. Third, no information is given concerning what level of radiation is currently thought to be acceptable. What levels did old

machines give? What levels do the newer machines give? No information is given concerning what the "known risk" of breast cancer is for women over the age of 50 and no information is given concerning what the "theoretical" risk is for mammography. In short, no information is given which might allow women to evaluate for themselves, the truth of these statements. Women are being asked to accept the dominant medical orthodoxy about mammograms without questioning the many assumptions upon which the orthodoxy rests.

It might be argued that it is not feasible to provide all the details in a small pamphlet, however, this does not preclude providing references or sources that will give them the details if they so desire. Most of the literature for the lay woman asks her to take at face value, the statements about the goodness of screening and diagnostic technologies. At the two hospitals studied, nurse practitioners represent the primary sources where lay women could obtain more detailed explanations of mammography and other screening and diagnostic technologies.

5.3 EXPERIENCES OF DIAGNOSIS:

5.3a Experiences of Needle Biopsy and Surgical Biopsy:

In chapter 4, I argued that biopsies are performed both to obtain a more definitive diagnosis as well as to remove the clinical risks and uncertainties of a possible hidden or future breast cancer. For women, having a biopsy is an unpleasant but often necessary experience. Because a biopsy is an invasive procedure, it symbolically brings a woman one step closer to the cancer experience.

Little attention has been given to women's experiences of undergoing a biopsy and in part this is because medical professionals

consider it to be a relatively minor procedure. However, for women, the biopsy experience is filled with the fears and uncertainties of what the outcome might mean and what one's future might be. For many women, having a biopsy represents a further loss of control over one's health and one's body.

As was discussed in chapter 3, needle and surgical biopsies are two types of diagnostic technologies. Some of the surgeons interviewed, explained that needle biopsies were less invasive and could be conducted in the examining room. If the lump was a cyst, the fluid could be withdrawn and the problem could be taken care of then and there. If tissue was withdrawn, this could be sent to the pathologist for analysis. In theory, the needle biopsy is supposed to save the woman and the surgeon the inconvenience of scheduling another appointment for a surgical biopsy. However, as I have shown, many surgeons are suspicious of the results of needle biopsies and don't fully trust negative results. Thus, for the clinician, the needle biopsy is a mixed blessing.

Women also may have reservations about the procedure. First of all, a rather large looking needle is used to aspirate either fluid or tissue. One woman reported:

> I asked him how much it was gonna hurt and he gets out this big needle! That was scary! It is a very big needle.

The surgeons I interviewed claimed that since there are no nerve endings in the area where the needles are inserted, that needle biopsies are not painful and, therefore, the surrounding tissue does not have to be anesthetized. While this observation may be true according to scientific medicine, some of the women who had the

procedure reported that it was painful. The following are quotes from women describing their personal experiences of a needle biopsy:

> What did bother me was that we agreed that it made sense to go ahead and have a biopsy so he took out his needle and everything and um...He did something which I find a lot of surgeons do and it bothers me. He was going to,...he wanted to just stick the needle in and see if he could get fluid or tissue without anesthetizing the skin! So, I really didn't like the idea but on the other hand, I didn't argue with him about the matter. And it did hurt quite a bit. But he got tissue back. So after it was all over, I thought, "Well, OK, I'm glad I got this over with because they got something they can look at and solve this...put this problem to rest once and for all". So if he hadn't gotten any tissue I probably would have left feeling a little irritated.
>
> I was there actually to do a needle aspiration because that was intermediate between a biopsy and it was really painful. It wasn't suppose to hurt but it was really painful and he just kept jabbing it and I was screaming, like real sharp pains. They couldn't get any fluid, they just kept poking.

And a woman diagnosed with a malignant condition described her experience:

> On Friday I had a needle biopsy. It was ghastly! He did it twice to make sure he got it. He sticks it in and it's like, Oh God! It really hurt! And he said those are the little capillaries breaking! My whole breast was black and blue. The whole thing. He really gave me the business on that. As I say, he did it twice. He is not gentle and I think that may be typical of surgeons. They are use to dealing with people under anesthesia. He's a very nice man and I feel he's very competent and I don't know if it's possible to do it in a better fashion but it's very painful...I remember when he was ready to do the needle biopsy, I said, "Well, I hope it dosen't spread it. And he said, "Well we don't think so." (laughs) I mean, I don't blame him for that. I mean medicine isn't an exact science. I mean that's not the way biology is but...I've always kinda wondered cause I started having this tingling right after that.

Contrary to clinician's beliefs, needle biopsies are painful for some women. This would suggest that women should be given the choice of requesting a local anesthetic if it makes the procedure more tolerable. This choice is especially important since many women will face the same procedure again in the future.

But perhaps a more important point is that these women did not express the belief that they thought they had a right to insist upon being treated differently. Often women do not know before hand that they might have a needle biopsy. Surgeons decide on the spot after conducting a breast examination. It is difficult for women to make choices and take control when they are seated on an examining table, with their breasts exposed and faced with a recommendation by the surgeon to go ahead with a needle biopsy. One woman explained her feelings of lack of control:

> Well, I was in the tub and I have always had lumps but I guess I was giving myself a breast check and I got secretion and I checked my other breast and didn't have secretion and so I thought that this is something to be concerned about. So I went to the doctor and they were just ready to cut it out!...I mean there wasn't any kind of talk about a blood check or other causes. It was just like, look at the lump, not preventative things....I wish people and doctors were more honest about what they know and what they're saying and give more choices. When I went in it was just wham, bam, boom! Let's open her up and find out what the problem is... The first time, when I was in there getting examined, the first time they were going to do a test to see if I had a liquid cyst. I said, "I can tell you right now, I don't have a liquid cyst, it's going to come up dry." And they wanted to test it anyway and they did and it was dry.

This raises the question of what kinds of choices women do have concerning needle biopsies? This question can be addressed in several ways. First, when women schedule an appointment at the breast clinic, they could be told before hand the kinds of procedures that they might expect. Second, when they arrive at the breast clinic for their appointment, they might be given some information to read concerning the kinds of diagnostic technologies and procedures which might be utilized. Third, women could be given a chance to first sit down with the surgeon and discuss these issues before they are undressed and placed upon the examining table. At the Breast Screening Clinic, when

a woman had the opportunity to see the nurse practitioner before seeing the surgeon, she often had the opportunity to be informed and to discuss these issues. However, women do not always see the nurse practitioner before they see the surgeon. Finally, in cases where the surgeon believes that a lump is not malignant but rather is most probably a cyst, women need to be given the opportunity to see whether it will go away on its own or to try other alternatives such as home remedies. One woman explained her attempts to get rid of her cyst herself:

> A couple of people looked at it and said, "Yea,...Well, we do this needle thing and take some fluid out." But to me, what I did was try to get rid of it myself. Golden seal, do you know what it is? It's like a diuretic, if you have a cold or anything, it makes you sweat and pee in 10 minutes, I swear! It gets rid of anything. So I drank the tea, it tasted horrible, it's yucky tea and I drank some about every hour for the rest of the night and I swear the next day, it was almost entirely gone. But I had a lump under my arm, my lymph gland was still a bit sore. Then I knew that it wasn't serious or anything. But I still went through with the treatment thing.

This woman went on to have a needle biopsy. However, the point is that by becoming informed before she had the procedure and by being able to take control over her own treatment, she was able to enter into a more cooperative relationship with the medical practitioners. By first being able to decrease the size of the lump herself, she began to take control over the diagnostic process. Additionally, she made the decision herself to proceed with further medical diagnostic procedures.

If needle biopsies are difficult experiences for women, surgical biopsies represent the next step towards a breast cancer experience. Until recently, surgical biopsies and removal of the breast if the results came back malignant was a one step procedure. Women went into surgery not knowing if they would wake up with one breast gone and a

diagnosis of cancer or free, healthy and ready to go home. Now, however, most women undergo what is referred to as a two step procedure. A biopsy is performed and the results given to the woman. If the results are malignant, the woman has a chance to decide on the most appropriate mode of treatment. Women have fought hard for doctors to accept this two step procedure as the norm. None the less, having to undergo a surgical biopsy can still be a traumatic experience.

Biopsies at both hospitals in this study were done as "same day surgery". This means that women enter the hospital as outpatients, biopsies are carried out under a local anesthesia and women need not spend the night in the hospital. Generally, the procedure takes no longer than an hour. However, biopsies are carried out in an operating room by surgeons and there is always uncertainty and fear for the woman concerning the outcome.

Two themes emerged from women's experiences of a biopsy. First, women expressed a lack knowledge about how the procedure would be carried out. Second, women expressed a sense of helplessness in that their future was at that moment out of their own hands and in the hands of the surgeon. Thus, in a real sense, undergoing a biopsy brings a woman one step closer to losing control over her body and loosing control over her experience of health and illness.

For example, one woman had her initial biopsy at a hospital other than the two in this study. For this biopsy, she was admitted to the hospital and the biopsy was done under general anesthesia. This woman had been living in the United States for about seven years, spoke broken english and was somewhat unfamiliar with the medical system. Her experience illustrates her perceived lack of control over the

procedure:

> After the mammography, he said he's not sure, there are black spots and he wants to make biopsies. So I went Thursday in and Friday morning they did biopsy and they put my whole body in sleep. I didn't know how it would work, the biopsy see. I knew that it could be locally done but because he didn't explain to me, I was thinking "Don't ask too much, he will do the right thing."

Often, if a suspicious spot is detected on a mammogram and it is difficult to palpate through a physical exam, the use of x-rays will help the surgeon pinpoint the area to be biopsied. Needles are inserted into the breast and then dye is injected into the site to be biopsied. The following woman describes her experience:

> The nurses were very supportive, very supportive. They knew I was scared to death. Anyway they punched all these holes. I looked like a dart board. I mean I had pins in my breast....then he took x-rays. Well, they took thousands of x-rays which of course hadn't been yet developed ....Then they took me upstairs about 2:30 in the operating room and they inserted blue dye where those pins were, so he could see where when he'd take them out. The only thing he told me that made me feel happy at all was the fact that he'd only have to make one cut instead of two. I was afraid he'd have to make two cuts. He didn't do that, he only did one. Well, from 2:30 to 4:15 I laid on that table while he...it was a long wait. I will never do that again. I would rather be out. I don't care how dangerous the anesthesia is. It was a long time... Dr. Smith wears glasses and so he was looking down with all these bright lights on him. I did not feel anything, I swear to you. There was no pain at all. I could not feel anything. But when he made the cut, the blood splashed on his glasses. "I think I'm going to pass out! I think I will die right here on this table!" It wasn't a lot of blood but I watched it right on his glasses...and he worked and worked and it went on and on and on. It was an eternity. Time is relevant. I mean it is. I cannot believe that he was taking this much time. And I was uncomfortable....Another thing! He cut with an electric something or other and I could smell my own flesh burning. They covered me so I couldn't see but I could smell that. It was a very strange sensation...All I know is that by the time it was ending the tears were falling without my sobbing...but the tears were falling. And of course everybody was saying, "Are you in pain? Are you in pain?" Well, of course I wasn't. I was, well, the nerves were gone, they were gone. ...He patched me all up with a bandage and I got into the dressing room, I mean, I came apart. I don't think I have cried that hard in my entire life. I mean I sobbed. I couldn't gain control of myself... I went to bed and...I mean to tell you, I cried for two full days. I hadn't lost a breast and I cried for two whole days.

There are several points I would like to highlight. First, the medical professionals were concerned with deadening only one of the senses, pain, through the use of a local anesthesia. The other senses however, were still functioning. This woman could see what was happening to her in the surgeon's glasses and she could smell her own burned flesh. She was clearly experiencing much distress. Yet when she expressed her distress, the doctor and nurses focused on her sense of pain. It was as if the experience of pain was a legitimate source of distress rather than hearing, smelling and seeing. Not being able to legitimize her distress as pain, she explained how she began to "fall apart". She experienced a loss of control over her situation. She says quite literally that she came apart and that she couldn't gain control of herself. In fact, her body did come apart and she did not have control over her self. While a certain loss of control in such situations is perhaps inevitable, medical practitioners need to realize that while a local anesthesia can deaden the body against pain, they cannot deaden the other senses. This is particularly important for surgeons who are quite use to operating with a general anesthesia. Doctors need to ensure that women know what to expect. In this way, women can take greater control over their distressing experiences. Doctors and other medical providers also need to address and acknowledge senses of distress other than pain. Care and support should be provided for women in these situations and this requires that surgeons have a greater sensitivity and understanding of the biopsy experience.

In the next case example, another woman expresses similar feelings

about the lack of pain but the experience of distress through other senses. Also illustrated is the lack of understanding of this distress on the part of the operating room nurse.

> Anyway, I had this needle with dye and everything and I couldn't be moved cause they didn't want to jar it loose. They wheeled me up in a wheel chair in the elevator and I felt so funny cause all these people were looking at you and I thought of the needle sticking out. Nobody could see cause I had a lab coat on, but ....And my sister came with me and she was very supportive and then all of a sudden I said good-bye to her and they wheeled me in the room and I started crying! I told the operating nurse, "I feel so damn stupid! I'm crying and I don't know why!" And she said "It's just shock or nerves, don't worry about it." I said, "I just feel so funny!" I was laughing and crying at the same time. I said, "I don't know why I'm crying!" But I did. It was just a nervous reaction... I never felt a thing cause I was so numb from all this novocain, which was good because I didn't want to feel any pain. ...When they made the incision with the scalpel, I could feel my blood running across my chest. It didn't hurt but it just felt like something was dripping. I'm sure that was what it must have been. And then I began to feel a little teensy bit of pain and they gave me more novocain. ...I guess coderize is the term when they burn you, solder or what ever they do, and that smelled to me when they did that, reminded me of, this is weird, like barbecuing chickens or something...

The issue of control is interesting as some women interviewed experienced taking a kind of control over their helpless situation through humor. The following case example is revealing as this woman reported having a joking relationship with her surgeon and was able to express her fears and concerns to him in humorous and perhaps non-threatening ways.

> I made the appointment that day for a needle local. I got there and saw Dr. Smith who inserted the needle and I was shocked that it was...not as...not painful. It was a little pressure. I mean, to see needles sticking out of your breasts, I mean, it hurts the head more than it hurts the body!...So then I put on a robe and went down and waited for some God forsaken length of time, like an hour or more with this thing sticking out of me, until I got into surgery. I think people went to lunch. I'm sitting around, you know, sitting there with this needle sticking out of me in my robe, waiting and waiting...maybe waiting 2 hours, I'm not sure...I thought that was...somewhat barbaric. ..When I finally got in there...it normally takes 20 minutes, it took an hour and a half. After an hour, Smith (the surgeon) says, "I can't take much

more!" And I thought he meant a breast! (laughs) I said, "Oh, ah, it's all right doctor." You know, here I am reassuring him!. "It's all right, you know, that one was always a little larger!" But then it was maybe a day or so later, I realized that he meant he couldn't take it! He was getting exhausted and he was feeling pressured!....At one point I said, "You have my permission to close." He was kinda relieved at that you know.

As pointed out in the previous chapter, some surgeons stated that they performed biopsies even when they were fairly certain that the lump was not malignant. Many of the doctors interviewed reported feeling badly about this; however, they also felt that biopsies were required in order to remove the risk of uncertainty. Thus, often doctors feel better doing something rather than nothing. Some women also reported similar feelings. For some women, living with a bit of uncertainty was not acceptable and thus, they felt that a biopsy would remove this risk. The following women describe their decisions to undergo a biopsy:

> I don't like not knowing. I like having tests done even though I know they really don't make that much difference sometimes. It's so much of a reassuring thing.

> He [the surgeon] said I had the option of waiting and looking at these things over a period of three years to see whether they if they became further defined or go in now and have a biopsy. He recommended the biopsy and my thing that I asked him was, "Well, if I wait three years and I find out three years from now that it's malignant, am I going to loose much time off my life cause I waited three years?" And he said, "I can't tell you that." And I thought, "Oh!" Right then and there I knew I had to find out now!

One woman expressed her concern because she had requested a biopsy yet her doctor had told her that the procedure was not appropriate. This woman had a strong family history of breast cancer and was very concerned that if a cancer should develop in her own breast, that it should be detected early. She had a generalized thickening in one of her breasts which showed up on the mammogram and which could be

palpated. However, her surgeon did not think that it represented a malignancy. She explained:

> I didn't want to fool around anymore. I wanted to know what this was. I wanted a biopsy and he was hesitant. He was really reluctant to do that. He said when you do a biopsy and you don't know exactly what you're looking for, you know, it produces scar tissue which makes it a lot more confusing. He was satisfied with the needle biopsies and the findings of that.

This woman ended up accepting her doctor's advice and did not insist on having a biopsy. At the time of the interview, she reported being satisfied with her current medical management as she sees her surgeon every three months and has been told that the thickening in her breast is not changing. Other women resisted their doctor's recommendations for biopsy and instead decided to live with the uncertainty of a possible cancer.

> Well, most of the people have told me it's OK, and that I didn't really need to go any further. It was really a minority of practitioners who told me to do a biopsy and actually last year I was tempted to go ahead and get a biopsy to finally finalize what it was in my mind, because having just gone through the death of a spouse with cancer,just to relieve my own anxiety...But I saw a couple of other specialists and they said it didn't seem like anything out of the ordinary and I'm pretty conservative myself in terms of surgery and will not do it myself unless I'm convinced it's necessary.

Another woman explained:

> Well, it seemed like they thought it was cystic at that point so that was nice to hear. The aspiration confirmed that. But then they were thinking, "Lets take it out." 'Cause it was kinda big. I wasn't too keen about that but I did go in after that. I was going to suggest to the doctor, "Why don't you try and aspirate some more and see if some more fluid comes out." But before I had a chance to do that they did take 3 more ccs out...so, as it stands now, I've tended to prefer to avoid surgery. A couple of reasons why is that that I have no desire to get under the scalpel. Another is that I don't have any desire to have my breast scarred up although it might not be too bad...I think I've been back a couple of more times and they tell me that it's maybe 90% sure [that it's not malignant] and I figure that two 90s make more than a 90!. The doctor that I had recently says that there are two schools of thought, take it out or leave it in. He's more the "take-it-out" type 'cause he says that aspirations are not

> 100% conclusive. I still haven't decided yet what I'm going to do. I know what his feeling is. I know that he would probably prefer to have it out just to be sure but I think I'll wait until he takes another measure. I don't think it grows any. It just comes back to it's original size and I think that's it. But I still haven't decided yet because it would be kinda foolish to risk leaving it in and then having it end up being malignant and then end up having more problems after that. So,...I'm still up in the air!

Decisions concerning whether or not to have a biopsy are fraught with uncertainty and the rationale behind performing biopsies is to remove this uncertainty, to obtain a definitive diagnosis. While the majority of biopsy results do in fact bring certainty to diagnosis, results can ironically increase both a woman's and a clinician's uncertainty over the meaning of the lump. I have discussed this issue as it pertains to clinicians and here, I want to focus upon women's experiences of diagnostic results.

5.3b Receiving the Diagnosis:

When a woman has a biopsy, she must wait for the results until the tissue has been analyzed by the pathologist. Some of the more disturbing experiences described by women were those associated with receiving their diagnosis. Women with benign conditions as well as those with malignant ones expressed a great deal of distress and general dissatisfaction with the way they received their results. The time between having a biopsy and receiving the results is an anxious one. Women wonder what the results will show. Will they be told they are healthy or ill? Will they be told that they are dying of cancer or will they be told they have nothing at all? One woman described her feelings during this time:

> It [the biopsy] was more emotional than painful, especially since I had to wait four days for the results. We had planned to go away to Yosemite that weekend and we went away but, naturally I was worried all the time and naturally we talked about it and I considered all the alternatives. "Well, it's probably benign 'cause it's been there all that long and he doesn't think it's malignant." So on the one hand I was saying that to myself but on the other hand, I was saying "You never know", especially with me, who knows what it could be! Especially when I think of the cases that come into the clinic and the young women who die of breast cancer.

Perhaps one of the more insidious aspects of cancer is its invisibility, its lack of symptoms in its early stages. And it is this invisibility that brings about a great deal of uncertainty and anxiety in women. Cancer in its early stages, is only visible to the medical gaze. Cancer is a condition where people can feel very well while at the same time be very diseased. Cancer can be a disease without an illness. Women are very aware of this contradiction between what they experience and what the underlying reality, as defined by medicine,

might be. One woman who had had her first biopsy seven years prior to participating in this study explained:

> I had to make an appointment with the surgeon and then I had to wait a week before I found out just what they had decided. The biggest feeling I remember is waiting a week to go in for that second appointment and then thinking, "Gee, I feel terrific! I feel fine and here somebody's telling me I may be dying!" You think, here you are going about your regular activities but in one week from now, you just may be really in bad shape and feel like you're really dying. I guess I had that to a lesser extent the second time [her second biopsy at the university hospital] but you still have that feeling, you know, you feel good and yet somebody's telling you you may have something really serious!

And one woman who received a diagnosis of breast cancer reported similar feelings:

> The strange thing was, I was finally feeling good! I felt better than I had in years! I felt terrific! You know, healthwise I had come through all these bad periods from February to July and then I felt really good. The world looked wonderful and then all of a sudden, I got that news...I don't know how long cancers take to grow but it was in its beginning.

At the time I interviewed this woman, she had had her breast removed and was undergoing chemotherapy. In contrast to how she felt at the time of her diagnosis, she described how she now felt:

> I've never been so sick in my life. It is as bad as I thought it would be. It is worse! My hair is falling out. I look like I got a lot of hair but I've lost about two thirds of it. I had a tremendous amount of hair. I just comb it and it just comes out...I chose the 6 month plan 'cause I figured I couldn't stand a year of this. So I go two weeks out of the month....I can't describe it to you. Your whole body is sick, sick, sick. My head aches, my bones hurt, my blood hurts, my skin hurts, nausea, diarrhea, and nose bleeds and bloody stools....Well, now that I've been through all this stuff, nothing scares me. I could face anything! Well,...since I'm not dead yet!

Much of the shock of breast cancer, then, lies in its invisibility. In part, it is this invisibility of disease and lack of illness which removes control from women. Instead, only medicine has the technology to draw the line between health and sickness. Thus,

medicine has the ability to redefine in an instant, an individual's lived reality or experience of health and illness. Women know that even though they may feel healthy when they go through breast screening and diagnosis, that disease can indeed be hidden, waiting to be discovered by the doctors gaze. Thus, the period between the biopsy and when a woman receives her results is a time when she experiences the ambiguity of being both healthy and ill.

If a woman receives a diagnosis of malignancy, then she must come to terms with being ill; with having disease in her body. She must recreate a new reality of health and illness. The treatment process begins and she enters into the role of a patient. She is legitimately sick. However, if a woman is given a diagnosis of "benign", she is expected to continue experiencing a state of health. But, because women have already experienced the <u>possibility</u> of illness, they have already begun to alter their experiences of health and illness. Making the transition back to the state of health they experienced before the biopsy is often difficult.

Experiences of health and illness are not defined purely by physical parameters but, rather, are socially constructed experiences. When women have a biopsy, they experience much emotional and psychological distress. A diagnosis of a benign condition means for the clinician, that no physical condition needs to be cured. And while this brings relief to the woman, her own experience of illness needs to undergo a healing process. In my research, women explained that they wanted more than just to be told that their condition was benign. They expressed the need for additional information about their condition and the need for their emotional concerns to be addressed. Most women

receive their diagnosis over the telephone and many women reported that they felt much frustration with the insensitive ways in which diagnostic results were communicated. The following quotes illustrate these themes:

> Ya got to wait a week for the results! And that's when you get paranoid. During that time, the lump went down and you could just feel where it was, and it certainly didn't show any. It was very small....and it went away the next day. And a few days later, I got a lump in my wrist! I thought that was really strange. I thought maybe, "Oh maybe it's just working its way out of my body" You know, Maybe I do have cancer! It's in my whole body!...And when it came to the occasion to call up on Friday, and I have a fear of calling for results anyway... I was with a friend and I knew I had to call that day and he said, "Are you going to call or am I going to call?" And he said I was as white as a ghost...So, I called up and I said, "I know there's nothing wrong. I know I'm cool." You know. And there was nothing wrong.

Another woman expressed her frustrations with the way in which she received her results. Her husband was a doctor and had received her diagnosis before she did. She explains:

> I was waiting for the biopsy report to come back and I remember being really anxious about what it was going to turn out to be. I had had the biopsy done one day and I was supposed to call the next afternoon or something like that. I was at work and I couldn't reach doctor. Somehow or the other , I guess I had left a message for him to return my call but he didn't return it. It was getting later and later and he didn't call back. He didn't call back and I was feeling pissed that he hadn't called all the while knowing that physician's days get very tied up and they often don't return calls to you until the evening or late in the day, or whatever. But in the meanwhile, somehow or other my husband had also called me, and I don't recall if he had actually reached Dr. Smith or whether Dr. Smith returned his call before he returned my call. But at any rate, my husband got the results of the biopsy first and I remember being really angry about that. You know, I was relieved to hear some of the results of the biopsy and I wasn't angry at David [her husband] for calling cause I know that he was very anxious but I was angry that somehow the report had gotten to him first. I mean, Tom Smith had gotten back to him first before me. I was the patient here you know. I was the one he should have called, so I was bent out of shape about it. But I don't know if it was because I had a need to focus my anxieties and angers somewhere and that happened to be it. You know, why had he returned Dr Black's [her husband] call and and not mine?

And two other woman explained:

> Then I called back the next week very very nervous. And I got on the phone and the nurse or the receptionist answered. I told her who I was, and she said, "OK, just one moment." And she went and she must have talked to him or looked at the records or something and she came back on the phone and she said, "It's negative!" and hung up! And I was just put off! I mean, not only was I very relieved, extremely relieved that it was negative, but I was really put off by the fact that my feelings through the week had been dealt with with this sort of blunt response, totally dismissed! 'Cause I was nervous! I was sweating! I was imagining all kinds of things. And I almost, I remember, I really wanted to write them a letter and tell them what I thought. I was very relieved that things were OK but I was also put off by the nurse getting on the phone or the receptionist, some person removed from the whole thing, and telling me. I mean, if it would have gone the other way, would he have also just had a nurse tell me that when my life is at stake and I got someone other than the doctor relating the information to me? So, that really put me off.
>
> The biopsy was on Thursday and I was told that they would possibly have the results on Monday. I went home on Thursday afterwards and I felt very..not weak, but just numb. For about two and a half days I just felt numb. My body was just dragging. And I think it was just a reaction to all that novocain in my system...Everybody was very sure that I would be allright but...ah...part of me said everything would be OK but part of me just had this sort of...negative attitude that, well, maybe kid, maybe this is it. I was trying to think positive but yet, I was trying to be realistic and thinking well, I don't know. And I thought, "Oh gosh, I hope not"...I went back to work on Monday and I called in the afternoon to his office and I said, "Well , I don't know if you have my biopsy results yet," and I went in another office and I closed the door. Yea, I thought I could scream...I don't want anybody listening to me. And I also went on the other side of the building. And so the gal came back on the line and she said, it was benign, dysplasia. And I said, "OHHHHHH Thank God! Thank you so much!" So I came out. Well, I didn't come out. I called my mother and I had tears in my eyes.

This last woman was able to gain emotional support from her mother. The other women all said that they wanted a less harsh transition back to the state of health. Simply being told that their condition was benign was not enough.

The Breast Screening Clinic is a busy place and many women are screened there for breast disease. It is difficult to enable all women

to receive their results in person as staff do not have the time to schedule special appointments. Additionally, many women find it inconvenient to return to receive their diagnosis. However, if staff were made aware of the concerns that women might have, they could arrange to spend more time on the telephone answering questions. Follow-up calls could be made by staff to see if women have any concerns or questions.

When I conducted my research, I had not expected this issue to be as important as it was to women. Some women reported difficulties in obtaining their results:

> They sent off the sample and it was very inconclusive. There was some suspicious looking cells and I tried to get the results and they wouldn't get the results. I finally got them, but they wouldn't give them to me. They were afraid of law suites they said. The doctor wasn't available, the doctor was out of town. I went there and demanded them. I said I'm going to stand here until you give them to me 'cause they're mine!"

If women with benign conditions experience much distress upon receiving their diagnosis, what kinds of experiences do women receiving malignant diagnoses have? While there may be no way to soften the shock of receiving the diagnosis of cancer, some women reported that they had received their diagnosis in a most insensitive manner. For example, many had received their diagnosis over the telephone; a depersonaled mode of human communication. There is no eye contact, the speakers do not have to acknowledge each other directly and each has the ability to cut the contact off at any point by simply hanging up the phone. When doctors give women a diagnosis of cancer over the telephone, they do not have to directly confront women's initial reactions. Doctors can remain distant and detached. Their patient must then deal with her initial feelings on her own. While this type of communication allows

the doctor to continue on with his or her busy clinic routine, it is not a humane way of communicating an often devestating result. I shall let the following women speak for themselves in describing their experiences and feelings when they received their diagnosis of cancer by telephone.

The first case study is given by Molly, the young woman whoes story I presented at the beginning of this chapter. Recall that her symptoms of cancer had been consistently overlooked until she was diagnosed with a late stage disease. At the time of receiving her diagnosis, Molly was living alone about 70 miles from her family:

> I went in for the body scan the next day and they told me that the reason I had the body scan was because I had these...all these holes in my bones. And I said, "Holes in my bones! Well, what is that from?" And they didn't even tell me. They said, "Well, your doctor just wants to get another scan to make sure." And I said, "Well that's not normal!" You know, "How do you get holes in...I mean what causes that?" I had no idea at all....After that he wanted me to come back again and get a biopsy for my breast...Then they did the biopsy and then he called me that evening. I was, Oh....I was really tired and I hadn't been...I was really out of it. As the days were progressing I was losing more and more energy and he called me that evening . It was Friday and he says, "Well, you know, we got the results back and we...we find,...we know that you have...you know...cancer." And I thought,"NO!" You know, I says, "Oh no, no, I think you're....." I thought surely not! I said, "Are you sure you have the right person?" You know, he says,"Oh yes, yes." So he goes, "So are you OK?" I says, "Well, well I'm not feeling well. But you know, I mean..." I...I just didn't believe him. So it took me a while to think about this. I says, "Sure", I says, "I'm sure this is not true." But then I started....I had this book. This encyclopedia, and I was looking through the book. It was a book on breast cancer and I was reading and it says all the symptoms and then...I thought, "Oh my goodness, I probably do!"... you know. I was thinking "Oh shoot. "... I was all panicky and what not and I was scared to call my mom. I was really so sick that I don't really think that it sunk in until the next day. I thought "Cancer!" And then I panicked and I thought, "Oh no! I'm dying!" And so then, they scheduled me to see someone on Monday after the weekend. And I thought, "Oh dear me." I didn't know what they were going to tell me....So then I went in and they were telling me the damage that had been done....They were explaining to me all this. Up until then I had all these chumpy doctors...none of my doctors....Dr Brown who was the associate of the breast surgeon was the one that

told me what I had. Dr Green, my orthopedic surgeon who I had seen faithfully over the summer didn't have the nerve. I didn't know if he felt bad or what but he never told me exactly what I had.

Another woman had had her biopsy done at a hospital other than the two in this study. Her doctors recommended that she have the biopsy done as an inpatient. She explains:

> I went through that in November and stayed in there for 3 days and that was just for the biopsy. I went home...and the following day,..I'll never forget it, you know, like Black Monday, well this was Black Thursday. He called and told me it was malignant. I just sat there, Sandy. I just sat there. I couldn't believe it and he kept saying that you know, usually these lumps are 80% of the time benign.

Another woman explains:

> I saw him on Wednesday for the biopsy 'cause I remember specifically it was on Friday that he called. And I had asked him when would I find out. He said I could call his nurse about 3 o'clock and I was kinda waiting till then. But he called about noon. I said that I was worried about that poor girl having to tell me and he said no, that if it was positive, he'd call. He said, I remember his exact words, he said, "It is indeed malignant." And he made an appointment for me Monday to go over what was going to be the next step. That weekend was not pleasant. I hung up the phone. I have arthritis which is not too bad. I've had a few bad flair ups but within 15 minutes my hip was...it hurt and that really proved to me that stress does affect arthritis....I was alone. My husband knew I was going to find out that day and I said, "Well I won't call you, I'll just wait till you get home"...But I did call him because it occurred to me that I think the appointment was for 10 o'clock on Monday and I wanted to suggest he not go to work Monday morning so he could go with me.

Finally, a woman in her mid 30's explained:

> She said, "You'll have to come back and we'll let you know the results." So, that was on a Wednesday...before I left, they said, "OK, Ms. Jones, we will call you between one and three on Friday and we will let you know what the results are, either way." So I said fine. I had gone to lunch and I came back about 1:30 and I had a phone call and it was Vickie Long [the nurse] and she said, "Miss Jones?" And I said yes. And she said, "Well, Dr . Smith would like to see you." Well, panic went on in my head right away you know...So I says, "Is something wrong?" And she said, "No, um...it's not for me to say." She was very polite you know but she said, "He wants you to come in at 3." And I said, "OK, fine, thank you." And I started crying and crying and crying in the

office. The people at work, my companions, were aware of what was going on and they said, "Well, that's not very nice!" And I said, "Well, maybe in the confusion, she wanted me to come at 3." But I called back and said, "Can I come early?" And she says, "Oh yes, you can come anytime you want." And so, one of the women drove me there. Anyway, that time was very suspenseful. An awful time for me 'cause I sat there and my name was called and Vickie, [the head nurse] she's had a mastectomy also. So then Dr. Smith came, he's a sweet doctor you know. He stands there smiling, nothing in his face you know. Then he starts talking. He says, "Well, I must tell you, what we found is positive." And he kept talking. "There are no alternatives." This is where it was very confusing you know, 'cause first he says it is positive, you can either have,...take a sample of it in the surgery and then we can call you back and see if it's positive or negative again and then we can schedule you for whatever you want to have in the hospital, mastectomy or you can go for chemotherapy or you can have a lumpectomy and he goes on and on and on and on you know. I'm just, tears are coming down my eyes. You know, and my head is about to burst you know. I don't know what the hell he's talking about and I'm just so confused you know....In my mind, I kept saying, "I knew it. I knew there was going to be something wrong. I have always been lucky. I knew it. I knew something was going to happen to me." I kept going like this, very very negative. But finally he says, "Miss Jones, if you were to be my daughter or my wife or my girl friend, I would definitely...just because of the size of it, the chances are very high that it's cancer, that you have the breast removed." And I'm crying and I don't understand what he's saying and I'm all confused and so finally I just said to him, "Doctor, you know I don't even know what you have said to me just now. All I know is that you told me I have cancer in one breast and you're telling me to make all these decisions." And he said, "I understand and I'm sorry but this is a new law in the state of California and we must tell the patients what your alternatives are but we know it's very hard for you to make a decision now." I said, "Yea, right now I don't even know what you said, all I know is that I have cancer. That's all I know.

Much has been written about the need for medicine to be more socially responsible and for clinicians to respond in a more human manner to people's psycho-social and emotional needs. And the last doctor is correct in pointing out that new laws make it mandatory for clinicians to inform women of all their alternatives. However, humane ways must be developed for informed consent.

It is perhaps appropriate to contrast the preceding experiences

with those of women who were happy with the way that their doctors addressed their concerns when they were given their diagnosis. The following woman had made arrangements to have a biopsy done. Her doctor and she both thought that the lump would turn out to be benign. However, the doctor did not like what he saw and arranged to speed up the diagnostic process. The woman explains:

> He was also very kind in that it was a Friday. I had arranged to have the biopsy done so I could rest over the weekend. He didn't ordinarily keep office hours on Saturdays, but he arranged for sending the frozen sections in to San Francisco and he arranged to see me at some ungodly hour on Saturday morning so I wouldn't have to wait an extra minute to make sure. I think I met him in his office at 7 o'clock in the morning. My husband was with me at the time of the biopsy and it was just by luck. I had been inclined to treat it very lightly you know. Less than getting a tooth out since every test was negative and everyone was saying that they really didn't think it was anything. It was taking a precaution and it's fortunate that my husband was there... I guess I was mostly stunned. I guess I had a little hope that the pathologist would say, "No, it's not really carcinoma." But I also felt that surely 99%, he was going to confirm what we thought...At the time he [her doctor] was willing to talk to me...I don't remember exactly what he said. His attitude was concerned but matter of fact....kindly. But he didn't act as if he were confirming a death sentence on me. He was just very pleasant and warm and I always thought I should have written him a note. He spent a long time in his office with me that morning. Like maybe 2 hours, making drawings and explaining to me about the breast, the breast tissue and about things...he explained to me the possible therapies and then he explained to me everything from do nothing in which case some women, a few women will survive...I talked with him about a lot of other things, about telling other people about it. He was really very good with me.

Another woman who had initially been diagnosed by a doctor at a hospital outside this study, was referred to one of the surgeons at the teaching hospital. Although she had already received her diagnosis, she explains how grateful she was with the way this surgeon treated her:

> When I saw Dr White, I didn't have anymore need to see somebody else....He said I shouldn't be afraid. Nothing would happen and we don't have to rush and we don't even know if we have to do surgery...That was the day he talked to us. An hour and a half,

> two hours...He was very nice to me. We were very close to each other. I know my husband said that he could feel that I was in very good hands. He hugged me so that you were feeling that you are in good hands and he doesn't have to do that really. But it was really nice.

And finally, a woman diagnosed with a benign condition describes her positive relationship with her surgeon:

> I think it was a week later that I saw Dr Smith. He acknowledged my emotional concern. He was very thorough and that was really reassuring to me. He listened to what I was saying about my feelings. I guess the thing was, I needed answers and I had to wait until all these tests came back and that was hard.

It is generally acknowledged that there is a great need for clinicians to spend more time addressing the felt needs of their patients. Many studies have explored the reasons why it is so difficult for clinicians to care for the psycho-social needs or <u>heal</u> their patients. However, what is illustrated here is that the ways in which women are given their diagnosis, whether it be benign or malignant, need to be given more serious attention by the medical profession. This is especially the case when such conditions are fraught with much uncertainty concerning both scientific and clinical meanings, when there are often no clear answers concerning treatment and prognosis.

<u>5.3c Understanding the Meaning of the Diagnosis</u>:

The meaning of the diagnosis very much determines the kind of treatment options available to a woman and the long term prognosis. With benign conditions, management is a more appropriate term as often no specific treatment will be prescribed and women will continue to be followed by their doctors. It is important for women to understand the meaning of their diagnosis in order for them to be able to take some

control over the medical process. While much has been accomplished to provide women with information about malignant conditions and the various treatment options, little attention has been directed towards providing women with adequate information about the clinical meanings of benign conditions.

Often, when doctors explain a benign diagnosis, they convey ambiguous or unclear information. This clinical ambiguity or uncertainity can be interpreted by women in different ways. First, a woman may believe that her doctor knows and understands what the condition is and that it is she who at fault for not understanding what the doctor means. Second, a woman may believe that the doctor knows and understands what the condition is but that he/she is purposely being evasive by not providing a complete explanation. Third, she may believe that her doctor does not have complete knowledge or understanding about her condition but that the knowledge does exist. In this instance, a woman might seek another opinion. Fourth, a woman may believe that her doctor does not have the knowledge about her condition because the knowledge does not exist; the current agreed upon state of knowledge is uncertain or ambiguous. And finally, a woman may deny or refuse to accept any information that the doctor is providing. In reality, these five situations are not clearly differentiated, however, each situation has different consequences for the kind of control women take over treatment and prognosis.

The first situation exists when the doctor clearly understands the meaning of the physical condition yet the woman does not understand what it is that the doctor is explaining. This situation is a common one. It is well recognized by both women and doctors and has resulted

in the production of literature about breast cancer and treatment options written in language which lay women can understand. It has also resulted in a California State Law requiring that every woman be given adequate information, that she can understand, about her cancer and her treatment options. It has also resulted in the production of a pamphlet by the State of California that every doctor is required to give to women diagnosed with breast cancer. However, little literature is available that explains the different kinds of benign conditions and their association to breast cancer. This leaves a woman with very little access to information to enable her to learn more about her condition. It also prevents women from gaining access to information which would enable them to understand their doctors and to ask relevant questions. One woman explains:

> The student doctor told me that it was probably nothing to worry about. I was starting to believe it. So many different people said it. The doctor at Planned Parenthood said it was probably just fibrocystic breast disease which doesn't seem to mean too much to me but I don't know too much about it. It worried me because I read somewhere that it increases your chances of having breast cancer like 50% or something like that. I don't really remember the figure and the student doctor said the same thing, it's probably just fibrocystic breast disease....It doesn't worry me too much. I don't think it's that serious. I put it in the same category as warts! Except that you can have warts removed. It worries me a little because supposedly it increases your chances of breast cancer

This woman expresses not only a lack of knowledge about benign breast conditions but is also misinformed. She says that she read that her condition increased her chances of breast cancer by 50%. However, she seems not to be overly concerned about the risk.

Most of the literature written for women about benign breast disease is included in literature about breast cancer. Little exists which focuses primarily upon benign conditions themselves. Women

expressed their frustration because the literature they read had as its main focus, breast cancer:

> During the whole time I was starting to notice how magazines and newspapers...whenever there was anything about breast cancer or whatever. I didn't even think of myself as having fibrocystic blaa blaa blaa, 'cause no one had ever even said that to me! Breast cancer. That's what I started noticing. I knew, I figured they were probably benign lumps but whenever I would look at them my heart would start to race and I would see it in the newspaper and I'd look and I'd think, "Do I really want to read that?" And I'd look away. Then I would think, "This is absurd! I've got to work through this!" So I would read it. And it was the same thing with magazines. But it was definitely cancer I was thinking about.

> She (the nurse practitioner) pretty much told me not to worry about it. But I did. She gave me a book, from the library... No, she showed me where the books were and it was, just...for people who definitely had breast cancer. So it was one of those, "What to do when you have breast cancer". You know, it freaked me out too much reading it and I didn't read the whole thing.

During the time that I conducted this research, several popular women's magazines published articles on benign breast conditions and breast health (Good Housekeeping 1980, Mademoiselle 1982, Family Circle 1983, Self 1982). However, there still is a dearth of information specifically about benign conditions. This makes it very difficult for women to become adequately informed about both what is known and what is unknown within epidemiology, medical science and clinical practice. Because women are not familiar with the kinds of terms used to describe benign conditions, they often have a difficult time understanding what their doctors are telling them.

In the second situation, a woman may think that her doctor has information about her condition that he or she is withholding. None of the women reported that a doctor at the teaching hospital had withheld information from them. However, several did report that doctors who they had seen before they were referred to this hospital had withheld

information. Molly very clearly believed that one of her surgeons knew that she had breast cancer and yet withheld the information letting his partner inform her of her condition. An older woman who also was diagnosed with a late stage breast cancer explained:

> Going back to the actual testing, the liver scan which was inconclusive, this doctor said to me afterwards, "It looks as if there are a few abnormalities". And that's all he would say. But after the bone scan, I asked him if he could be a little bit more specific and he wouldn't commit himself and I realized afterwards that the reason he wouldn't commit himself was because there was very definite metasis and he didn't want to tell me. Of course doctors let the main doctor have the fun of telling the patient!

In the third instance, a woman might believe that she hasn't been given complete knowledge about her condition but that such knowledge is available. In this instance, women need to search further for additional information. The following woman had gone through medical school and practiced medicine. She had the background and knowledge to complete her search for information about her condition.

> They just said mammary dysplasia, benign dysplasia. So it wasn't an adenoma or another kind of disorder. They just said dysplasia... When I hear the word dysplasia, its a word I'm more use to hearing in terms of cervical disorder and you know, as I'm sure you're well aware, they talk about dysplasia as being on a continuum from carcinoma to just inflammation. I had remembered that breast dysplasia was not considered in a similar way of being necessarily preliminary to cancer. But I just decided to check that out. I wanted reassurances that dysplasia wasn't the same kind of thing.

Fiona, the woman whose story was presented at the beginning of this chapter, explained that it was difficult for her to gain an adequate understanding of just what it was she had. She had been diagnosed at a previous hospital with lobular carcinoma in situ yet her biopsy conducted at the public teaching hospital had not confirmed this diagnosis. Rather, she had been told she had mammary dysplasia. As discussed in Chapter 3, there is much uncertainty and controversy

concerning the scientific and clinical meanings of both these conditions. Fiona explains:

> I think they ought to make what they're talking about clearer because it took me a long time to understand what in the hell it was I had, how really serious it was and what the alternatives really were. They tend to talk around you, like you're...you know...an idiot. They say all these things while they're in your room or whatever, like your some sort of idiot and you don't understand what they're talking about. It does make it an emotional experience for you. I think it ought to be discussed in very plain english. It should be encouraged that you see somebody else. Doctors seem to have more ego than most professions have. They have got to be able to say, "Here is what I think. Now you ought to go find somebody else. In fact, I will recommend some people to you that you can go to and get another opinion." If you've got enough time you've got to be able to talk with enough people that can help you to understand what it is you have and what your options are. I find that many times, doctors talk to women like they're stupid...They think we're too emotional! And so they have to be able to take us by the hand and tell us that everything is all right or that they will make something all right. They are after all, men. And I have nothing against men. They are wonderful people. But we have to raise them to the point where they seem to feel that they know everything. I am not altogether certain that that is true anymore. Maybe it never was....

In the fourth instance, women may believe that the information which they have been given is incomplete but that no complete information currently exists. For example, the following woman explains:

> They first described it as a fibroid or something like that, so they didn't really have any idea whether it was malignant or benign but they just said, you know, generally it is benign....I guess it's written down, fibroid or something like that. Although they've never been specific about defining, giving it a label...See, I've gone through mammographies there and the ultrasound, and I listen to what they say even though they aren't directing it towards me and I also like to ask questions. They say my breasts are very,... I don't know if she said cystic meaning that it has a potential to cysts, I guess it's dense is what it is. So you know, I'm maybe putting 2 and 2 together and getting 5 but I guess in my own mind, it's pretty dense material and this is just a little denser than the rest of it.

This woman illustrates a number of points. First, she is unsure

about her own understanding of the information she has been given and second, she also believes that the medical practitioners are unsure about just what it is she has. Third, she did not report asking her doctors specifically to explain her condition to her nor did she seek out further information. She has in part, accepted the fact that the current state of medical knowledge concerning her condition, is incomplete. The same woman reported being pleased with her care at the university hospital and said that she liked the attitude of the doctors.

> At the hospital, they're excellent in terms of treating you as someone who wants to know about their body and their condition and they explain to you a lot. They don't just say, well, this is this and that is that. But then again, I'm the type of person who takes the initiative...it's obvious that I want to know all the factors about my body. Even so, I think they're all very good there. Their bedside manner, their explaining everything. I've been just really pleased.

The point to be stressed here, is that even though this woman did not obtain a clear understanding of exactly what it was she had, she was satisfied with her medical encounter. She felt that her doctors had at least been straightforward with her and had not attempted to pretend they knew the answers to things that in fact, they were uncertain about.

Finally, in situations where scientific and medical understandings of a given condition are incomplete, it is the doctor's responsibility not to hide this but to share this with the woman she or he is treating. Furthermore, doctors need to be able to share the inherent uncertainties about knowledge with women in a sensitive manner. The following woman explains how her surgeon informed her that they found a rare cancer in her breast, one which they knew very little about and

how she felt about the way in which the doctor's uncertainties were expressed to her:

> The thing that did disburb me and I did have a confrontation with Dr Smith, was he came one day and he came to visit and he said, "How are you" and I said, "Fine." He said, "The cancer that was found is a very rare cancer in women's breasts that we have never seen before." I really don't know what that means and the next time I go I'm going to check that out. Anyway, he says, "I guess you opted for the right decision. You went for the right decision of not having chemotherapy because if you had opted for chemotherapy that kind of cancer would have reacted in a bad way." And I said, "Well, what do you mean? What is it?" And he says, "Well, I really don't know but I have to go back to my books and the pathologist is still researching on it 'cause it's a very unusual cancer." So you know, and then by the time I was going to say something to him, he was out the door! And you know, and gone! ...Anyway, that left me with terror, with confusion and in my opinion, he was very untactful the way he went about it. Especially since he operated and he's going to tell somebody something they have and then don't have a good answer for it you know. And so I said, "I'm going to get him." So the next time he came I said, "Oh, Dr Smith, I have a complaint." He says, "OH, what is that?" I says, "You were not very kind to me the other day the way you left me. You had me crying here." I said, "I don't think that's very nice the way you handled yourself the other day." Now of course this is the surgeon! His eyes just popped out and he just looked at me and he says, "OH!" and I says, "Yes ! You know, I'm confused. I don't know what you mean. What's going to happen to me now?" And he says, "I'm sorry." and I says, "Apologies accepted." And he says, "I didn't mean it to come out that way but to tell you the truth, we don't know what type of cancer you have. It's a very unusual type of cancer you had in your breast and it's the kind that's not usually found in the breast." And he says, "I'm still studying it." And to this day, I still don't know."

Finally, the last situation occurs when a woman completely dismisses what she has been told. This might occur for many reasons. The process of denial has been written about extensively in the psychological literature and I do not intend to address this issue at any length. Rather, I would like to point out that a diagnosis of breast cancer or a benign condition is often without symptoms and it represents a sudden redefinition of a person's reality. And in the case of breast cancer, many women never feel ill from the disease

itself but only from the treatments. They are asked to believe in the existence of an invisible disease. One women confessed that she did not really believe that she ever had cancer:

> Sometimes I'm thinking what happened with me, but it goes so fast over, maybe in seconds, and not everyday, but...thinking not every day...I am happy that I didn't have anything to take, no medicine or radiation, nothing. You know what I am thinking in my mind that it was a mistake of mine. It was a lump and it wasn't clear, clear from the doctor. It's OK to go for the labs and tests but at the same time I'm thinking it's a mistake and the doctor would never say to you that he made a mistake or whatever. I don't know. In my own mind, my own opinion of it, that's what I am thinking. I always believe that it wasn't anything. ...I think it was some mistake.

What is important about all five of these situations is that the level of understanding that a woman has about her diagnosis has consequences for the amount of control she takes over treatment or medical management and her understanding of her prognosis. It also has consequences for the way in which women redefine their experiences of being healthy or ill.

5.4 EXPERIENCES OF MEDICAL TREATMENT AND MANAGEMENT:

When a woman receives a diagnosis of breast cancer, it is usually clear to her that she has a disease about which something must be done. She may not adequately understand just what kind of disease she has nor may she understand all of her treatment options. Nevertheless, most often, women are clearly told by their doctors that they have cancer and that they must undergo some form of treatment. Rarely is the option of doing nothing presented or discussed. One woman diagnosed with breast cancer explained that she would have preferred doing nothing and that she had a difficult time even raising the issue for discussion with her doctors. She explains:

> Dr Jones is a pleasant fellow and he was very matter of fact. Poor thing, he's very tall and he'd sit down on the chair and there I was on the examining table and he sat down on the chair as if he was exhausted which he probably was and he said, "Well now, I've seen lots of breasts during my days here and your's really should come off." He said, "You have four choices. You can have surgery, you can do nothing..." I don't know what the others were but there were some alternatives. And I said, "Well, I like number two." And then he couldn't remember what number two was....But eventually, I came to the conclusion that something should be done....and that's been on my mind, on my conscious because I'm a little bit fatalistic because I thought maybe I shouldn't have pursued it that much."

Much has been written concerning the need to inform women of their various treatment options for breast cancer and the women interviewed in this study were aware of the need to make informed choices. They expressed that they should ideally enter into a partnership with their doctors to decide on the appropriate cancer treatment. They were aware that the issue of proper treatment was a matter of debate.

However, such is not the case with benign conditions. Women interviewed often reported feeling powerless in the management of their benign conditions. In part, this is because they were unclear about

the meaning of their diagnosis; they were often unclear about whether they were supposed to be healthy or ill. Because of this ambiguity, women almost always end up letting their surgeons or doctors decide for them whether or not their condition is risky enough to be construed as ill health. This often results in continued medical surveillance and can increase a woman's anxieties about her breast condition. Alternatively, it can also result in women discounting medical advice and failing to return for regular checks when such a course is strongly indicated.

The lack of lay knowledge about both what is known and what is unknown puts women at risk of being over medicalized or under medicalized. It can lead to a woman having multiple unnecessary biopsies or to her failing to have further necessary diagnostic procedures undertaken. In order to begin to take more control over their health, women need to begin to take responsibility together with their doctors, for medical uncertainty. This involves at one level, the acknowledgment that medicine does not currently have an adequate understanding of benign conditions. This uncertainty must be brought into the public realm of dialogue and debate. Both women and doctors must learn to accept and live with a certain amount of risk and both parties must enter into a more equal relationship of sharing the responsibilities and consequences of risk. To a certain extent, this is already happening in that some doctors interviewed reported that they did share their uncertainties with their patients and some women interviewed reported that their doctors were very frank about what they did not know. However, for the most part, women in this study reported that they felt a lack of control over management of their benign

conditions.

5.4a Theories of Causation:

In part, this perceived lack of control is related to the uncertainty amongst both women and clinicians about the causes of benign conditions. Because of this uncertainty, women feel that there is little they can do to resolve their breast problems. One of the issues I explored with women concerned their own theories about the causes of benign breast conditons. The most widely held view was that no one really knew what caused benign conditions. The following responses are typical of this view point:

> I'm sure there must have been a reason but I can't really say. I feel that it just appeared out of nowhere...I mean I don't recall any traumatic thing....I guess I've always felt that that's still sort of a mystery why,... you know, women get benign lumps. ...My perception of it was that it was just a medical problem and we don't know the cause and ...you have it and that's it.

> I don't know, I don't know. I was really healthy at the time. It was not a particularly stressful time. I don't know what causes a lump to show up out of nowhere. It was like that you know, "Where does this come from?" And it went away just as fast. But it gave me a lot to think about.

Upon exploring ideas of causation further, women expressed two general types of personal theories. First, women thought that benign lumps might be caused by biological or environmental factors, primarily by agents they ingested. A popular theory at the time I conducted the research was that caffeine products somehow caused breast lumps. However, none of the women who mentioned this theory took it very seriously. One woman explained:

> Well, even at my first exam, they began to talk about how people were concerned that coffee was a culprit. Well, I had resolved to give up coffee at that point because my stomach was bothering me but I really poo pooed the connection. I didn't argue with the nurse. I thought it was a little bit,... its very in keeping with the model of there being one etiological agent and we got to find <u>it</u>, you know. And I don't look at disease in that way. I look at

it as multi-factorial so when they talked about the big scare about coffee, I thought, "I wonder what kind of a study was done?" You know, in two years they're going to say it's really not...so I took that with a grain of salt.

Another woman explained:

I use to eat chocolate all the time and people were sure that it was chocolate. And then they discovered that caffeine products were bad. But then it was too late. I had already downed the chocolate candy bars and I was in the hospital!

Two additional women explained:

My Mom is always listening to the news or reading things and she'll find out a cause or a reason for something and call me up and tell me to stop. The first thing was coffee. I'm a heavy coffee drinker and she called me and said her next door neighbor had so many cysts removed that they finally did a mastectomy on her just for the cysts removal. And her doctors were taking her off caffeine and every complete form of chocolate, watching her diet...In fact, when I saw the very first doctor at the breast screening clinic, she had a bag of empty gourmet decaffinated, just an empty bag on her bulletin board and pointed that out as being something good to do. And then the next two doctors I have seen, I brought the question up. I asked them about coffee, I do drink coffee, I don't drink a high excess but I do have coffee and they both said OK. I'm one who doesn't question much. If they tell me it's OK I don't question why. And they both said in my situation it probably wouldn't matter one way or the other. I always left it at that... I never take it beyond that. So, I've never stopped drinking coffee.

I think it's really like this because I drink so much tea. I really did drink an awful lot of tea. I know there is something in caffeine that makes cells grow, but that's all I know....I gave up tea completely for a while, but I go back to it every now and then.

Another woman said that she thought that the production of breast milk might have something to do with causing breast cancer:

I thought that conceiving must trigger lactation and I have always wondered if the human body could absorb human milk. You know, it can digest it and break it down but what about re-absorbing it? I think somebody like my mother who has eight babies, you know, her breasts would get big and she would take pills and they went down and I don't think you get cancer from the pills. I think you get it from not being able to absorb the extra cells which grew for a reason. ...I do worry about it and I have friends who have had 9 abortions ...and they are worried about getting cancer cause their breasts are up, down, up, down. And what happens in between?

A second theme expressed by women was that benign breast conditions were believed to be the result of psychological factors such as internal conflicts about one's role as a woman, and feelings of guilt or stress. Here, women felt that their breast condition was the external manifestation of internal disharmony. This theme is particularly important as medical treatment and management does not attempt to address these issues. Rather, it is containted to external causes. Thus, while doctors attempt to cure, they do not attempt to heal. Many women complained that what they needed was someone to address their emotional concerns as well as the physical condition. The following women explain their feelings about internal causation:

> You know, I wanted to have children. I think that maybe my breasts filling up was almost like I was punishing myself for something, for the feelings I was having and these ambivalences, "Yes, I want to be pregnant. No! I can't be pregnant"...I kept thinking that it was my body telling me that I should have children. Going through all those things in my head was fighting my body. It was punishing me. God was punishing me. My body was punishing me. I guess one's body prepares for having children every month, cause that's what your period is. There are just so many cycles and we seem to have just so many eggs and ,...I mean I should have taken advantage of it when I had....maybe this is the end you know. It's like the biological time clock is coming to an end and my chances are over.

> Some of the feelings I had at the time was a kind of self-criticism. I've done a lot of exploring in alternative medicine and was practicing some alternative medicine for a while. I had really neglected some of the allopathic approaches. I call it neglect now. I also did not acquire the habit of self-breast exams. So when the lump was discovered I thought, "Oh no!" You know, I did it to myself somehow." ...I think of the breast, it's obviously a female organ. And it being an organ of nurturance to babies, you know, we feed our children through our breasts and...if there's a disorder in this female organ of nurturing, then there is something going on within myself and within my relationships and in my life as a whole that's disharmonious and somehow I haven't established a really good relationship with that part of me.

And one woman explained a similar theory of the cause of breast cancer:

> I think that personality type is connected with it, I think that somebody who gives and resents it. And I think that the metaphor for this particular disease is "You're not going to suck off me anymore!" [laughs] Yea , "I won't nurse you anymore. I don't like to. So I'm going to give myself a really good excuse!" And then of course, the secondary gains for it are, "Now I can control some of my family life 'cause I have this strong infirmity and if it doesn't improve, I'll check out." I think...unfortunately not being able to take care of ourselves and really resenting taking care of others.

5.4b Ambiguities in the Management of Ill-Health:

One of the most striking contradictions that women experience is that while on the one hand they are told by their doctors that what they have is normal and they shouldn't worry about it, on the other hand they are told that they must keep a close watch on their condition. This often requires regular visits to their doctor, repeated needle aspirations and mammograms. Thus, women are being told that they are healthy while at the same time undergoing further medicalization. Through this process, women come to redefine their experiences of health as a state where they are not quite healthy yet they are not quite ill.

The distinction between health and illness becomes an ambiguous one. In fact, it may be seen as a sort of vicious cycle of health and illness. Often, a woman will be told to return for regular check-ups every three to six months. After her visit, when she receives a clean bill of health, she will feel good, she will feel healthy. But as her next appointment approaches, she begins to feel anxious and wonders if indeed there could be a hidden disease waiting to be discovered. A woman's experience of health begins to transform itself into an experience of illness that only a doctor can change. Only the doctor

can bring a woman back to a healthy state of being. In this sense, a dependency is built up whereby a woman needs a doctor to create for her, her experience of being healthy. Disease is something that is hidden. It is asymptomatic and only the doctor's gaze, the doctor's hands or the doctor's instruments can detect it. For women, breast cancer lays hidden ready to become a reality, to show itself at the next visit. One woman described this cycle of health and illness and her dependency upon her doctor:

> I go back every...I'd say at least every three months...I have "very" lumpy breasts which are very hard to examine because I have all these little bumps in there and he wants to keep a very close watch because my mother had cancer. He said, "Not that you're going to get it but we want to be very sure." And I said, "Well, I'm glad because I want to keep a close watch myself." And he said, "I feel that at some point you will be where I won't have to see you this often but until you get to that point, we're going to watch it." I have this feeling that it's not going to be for at least five more years. I don't know why, I just feel like it's way down the road and maybe I'm wrong, maybe I'll never be at that point anyway. Maybe I'll always have this problem but, I ...as...he has told me on subsequent visits that he thinks I'm getting a little better....but that he still has a difficult time examining me and like this time, I had to have the needle biopsies and stuff so...but he says, "I want to be sure, we want to watch you, we want to be careful." And all that sort of thing and I appreciate that....Usually when I go to see him, I get worked up...when I go. This time when I went to see him I really didn't get worked up at all and I was glad cause I thought, I've been very busy. So psychologically, this was very good for me...I went into see him, it was sorta depressing 'cause I thought, "Oh crud, here we go again." I was sorta feeling sorry for myself. And I was not having a good day. And then on Friday, when I knew I was going to have to wait over the weekend [for results] I thought, "What the heck, here we go. Just think positive, try and just keep a stiff, upper lip." And that was the weekend when I had car trouble and everything. I thought, "Oh God! What else is going to end up on the kid here?" You know, and then I started having these fantasies and I thought, "Oh my God! It's malignant, they're going to have to throw me in there and do this quick mastectomy! Here my car's in the garage. Someone's going to have to get it out and I thought, "No, calm down, be realistic. Take it as it comes." I thought, "Take first things first." You know, sometimes you get carried away.

This woman clearly articulates the ambiguous nature of her

experiences of health and illness. Many of the women interviewed explained clearly the kinds of double messages they received from their doctors about the meaning of their condition and their need for medical management. One woman explained the impact of these messages on her experiences of health and illness:

> I was getting this sort of double message, "Don't worry about it and many women have it, but on the other hand, keep an eye on it, do the exams, blaa, blaa, blaa." I recognize that breast cancer is number one or number two you know, in terms of women's deaths. So I knew that it should be taken seriously but at the same time I didn't see why me with this supposedly benign condition should have to keep an extra sharp eye on it. And then they set up an appointment to do an aspiration, and after that, I went home feeling a little better. Again I had been told that right now I didn't have a serious problem but each month again, when I would get very sore, I would get really depressed, more depressed than I had been before I had my periods. And it wasn't something that I was really acknowledging. I just felt, really like, it was almost impending death. It was almost like every time they would get really sore it was like I could just see them being cut off, or, or whatever....Or very drastic images came into my mind.

A striking aspect of the management of benign breast conditions is the subtle way in which states of "health" can be redefined to states of "less healthy than before". When a woman has "more" benign disease, she comes under closer medical surveillance. One woman explained:

> I go back,... it's been every 3 months or 6 months. Before they discovered this little thing under my arm, they said, "You look like a low risk person, you don't have to come back for a year." But then I felt that additional lump...If this lump disappears then they'll follow me in longer intervals but if it develops into something, it will be shorter.

Very few women interviewed in this study said that they would not return to the doctors for their regular check ups. However, one woman who had worked as a nurse in the area of women's health and who was quite knowledgeable about breast conditions and the ways that doctors managed these conditions explained that she was willing to take

responsibility over the management of her own condition:

> I was supposed to go back for a mammogram in 6 months. I did not. Actually I made an appointment and something came up fortuitously. I cancelled the appointment and was going to make another one and ah...they wanted me to make it too far ahead. And I just didn't. I also realized you know, I'm taking - I feel like at some point I take the responsibility for what's going on with me. I know the growth rate of cancerous things you know. I feel like I'm willing to take certain risks. If what they saw there on those things [referring to mammograms] was not cancer, these things [lumps] are not cancer either. And it's like I know they're doing a lot of ass covering and I know they're doing a lot of super cautious conservatism and I'm also willing to take some of that risk, of the 70/30 odds."

Both of these above women speak of their risk associated with benign breast conditions. Risk is central to experiencing benign breast conditions as a state between health and illness. The experiences of risk will be discussed in chapter 6.

5.5 PREVENTION OF BENIGN CONDITIONS:

Because the causes of benign conditions remain unknown, it is difficult for women to take any preventative actions that might enable them to increase their sense of well being. Many women reported their frustration over their perceived lack of control to prevent any future problems. This feeling of a lack of control over prevention further serves to place the management of breast health in the hands of the medical profession. The following women illustrate these problems:

> Dr Ryan suggested that I take 800 units of vitamin E a day, try that to see if that might help. Now he did tell me at one time possibly on cutting down on coffee, caffeine, chocolate, etcetera. And I really haven't done that. I don't drink a lot of coffee all day long. I have maybe three cups a day, four on a weekend. But I haven't quite gotten to that and I will if he really wants me to but...there are a whole bunch of theories. It could be caffeine, it could be anything. But as far as preventive, the only thing I've really gone with is this vitamin E.

> I read somewhere that if you take vitamin E it decreases a lump but the doctor told me vitamin C or something else. But, I have also heard that it doesn't make any difference, it's all in everyone's mind. Libby Brown [a nurse] told me that. She said that she knew of a study, I think it's on vitamin E and it's at the hospital, where she said the results were starting to suggest that it really didn't make any difference, except in people's minds...that it made them feel better, but the breast lumps really didn't get smaller. I gave up tea completely, for a while...but I go back to it every now and then.

> Well, you know, no coffee, no tea, no caffeine, none of which I do anyway. Which was a great let down to the doctors. Which was another thing that frustrated me because they said, "Well, do you drink a lot of coffee?" I said no. "Do you drink a lot of tea?" I said no. "Chocolate?" I said no. I don't do any of that. And they would sigh, like, "Um, what <u>is</u> going on?" You know, "You really got a problem." So part of my frustration was feeling like I already do everything that I'm suppose to be doing.

> I keep thinking that they're on top of all the research and they may have heard of something. I was in a study for women that didn't drink coffee or tea or chocolate, that kind of thing. But when I went in for the last biopsy, the fellow that actually did it wasn't the doctor who I see all the time 'cause the doctor I see was on call. So when I talked to the doctor who actually did it, another man, he said that there is nothing you can do. And I said, "Well, is there anything about diet that they've discovered

> recently?" He said, "Absolutely not. There's no connection. Nothing. They have proven absoutely nothing. Don't read all the articles in the magazines. They don't know anything. There is no connection." So, I ...I keep thinking that sometime when I go in, they'll say, you know, what you might do would be this cause it appears that it might be a factor. But I've never run into anybody who has said that.

This lack of personal control over the prevention of breast problems has consequences for the degree of responsibility that women take for the early detection of breast cancer through the practice of breast self exam (BSE). Because there is currently nothing women can do to prevent breast cancer, the focus has been upon helping them learn how to detect cancer. The only thing women can do for themselves then, is to conduct a monthly search for cancer. Much has been written about the value of breast self examination and the reasons why so many women fail to do it regularly. I would argue that in part, women's failure to conduct regular breast exams is related to their perceived lack of control over anything they might do to prevent cancer from developing in the first place. Therefore, the act of breast self examination comes to symbolize even further, their lack of control over a possible future or hidden cancer. Every time a woman performs a breast self exam, she has to confront the possibility that she may have cancer. Thus, women are asked to actively search for something that they can do nothing about except discover. Healthy women are being asked to search for unwanted and feared illness.

Clinical and public health professionals argue that if women do not detect cancer early, they are at greater risk of dying from the disease. What is little understood is that the monthly search for cancer constitutes a very real and immediate lived risk for women; the risk of finding something unwanted. Thus, one might question the very

risks of the anxiety brought about by BSE. It is a terrible irony that women are being asked to search for invisible disease within their bodies and then are rewarded for finding it with mastectomy, chemotherapy or radiation. The rewards for not finding an invisible cancer are knowing that they must search again the next month.

Searching for the feared, the unwanted, the invisible is talked about by the medical profession in the guise of prevention; while it may prevent death, it certainly does not prevent illness. Indeed, within scientific and clinical medicine, there exists some debate over the extent to which early detection of cancer actually prolongs life. In fact, some argue that early detection may only increase the length of time that women live knowing that they have cancer. Given all these problems, it is no wonder that most women do not conduct breast self exams on a regular basis.

During my interviews with women, I asked how they felt about conducting breast self exams. One woman explained:

> Well, if surgery or if treatment has value and can change the quality of life for the better, for the positive or prolong it for the quality of life, I think terrific. However, if it's not, and I don't know that it is, then I think that it's,... I think it doesn't matter. What's the point of examining if there's nothing can be done about it? I forget when I palpate, depending on where I am in my menstrual cycle and all. I'll find something and there's the initial big question mark that turns up in my head and I have to remind myself that I know what I'm looking for and <u>that ain't it!</u> I have to say, "Hey, you're not an amateur at this, you know what you're looking for and that's not it is it?" Then I'm saying, "No, I can't worry about that one, that one's OK. I know what that is. That's just a lump.

Another woman explained:

> I'm still very reluctant to do the breast exams. Part of it, after my period I count the days and I know that there is a certain time period that I should do it, but um, somehow that time always goes past. My feelings are, well, I've probably done it once since the last exam, which was four months ago. I started to do an exam once and it's hard to know what's normal and what isn't normal. No matter what they say, there are many things you can

> feel; you can feel your ribs and you feel the bottom of the tissue and there's just various things you can feel and everyone's different. So when I do it, I feel like, I've been,... I've read don't think of it as looking for something, just think of it as learning to know your breasts. Um,... I think that when I do it, I feel angry. I feel so angry that, that I'm trapped with this body that's malfunctioning. That's the way I feel about it. And so I start to do the exam and I just get mad at them [her breasts] you know. "You're not right!" You know, "You don't feel like you're supposed to feel and I'm not quite sure <u>how</u> you're suppose to feel!" And so, I never quite get through. Like in this breast, I think I feel even a second tiny little nodule. There's times in the shower and I'm thinking, "Here I am in the shower and it's relaxing and let's just, let's just start an exam here." And so I'll start feeling and I'll get around that area and I get more and more reluctant and, like when I felt that second thing my first impulse was to go to the doctor immediately 'cause you'll feel relieved if you just go do it. Then I thought, well you know, that's just absurd! You can't just go running to the doctor every time you get upset about it.

This fear of conducting breast self exams can indeed result in women becoming more dependent upon their doctors. Several women explained:

> He watches me every 3 months. I do not examine my breasts, it makes me too God blessedly nervous. I just as soon not know. I can not possibly die of whatever it is in 3 months time.

> They're always after me to try to examine myself and I do. I know all the things you're suppose to do. You know, feel yourself in a clock wise position, stand up, look at yourself in the mirror, see if there's any change, you know. If they shift or the nipples,... Up to a point I can do it, Sandy. But I can't get...you know...as I said, I wear a 43 bra so,...so that's why it's a good idea that I have the mammograms too, and see the doctor. I just hope that I build up the confidence in him. I'm sure I will, he's such a nice doctor.

Finally, some women reported that while they thought that breast self exams were important, they didn't do them because it didn't fit into their routine:

> It surprised me that there was anything 'cause I thought I had done breast checks. Not every month, like maybe twice a year or something and I could never find anything but I really wasn't that well trained on how to find them 'cause now I can tell that I do have little lumps kinda around the edge. But that's not where I was looking and I kinda expected to find something right on the top of my breast or something and I guess it's more common right

around the outside or something. ....I do it [BSE], it's been about 4 months. I just wrote it on my calendar again. I try and write it about two weeks after my period starts, to remember....It seems like it shouldn't take but a few minutes but it,...I just put it off. I don't have time, I'm running to work, or whatever. So, I did put it on, it is something I want to be good about, especially having had one small encounter....I was just reading over the thing I got from your clinic, about a week ago and it was saying that most women do find the lumps themselves and that makes me see a great deal of value in it. Although my little lump was found by somebody else, but the idea that I should know my body better than anybody else, that I should be able to notice any changes, I guess that's the significant thing. That makes it seem very important.

WOMAN: I think it's (BSE) a good idea but I think you can over do it. If you get to the point where you're obsessed with checking your body once a week or every day, then you got a problem. You're thinking it's going to happen. You got your mind in a place where you're expecting a problem. I think you have to be realistic, you have to be knowledgeable about yourself. I think a check up once a month, once maybe every two months, or even on a quarterly basis, just so you get to know the way things are working and feel it. I think that you're doing a lot right there. So I'm in favor of it.

SANDY: Do you do yours?

WOMAN: (laughs) This is where I become a big bag of wind! I forget! That's the problem. I do forget and as I said, right now when I'm nursing, everything is lumpy so I'm sorta just letting it slide.

Another woman pointed out:

I think it's [BSE] very valuable. It's just that I guess now that I know something is there, hopefully I'll do it more regularly. Especially while I still have this and hopefully if I got it removed, I'd still do it regularly. That's my hope...I know that I really should have been doing breast exams but that was as far as it went. It was laziness you know. Tight schedule in the morning, you know, You have to get into a routine and you have to remember the right time of the month to do it and if it passes you think, oh well, I'll do it next month.

The trap for women if they do not do breast self exams is that they do run the risk of failing to detect an early cancer. One woman recognized this and she explained:

I know that I'm supposed to do them but I don't, unfortunately. I do think it is important, but in the back of my mind, and I bet you've heard this one before, I almost get this sensation that

since it's been benign, it's going to be benign. It's like the psychological effect of it. You know, once you're safe, you're always safe and that isn't always true.

At this point, a crucial question emerges. If there exists no accepted knowledge within medical or clinical science about how to prevent breast problems, how can we expect women to be able to take more control over their own breast health? To answer this it must be stressed again that it is important that women not only have access to what knowledge does exist, but also, to knowledge of the limits of certainty. Women must be able to assess what knowledge does not exist and then they must be able to enter into a relationship with their doctors where this uncertainty is shared between them. Women need to be able to expect their doctors to tell them what is not known and doctors must not think that they should be able to provide answers when there are none. Both women and doctors need to learn to live with uncertainty, to live with risk.

This however requires that the relationships between doctors and patients become more equal in terms of who controls power over decision making. The consequences of removing this uncertainty or risk are often greater than simply learning to live with it. As we have seen, doctors often perform unnecessary biopsies and in extreme cases, prophylactic mastectomies in order to remove risk by removing the physical condition giving rise to uncertainty.

5.6 RELATIONSHIPS BETWEEN WOMEN AND THEIR DOCTORS

As we have seen, both women and doctors are caught in the bind of the uncertainties of benign breast conditions and their ambiguous meanings. Doctors are torn between the possibilities of a misdiagnosis, unnecessary and early deaths and possible malpractice

suits on the one hand and unnecessary medicalization, unending surveillance and prophylactic mastectomy on the other. Women are torn between the fear of cancer, uncertainty about their need for medicalization and their desire to take control over their own health. For women, this often results in self blame and surrender to a medical practice of uncertain efficacy. There are no easy solutions to this many sided problem. However, one possible step towards finding acceptable solutions lies in re-addressing the kinds of relationships women have with their doctors. Two general of themes are apparent in this research concerning the kinds of relationships women valued. First, women appreciated doctors being frank about what they did not know or about when they were uncertain. But women wanted their doctors to talk about this uncertainty in a competent manner. One woman explained:

> I felt that Dr Waters was more competent than the others. It was his attitude. I was asking him questions flat out and he answered them flat out, what he could, and it was still obvious that he didn't know everything. His mannerism was just more confident as were his assumptions even though I think they were incorrect. But then no one can ever be sure of anything. So if you're going to say anything, you might as well act as if your saying the right thing!

While this woman's explanation is a bit contradictory, the important thing that she expresses is that her doctor felt comfortable about being uncertain and not knowing everything. Another woman explained:

> I would like people and doctors to be more honest about what they know and what they're saying and giving more choices. When I went in it was just wam bam boom, let's open her up and find out what the problem is. And it seems like there should be a little bit more investigation. At that point, if I had gone in for surgery, I would have been on Medi Cal and I thought, I said to Dr Smith, "I think this is a stupid waste of Medi Cal money. You don't know what's going on there, I don't know what's going there. It now appears in both breasts and so now, why surgery? It seems like a foolish expense and too quick on the gun.

The second theme apparent is that women wanted their doctors to acknowledge their emotional and psychological concerns. Because of the relationship of benign conditions to breast cancer, women want to be able to discuss their anxieties about this ambiguous condition. Criticizing their surgeons, several women explained:

> I'm not terribly fond of surgeons. Surgeons think they are God's gift to the entire world. God gave them wonderful hands and therefore they can do anything they want to do and they have all the personality of a dead letter! I mean they have no bedside manner in my opinion, at all.
>
> I just get the sensation that you know, you're just another body and you don't have anything else behind it. Just feeling uncomfortable from their personality too.
>
> I just had a physical last week, and I did tell my doctor about this [breast lump] and it's funny that we're talking today because one of the feelings I had last week, was a feeling of wondering why doctors,...why it is I come across doctors that are not providing a little more thorough breast examinations with physicals except for Dr Street [a female doctor]. It's sorta frustrating. He said, "Oh, I don't feel anything." But he didn't show interest in the fact that I had a history of something that was there. So I feel a little like I'm sorta on my own with this thing. I would contact Dr Street because I know that I would be talking to a person who really showed some interest. Not only competence and professionalism as a doctor, but personal interest too. That really makes a difference. I hate to get hung up in this whole issue of men and women and isolating them and polarizing them, but just on experience alone, the three women doctors that I have had over the past several years, have been doctors I have remembered because of the impact they had on me for talking and providing information and showing a little bit of concern. I wasn't just another person in one of those tissue paper robes sitting there on the table. Because they are women and they understand women's bodies, I think they understand the nuances and the way women think. There is a little something there that we need that men don't give us in the medical field.
>
> I had a referral to see someone there two years ago. I saw him and had one good experience and a couple of horrendous experiences with him. He was outrageous. He'd make an appointment and then he wouldn't be there and then he'd rush in and he'd have 2 seconds and then he'd rush down to surgery and ...I mean he just wasn't available. He just wasn't there to answer my questions. And then he just made some outrageous, what I thought were outrageous statements. You know, I asked about the possibility of biopsy and each time I'd see him he'd say something else. He'd say yes and

> and then the next time he'd say, "Well, your breasts are just very nodular you know, you want me to cut here, here here, here? Chop them all off?" The first time I was very impressed with him, the next two times, you know...He said to come back at regular intervals, but I said, this is ridiculous!

All the women who I interviewed said that they felt that the kind of care they received from the two nurse practitioners at the university hospital was excellent and that their emotional needs were cared for as well as their physical condition. One woman explained:

> Jane was wonderful! I was just really upset. I had been crying and they were addressing the fact that granted, there was some ambiguity about what this thing was. It wasn't like somebody had said, "Yes, this needs to be biopsied." ... Anyway, Jane came in and she took a good history which was the first good history that anybody took. This was the first time anybody had gone step by step through the whole thing. And she did a really thorough history and a thorough breast exam, which was again very reassuring. She said, yes, this needed to be checked out but from what she could feel, she wasn't alarmed with what she felt. It felt good. I also knew then that I was connected up and that what ever needed to be done would get done. So it was really reassuring.

Most women explained that what they wanted were straight answers concerning their physical condition and an acknowledgement of their emotional concerns. However, one woman explained that she appreciated the technical expertise of her doctor and believed that they had a good relationship even though he was not able to address some of her more personal feelings about her condition:

> I went in for a nine o'clock appointment. I went in to see him and his attitude at first put me off because I felt, "Gee, he doesn't have much personality at all." And I thought, "Well, I guess he's just one of those far removed persons." And as I began talking with him I realized that he was so far removed personally that technically he was right in there with me. And I really began to like him because I thought, "He really cares what's going on inside of me." And that really meant a lot to me 'cause I felt he was going to do 100% what he could.

This woman clearly articulates the distinction between the personal qualities and the technical skills of her doctor. She treats

these as two separate dimensions and explains how, even though her doctor did not give her the personal care she expected, she judged him in terms of his concern with her physical body, with his attention to her internal physical processes. This example points out that women take into account many factors in assessing their relationship with their doctor.

5.7 DISCUSSION:

I have argued that within medical practice, there is and always will be an inherent amount of clinical uncertainty. This uncertainty arises both from doctor's personal limits on being able to know all there is to know, and from the state of scientific knowledge; where what is known may have ambiguous meanings or where there are gaps in a given state of knowledge. This state of medical uncertainty represents risk for both doctors and women. Doctors risk failing to detect a hidden cancer or failing to predict the development of a future cancer. Uncertainty for doctors results in personal, professional and legal consequences. I have argued that doctors attempt to control clinical risk by transforming it into a physical entity, a sign of disease residing within women. This transformation allows doctors to control uncertainty through the diagnosis, treatment and prognosis of risk. Thus, we find a subtle but important shift occuring as risk is understood now to reside within individual women.

The consequences of risk also affect women. When a woman is diagnosed as being at risk she is transformed from a healthy individual into a patient. As a patient she has the social obligation to become well and this requires that she follow her doctors orders. The catch here is that in order to return to a state of health, risk must be

removed and there is no way of removing risk short of removing the breast. And as we shall see in the next chapter, even this extreme procedure is fraught with controversy about how much risk is removed with removal of the breast tissue.

Because women have little control over the management of uncertainty, they are at risk for further medicalization. A key issue concerning women's control over uncertainty pertains to understanding the many dimensions of risk experienced by women. On the surface, this would seem to be straight forward. Women experience the risk of getting breast cancer, the risk of losing their breast and the risk of death. And, as I have pointed out in this chapter, they also risk repeated biopsies and indefinite medical surveillance.

But risk for women also has other qualities that are different from those of clinical risk or epidemiological risk. Risk for women, is the experience of being at risk. It is the experience of being labeled neither healthy nor diseased. It is the experience of being between health and illness. Risk for women, is "lived risk". The legitimization of lived risk along with epidemiologic and clinical risk is central to women being able to acquire the power to share with their doctors, the control over uncertain outcomes. This leads us into the next chapter, which focuses upon exploring the many dimensions of the concept of risk.

> Since the majority of relative risk estimates are fairly modest, our current state of knowledge indicates that in most women there are many variables acting together to determine risk for breast cancer. Whether several of the known risk indicators can be related to some common underlying mechanism, such as a particular hormonal profile, remains to be determined. Also, most of the risk factors identified so far do not readily lead to the implementation of preventive measures.
>
> -Kelsey 1979, A Review of the Epidemiology of Human Breast Cancer.

> Consider you're at significant risk of developing breast cancer, but I can't tell you that you're going to develop cancer. All I know is that every woman suffers some where around a one in eleven chance of having breast cancer and your risk is greater than that and you're very young. That means for another thirty, forty or fifty years, you suffer that risk.
>
> -Surgeon specializing in management of breast disease

> I've always known that I'm high risk for breast cancer, after my mother had her first mastectomy. I knew intellectually that I was at high risk but I didn't feel it inside. And then, my mother died of cancer of the pancreas and at the same time I turned 30...and I started to really internalize it, that yes, this could happen to me and I started getting a little bit scared.
>
> -Woman diagnosed at high risk for breast cancer

6.1 INTRODUCTION:

In the previous three chapters, I have explored the ambiguous meanings of benign breast conditions within medical science, clinical practice and the lay world. I have shown how these ambiguous meanings give rise to uncertainties in both clinical practice and lay experiences of health and illness. In this chapter, I develop a concept of risk that acts to condense the scientific, clinical, and lay uncertainties about the meaning of benign breast conditions into a

concrete entity, thus enabling uncertain understandings to be translated into practical activity. The language of risk makes it possible to talk about, and control for, what is unknown.

Power in medical science and practice lies not only in control over knowledge, but also in control over knowledge about what is not known. In a world where medical knowledge is rapidly shifting, where our futures are becoming less and less predictable, the ability to manipulate what is not known represents a major source of power. The concept of "risk" gives reality to possible futures and has the potential of allowing doctors and women to control possible health outcomes. This chapter explores the meanings of risk within epidemiology, clinical medicine, and the lay world. I argue that the meanings of risk and their uses, are fundamentally different within each of these areas and that a failure to understand these differences has serious consequences for clinicians in the management of their patients and for women in the management of their own health.

Within both epidemiology and clinical medicine the concept of risk is playing an increasingly central role in explanatory models of the etiology of chronic disease and patient management. The language of risk is about scientific uncertainty concerning causal relationships and clinical uncertainty concerning the prediction and control of unhealthy outcomes (1).

The popularity of the concept is linked to the inability of epidemiologists and medical scientists to produce models that adequately explain the etiology of chronic diseases and from the inability of clinical medicine to prevent and cure these diseases When epidemiologists, clinicians, and patients talk of risk, all are

expressing ideas about uncertain knowledge and the prediction of future danger. Yet, within each context, the concept takes on subtle but important differences in both meaning and use. Currently there is much confusion and debate between epidemiologists and clinicians about how to translate epidemiological risk into clinical risk. Part of this confusion arises because the contextual differences between the meaning and use of the concept have not been fully recognized.

This chapter, explores the concept of risk as taking on two distinct dimensions; an objective, technical, scientific dimension and a socially experienced or lived dimension. The assessment and evaluation of risk for the epidemiologist is an objective, technical, scientific process while for the layperson it is a subjective, lived experience. Lay assessment and evaluation of risk must be understood as a social process, not a scientific, technical one. Clinical medicine bridges these two dimensions as risk for the practitioner is sometimes objective, sometimes lived, and sometimes both. The practitioner is faced with the task of translating scientific risk into clinical practice. Confusion between the scientific and lived dimensions of risk has led to serious consequences for clinicians who are faced with managing patients at risk and for patients diagnosed as being at risk.

While epidemiologists speak of risk as being a measured property of a group of people, clinicians speak of risk as a specific property of an individual. Within clinical practice, risk is transformed from an epidemiological concept describing generalized observations within populations to a clinical concept describing a specific entity within an individual. Thus in clinical practice, risk is something that the

patient suffers. The clinician transforms risk into a sign of a future disease entity, enabling clinical diagnosis, prognosis, and patient management. For the patient, risk becomes transformed into a lived or experienced state of ill-health, into a symptom of future illness. Risk is rarely an objective concept. Rather, risk is internalized and experienced as a state of being. The different dimensions of risk as understood and experienced by epidemiologists, clinicians, and laywomen further blurs the already ambiguous relationship between health and disease. This ambiguity results in the creation of a new state of being healthy and ill; a state of being that is between health, disease, and illness and that results in the medicalization of the unknown.

In this chapter, I discuss the theoretical assumptions informing the meaning and use of risk within epidemiology and clinical medicine. I then discuss the two fundamental dimensions of risk: objective scientific and measured risk as opposed to subjective or lived risk. I conclude by discussing the implications of the medicalization of risk for public health policy and program planning, clinical practice, and lay control over states of health and illness. While the argument concerning the medicalization of risk emerges from and relates specifically to this case study of benign breast conditions, I suggest that it may have applications to medical thinking and practice for other chronic non-infectious diseases.

6.2 EPIDEMIOLOGIC AND CLINICAL CONCEPTS OF RISK:

To begin, I first want to reflect upon the more general meanings and uses of risk. Douglas and Wildavsky, in their book entitled "Risk and Culture", argue that "The perception of risk is a social

process"(1982:6). Risks are a direct reflection of a community's values and social organization. The selection of certain risks as opposed to others represent a particular society's shared values about present and future dangers. Risk perception is a social and cultural process.

While Douglas and Wildavsky argue that the selection of specific risks is a social process, they do not question the social construction of the concept itself. That is, risk is a concept that is socially constructed to describe and explain collective experiences of a reality that is becoming increasingly unpredictable; a reality in which many kinds of knowledge can no longer be relied upon. Risk is a concept central to the experiences of modern life, a life of collective uncertainty. When applied to experiences of health, risk arises out of the inadequacy of contemporary models of illness and disease to explain how and why we get sick or stay well. Epidemiological models are complex and imprecise, clinical medicine is largely ineffective in preventing and controlling many of the chronic diseases, and there is much lay confusion over which kinds of life style habits will protect a person against disease. The social construction of the concept of risk allows us to think and talk about ambiguous meanings of health and illness and unpredictable relationships between our world and our health. Not only are particular risks the result of a social process, but the creation and use of the concept itself is a social construction arising from contexts of collective uncertainty.

While the concept of risk has always spoken about danger, it has not always spoken about chance. The etymological meanings of risk derives from the Latin word "resecare" meaning to cut back, cut off

short. From the Latin meaning, the concept can be traced to both French and Italian meanings of peril and to the Spanish meaning of to venture into danger. The concept of chance is introduced in the modern day definition. The Concise Oxford Dictionary gives the contemporary meaning of risk; "the chance of injury, damage or loss. A dangerous chance, hazard." Contemporary concepts of risk describe relationships between uncertain knowledge and unwanted outcomes. The language of risk is essential to being able to speak about, understand, and live in an unpredictable world. To speak of risk is to talk about the probabilities of uncertain and unwanted futures. Within the scientific world, risk describes theoretical, measured, objective, mathematical associations leading to possible outcomes. Here, risk is never more than a theoretical possibility. However, risk within the lived practical world is about a current state of being; a state of being defined by an uncertain and dangerous future. Thus, risk must be first understood as a more general cultural concept created to describe and explain contemporary experiences of uncertainty concerning relationships between knowledge and unwanted futures.

Within both epidemiology and clinical medicine, risk describes uncertainty in knowledge about the causes of disease. Thus, risk when applied to health and illness, is about ambiguous and uncertain etiological relationships. This uncertainty has stemmed from changes occurring in both epidemiologic and clinical models of thought and practice. Current epistemologic assumptions underlying models of disease etiology can be traced to ideas about knowledge and the body arising from the Scientific Revolution in the sixteenth and seventeenth centuries. It was during this period that great shifts in thought

occurred about how the world was understood and explained. Conceptions of the world as an organic whole shifted to that of the world as a machine; a world that was governed by uniform laws of nature. Copernicus overthrew the view that the world was the center of the universe and Galileo introduced methods of scientific experimentation and the empirical approach. The laws of nature were described in mathematical language so that they could be measured and quantified. Bacon formalized the empirical method and introduced scientific procedures of inductive reasoning which continue to form the heart of epidemiologic logic. Descartes argued for belief in the certainty of scientific knowledge and claimed that the laws of nature could be discovered though the application of the analytic method and expressed through the language of mathematics. Within this model, natural phenomena could be broken down into bits and pieces and then explained in terms of their relationships to each other. The world to Descartes was like a machine and he readily applied this metaphor to the functioning of the human body. Finally, Descartes had a profound influence on the conceptualization of the human as separated into two dimensions; mind and body (Capra 1982, Chalmers 1978).

This mechanistic, reductionist view of the world and the consequent belief in the certainty of knowledge greatly influenced the development of the science of biology. Biological models aim at reducing organisms to their functioning parts and then explaining the relationships between these parts. This biological model gave rise to contemporary concepts of disease causation and it is these assumptions about disease etiology upon which both epidemiologic and clinical thinking and practice are based. Despite its inadequacies,

epidemiology and clinical medicine continue to adopt a Cartesian model of the human body, one based on the mechanistic and reductionistic approach of biology. The result is that both epidemiologists and clinicians are finding it increasingly difficult to explain the etiological relationships of modern disease. The concept of risk as used within contemporary explanatory models of epidemiology and clinical medicine has emerged directly from the growing awareness among researchers, practitioners, and the lay public that our current models and knowledge of health and illness are undergoing important conceptual shifts. In a sense, the concept of risk arises from shifts in epidemiologic and medical thinking, thinking which has been based upon the postulates of biology. Risk, then, points to and describes anomalies arising in the currently held paradigms explaining the etiological or causal process of disease (2).

6.2a Risk and Concepts of Causality:

Up until the end of the nineteenth century disease was thought to result from an imbalance of the humors within the body or from a lack of harmony between a person and their environment. The concept of a specific causal agent, or what Dubos (1959) has called, the doctrine of specific etiology, became the most popular explanatory model during the latter half of the nineteenth century. Louis Pasteur's work gave rise to two central ideas concerning the relationships of health and disease. The first was the idea that a specific micro-organism had a specific effect and the second was that the immunity of the host played an important role in the susceptibility to a particular disease (Susser 1973). Pasteur's discoveries made it possible for Robert Koch to formulate postulates of disease causation. Using Henle's earlier

postulates concerning disease causation, Koch demonstrated that many types of disease could meet these postulates (3). It was through the formulation of these postulates that the doctrine of specific etiology took hold as the most powerful explanatory model of disease causation.

Both Pasteur and Koch devised elaborate experimental situations in order to illustrate their hypothesis that a particular disease agent caused a particular disease. The doctrine of specific etiology has great utility as it has enabled clinicians to describe with more precision, distinct disease entities. The refinement of diagnostic categories increased the physician's ability to predict the outcome of specific treatment regimens and thus allowed for greater clinical control over diagnosis, treatment and prognosis.

The development of the microscope and other scientific technologies has enabled the experimenter to focus more precisely upon micro-organisms and to gain detailed knowledge of the cellular and molecular mechanisms of the human body (Dubos 1959, King 1982, Reiser 1978, Susser 1973,). While the development of molecular biology has allowed medical scientists to study the mechanisms of disease in its most minute parts, it has also led to further entrenchment of reductionist, mechanistic medical models. Modern medical thinking and practice has continued to follow this experimental reductionistic approach and while these models have produced many triumphs in understanding and treating disease, they have also inhibited the creation of a broader, more holistic approach that might better explain the many complex relationships between health and disease (4).

The doctrine of specific etiology has had the strongest explanatory power when applied to the infectious diseases. Yet even in

well controlled experimental conditions direct cause-effect relationships fail to account for all cases of disease. However, the doctrine of specific etiology becomes even more problematic when applied to biological phenomena in their natural context. The natural external and internal environments of the host are composed of a complex set of dynamic relationships that are all but impossible to control for, outside of the laboratory setting. This, combined with the increasing incidence of non-infectious diseases, has led to much uncertainty concerning the nature of the concept of cause both within scientific and clinical medicine. The concept of risk arises directly out of the current inadequacies of the mono-etiological approach to understanding, preventing and treating disease. The use of the concept of risk in relation to the language of health and disease is rapidly replacing the use of the concept of cause.

Risk is another way of talking and thinking about causal relationships, and while in one sense its use represents a first step towards shifting away from mono-causal thinking, in another sense, its use can be understood as covering the ever growing anomalies in the paradigm of cause and effect thinking. Although epidemiology and clinical medicine are adopting multi-causal models of health and disease, both continue to operate on a basic belief in the doctrine of specific etiology. Thus we find an emerging rhetoric speaking of holistic, multi-causal relationships yet a practice that continues to adopt a reductionist, mechanistic approach towards understanding and managing disease. Thus, the language of risk represents efforts to explain the many anomalies arising in our contemporary bio-medical models and points to a shift in understandings of health, disease and

illness (5).

6.2b Ideas of Cause and Risk in Epidemiology:

Epidemiology is an inductive science and biological plausibility is intrinsic to all accepted epidemiologic hypothesis. Evaluation of the consistency of epidemiologic data continues to be based upon etiological hypotheses developed from within laboratory or clinical models (Lilienfeld and Lilienfeld 1980). This points to a fundamental dilemma in epidemiologic reasoning. While explanations for hypothesized etiological relationships are validated in the laboratory, the etiological relationships are properties of large populations. Uncertainty concerning causal relationships and factors arises because it is difficult if not impossible to obtain a one to one correspondence between what is observed in the laboratory and what is observed within large populations. Risk, as used within epidemiology, is a scientific construct describing measured uncertainty about these etiologic relationships. Thus, while the justification of etiologic hypothesis lies in a specific biochemical or patho-physiological process within an individual, etiological relationships are expressed in terms of numerical probabilities and are seen to be properties of populations rather than of individuals.

> The level of organization of populations and societies introduces a set of variables over and above those germane to individuals...The study of disease in individuals can suggest the nature of the disordered state of functioning and its progress through time. Studies of individuals cannot determine, even in a series of cases, the limits of the disorder in relation to normality or securely predict its onset, progress, and outcome. To garner this knowledge, the epidemiological method must be used (Susser 1973:7).

When epidemiologic and clinical models of infectious disease etiology are applied to chronic diseases, several dilemmas emerge. The

multifactorial nature of chronic disease etiology makes it impossible to isolate a specific causal agent and this has lead to a number of difficulties. It is often difficult to obtain an accurate clinical diagnosis, and the distinction between diseased and non-disease persons is difficult to ascertain. For epidemiologists, this has made accurate case definition difficult. Non-infectious diseases have long latency periods thus making it difficult to pin point the time of onset. This has made it difficult for epidemiologists to collect accurate incidence data and to understand the natural history of many of these diseases. Because of the difficulties in both epidemiologic and biomedical understandings of chronic disease, it has been difficult to translate knowledge into public health policy and clinical practice (Cassel 1964, Mausner and Bahn 1974).

In the early 1950's, these problems led epidemiologists to question whether models of infectious disease etiology could be applied to the chronic diseases. Was a shift in the logic of epidemiologic thinking needed in order to account for the anomalies presented by chronic disease? Or rather, was it simply a matter of the need for new knowledge about these diseases? Much of this debate was formally carried out in the major epidemiologic and medical journals, with the majority of authors arguing for the creation of new knowledge rather than for a shift in epidemiological thinking. Thus, epidemiologic efforts were directed towards re-defining the concept of cause and creating more complex models of causation rather than questioning the very nature of epidemiological thinking (6). The Henle-Koch postulates were redefined to explain and account for the multi-causal nature of chronic disease (Evans 1976, Lilienfeld 1959, 1973, Lilienfeld and

Lilienfeld 1980, Sartwell 1960, Susser 1973, Yerushalmy and Palmer 1959).

> Differences in causal thinking about infectious and non-infectious diseases - the latter being more likely to have multiple causal agents - depend upon the frame of reference within which the investigator operates, and reflect differences in our knowledge of the etiology of these two general categories of disease, rather than differences in logical reasoning (Lilienfeld and Lilienfeld 1980)

In contemporary epidemiologic models of non-infectious diseases, a number of shifts have taken place in re-conceptualizing causal relationships (7). Instead of thinking about the causal relationship between an agent and a disease, we think about the possible association(s) between one or more factors and a disease. The notion of probability is introduced to describe the degree of certainty (or degree of uncertainty) concerning suspected relationships between factors and diseases within populations. The concept of risk stems from the dual notions of probability (replacing certainty) and association (replacing cause). Thus, we find a language of chronic disease etiology that speaks of the factors to which a population is exposed which may be associated with an elevated risk of developing a disease. These factors are spoken of as "risk factors". Models of chronic disease etiology replace "etiological factors" with "risk factors" (8).

The points to be stressed are that risk describes relationships which are objective, depersonalized, quantitative, and scientifically measured and suspected causal agents are understood as "factors". Risk in epidemiology expresses a measured degree of belief about the relationship between one or more factors and the incidence of a disease

in a large population (9).

Drawing upon Toulmin's (1976) distinctions between general and particular knowledge within medicine, risk within epidemiology represents scientific knowledge about generalized relationships between causes and effects while within clinical practice, risk is understood to be an attribute of an individual. Within epidemiology, risk speaks of states of health which are located outside of any one particular individual; it depersonalizes causes of disease. The language of risk, expressed in quantitative mathematical terms, is objectified and measured. It is detached and descriptive; an onlooker's analytical understanding of collective relationships (Toulmin 1976:35). Furthermore, risk as used within epidemiology is precisely defined and operationalized. Much attention has been given to delineating different kinds of risk, the kinds of relationships they describe, and the methods by which they are to be calculated. Risk precisely describes measured uncertainty. It describes probable multifactorial and multidimensional relationships; relationships which are too complex to be observed and measured with any certainty within a particular individual.

Here lies the crux of the problem; the translation of epidemiologic risk into clinical and individual risk. Bateson (1979) has argued that there is a great difference between statements about a class and statements about an identified individual. "Such statements are of different logical type, and prediction from one to the other is always unsure" (1979:42). Bateson argues that while we may gain a certain amount of knowledge about the generic, the specifics always eludes us. Toulmin (1976) applies these ideas to the intrinsic

uncertainty of particular knowledge in medicine. He argues that "in any developed natural science, our understanding of general principles will eventually outrun our ability to apply those principles to the detailed facts of particular cases" (1976:43). There is always an element of intrinsic uncertainty in the practice of clinical medicine because the practitioner is required to translate generalized knowledge into the treatment of a particular individual. And in these situations, there is always an amount of uncertainty that can not be measured. Risk then, for the clinician, comes to take on the added dimension of unmeasured uncertainty. And here we have the fundamental distinction between two kinds of risk. The first is measurable uncertainty represented by the laws of probability. The second is unmeasured uncertainty, where numerical probabilities are not entirely applicable. Knight (1921) has argued that unmeasured uncertainty prevails where:

> ...numerical probabilities were inapplicable - in situations when the decision maker was ignorant of the statistical frequencies of events relevant to his decision; or when a priori calculations were impossible; or when the relevant events were in some sense unique; or when an important, one-and-for-all decision was concerned (Quoted in Ellsberg 1961:643).

These two dimensions of risk, measured and unmeasured, can be applied to understanding the different dimensions of epidemiologic versus clinical and lay concepts of risk. On the one hand, we have what I have called objective, measured risk and on the other, is lived, unmeasured risk. What distinguishes the two dimensions is both the ambiguity in meaning and the uncertainty in translating meaning into practice. Objective risk is quantitative, measurable and unambiguous.

Lived risk is qualitative, subjective and highly ambiguous. Epidemiologists create objective risk, lay people create and experience lived risk, and medical clinicians mediate and bridge these two dimensions of risk. It is to the clinical experience of risk to which I now turn.

6.3 THE CLINICAL DIAGNOSIS AND MANAGEMENT OF RISK:

> Epidemiologists have identified certain groups of women who are unquestionably at higher risk for developing breast cancer...For those of us who practice clinical medicine, it is essential to separate those factors that are significant enough to influence our own practice of medicine from those factors that are perhaps statistically important when dealing with large populations but which are not enough to make us alter the advice we give patients about the frequency of clinical examinations, intervals between mammograms, and so forth....This then, becomes the crux of this discussion, namely, the clinical implications of these risk factors. Which, if any, of the recognized epidemiologically significant risk factors should trigger special treatment or follow-up for women (or men) so affected? By identifying these groups of individuals can we detect breast cancer earlier and thereby alter the course and outcome of the disease? (Schwartz 1982:26)

The language of risk within clinical medicine arises from the translation of often ambiguous scientific knowledge into clinical practice. Within clinical medicine, risk comes to take on at least two kinds of meanings. First, practitioners use epidemiologic concepts of risk to aid in the diagnosis, management and prognosis of patients. In this instance, clinicians must interpret scientific concepts of risk in such a way as to have clinical significance. This type of risk I shall call objective clinical risk and I shall argue that clinicians understand this risk as residing physically within individual patients. A second type of risk concerns the clinician's own experiences of uncertainty concerning diagnosis, management and prognosis. This uncertainty is a necessary part of clinical practice because clinicians

can never have perfect knowledge of all the variables that lead to disease states within particular individuals. Thus, necessary fallibility is always a part of clinical practice (Gorovitz and MacIntyre 1976). This type of risk I shall call lived clinical risk. It represents the clinician's uncertain application of medical and epidemiologic knowledge. It points out that clinicians are always at risk for medical error.

Before exploring in some detail these two types of clinical risk, it is useful to review some of the similarities and differences in the application of knowledge in epidemiology as compared to clinical medicine. While epidemiology and clinical medicine share many common assumptions about states of health and disease, the specific applications of knowledge give rise to important differences (10). As I have argued, knowledge about risk within epidemiology is scientific, objective, and measured. Risk is a relatively unambiguous and well defined concept. Furthermore epidemiologic knowledge of risk is a general type of knowledge that seeks to explain relationships between a factor and a disease among large classes of people. Unlike the medical practitioner, the epidemiologist does not need to translate knowledge into practice and states of scientific uncertainty serve to stimulate the search for new knowledge (11).

In contrast to epidemiology which might be best understood as a science of universals, the practice of medicine can be understood as a science of particulars. While clinical medicine stems from similar historical traditions and shares with epidemiology, basic biomedical assumptions about causality and the nature of health and disease, the application of such knowledge is vastly different. A basic problem

facing the clinician concerns the interpretation of theoretical knowledge about universals into practical knowledge of particular individuals.

> One cannot expect...to be able to move from a theoretical knowledge of the relevant laws to a prediction of the particular's behavior. The history of the law-governed mechanisms and of the particular which is their bearer is, so to speak, an intervening variable which always to some degree eludes us (Gorovitz and MacIntyre 1976:57).

The practice of clinical medicine relies upon the creation and application of known, certain knowledge and thus, uncertain knowledge represents clinical risk. Errors within epidemiology have theoretical consequences while errors within medical practice have immediate practical consequences. Risk within clinical medicine derives directly from the translation of epidemiological and other scientific knowledge into clinical practice. To recapitulate, objective clinical risk refers to the translation of epidemiological risk into patient management. In this sense, I am speaking of reinterpretations of objective measured risk into risk as signs and symptoms of disease. The second dimension concerns lived risk or the clinician's experience of the risk of being wrong.

The two dimensions of clinical risk, objective and lived, are well illustrated by the problems clinicians face in the management of women at risk for developing breast cancer. We can begin by examining the first dimension, objective clinical risk. The assessment of risk factors plays an important role in helping the practitioner reach a clinical diagnosis. To make a risk assessment, the clinician must translate epidemiologic risk to have clinical relevance. This

interpretation entails two shifts in meaning. First, risk comes to describe personal or individual risk rather than population risk. Thus, instead of thinking of risk as existing within a population of people, the clinician thinks of risk as existing within a particular individual. The second transformation that occurs is that the meaning of risk shifts from that of a theoretical statistical concept to have a physical or real existence. The clinician comes to think about risk within existing modes of clinical thought and practice by transforming risk into a sign of a "possible" current or future disease. Thus, objective clinical risk comes to be understood and talked about in the same way as other objective clinical signs of disease.

This transformation is partially illustrated by examining the clinical diagnostic process that occurs when a woman first sees a clinician for a breast condition. When a woman is first seen at the Breast Clinic at the university hospital, a patient history is taken. During this process, risk factors are elicited along with other signs and symptoms. One nurse who worked in this breast screening clinic explained:

> We have on our history form, significant risk factors and they are the ones that Dr Jones and Dr Smith have identified as the most significant...but these are not proven yet. The ones we have identified are sex, age, obesity in postmenopausal women only, personal family history of invasive breast cancer, and premalignant conditions...My role when I see a woman for screening is to identify and check off which ones she has. Then it's up to the physician to make the risk assessment and outline a plan of care for the patient.

Here, the nurse is speaking of risk factors as properties of the patient. She speaks of risk factors as entities that the doctor has identified to be significant. The clinician will assess the meaning of elicited risk factors in the same way that he or she assess the meaning

of other signs and symptoms.

Although clinicians elicit and assess risk factors, there remains much uncertainty concerning their significance. This is due in part to the ambiguity of their meanings both within epidemiology and medical science. One surgeon explained:

> The problem is that there are certain accepted statistics for the female population as a whole and then there are these statistics that involve specific populations that seem to contradict the general, national, accepted, cancer study statistics. So I don't know. And whatever the genetic predisposition, the environmental predisposition, what ever, I can't tell them how to eliminate that risk!

Many of the clinicians interviewed expressed high levels of uncertainty concerning the clinical significance of the risk of benign breast conditions. One obstetrician explained:

> Doctors don't really know what the relationship of fibrocystic breasts are to cancer. Fibrocystic breasts are very common. No one knows how you preselect from one to the other. We're all groping in risk factors and trying to define the high risk population.

When faced with interpreting the uncertainties of risk for patient management, clinicians explained that they were hesitant to talk of risk in statistical terms. One surgeon explained how difficult it was to discuss with women, their chances of reoccurrence when they had already had a diagnosis of breast cancer.

> I know what the literature says but when it comes to me talking with that young woman with a breast cancer, all I can do is talk about these ridiculous impersonal statistics. For her, the statistics are truly meaningless because for her, she is going to have a metasis or reoccurrence either 100% or 0%. We can talk about 60 and 80% and 45% and all that other business. They are hollow statistics. They do nothing when applied to an individual. I have to tell every single woman that our knowledge has limits. Even if I do this disfiguring operation, I can't offer any more than a statistical hope of cure and only time will tell that with any certainty. And that is awful and so, the "I don't know" exists in every aspect of our approach.

Despite problems in translating statistics to have personal relevance, clinicians do translate population risk into a risk figure for individual patients. This is illustrated by the surgeon who expresses concern over the chances that a benign condition might develop into breast cancer:

> Those women who have multiple cysts, and I mean come in with 4 or 5 cysts in each breast over a period of a year, in this type of patient, 25% will develop cancer. So I do worry about these patients. I have one here...who I am a little bit concerned about. She has been coming in since 1976 and each time she comes in she's got another cyst...and she's been in seven times so far. I'm getting worried about her. There come a time when you have to sit down and say, "Well, look, statistically you've got about a 25% chance of developing breast cancer," and ask them to start thinking a little bit about having a subcutaneous mastectomy.

Here the surgeon has translated a population risk into an individual risk and, after doing so, has suggested a method to remove the risk altogether.

And this brings me to my final point concerning objective clinical risk. When faced with management of risk, surgeons have a tendency to treat risk as they would other undesirable physical conditions; removing the physical condition that is associated with risk. For example, biopsies are performed both to obtain a more definitive diagnosis and to remove the lump itself. Removal of the lump results in the removal of the risk of a possible pre-malignant condition. Thus, we find that clinicians speak of risk as not only a sign of possible current or future disease, but also of risk as something that resides in a particular part of the body and something from which a patient then suffers. Two surgeons explained:

> You really have to say to the woman, "You have this much risk in each breast over the next 25 years." Then they really have to decide how they feel about the risk.
>
> I tend to see a younger population, sometimes a lower risk

> population but I also get a higher percentage of involvement with the issue of future risk. If a lady 65 or 70 years old has breast cancer, because of her age, the other breast is not at nearly the risk as if she was 30 years younger. [with younger women] That breast has 30 more years at risk.

In clinical language, risk is spoken of as if it were a sign of a possible future or current disease, a sign that resides in a particular part of the body and can be observed by the clinician. Risk, then, becomes transformed into a clinical entity, an entity that can now be manipulated and physically removed by the clinician. Faced with their own uncertainties concerning the meaning of organs or tissue at risk, surgeons remove risk as they remove other diseased parts of the body. By doing so, they remove the physical risk of a possible malignancy and their own risk of being wrong or failing to detect a cancer. One surgeon explained:

> I tend to be rather aggressive about doing biopsies and sometimes I get a little guilty about that. But you know, you have a situation that you feel a little guilty about only to have it pop up to be pathologic! I mean we are legally at risk, emotionally at risk, and physically, the patient is at risk.

This comment is revealing as it introduces the second dimension of clinical risk, the lived dimension. Lived clinical risk refers to the clinician's own experiences of risk, primarily the risk of being wrong. Lived clinical risk results from uncertainty concerning clinical knowledge and its application in practice. Objective clinical risk acts to increase clinical uncertainty as the transformation of risk into a sign of disease further blurs the already ambiguous distinction between states of health and states of disease. Risk changes both clinical and lay concepts of normalcy. A patient diagnosed with one or more risk factors enters a state where she is neither healthy nor diseased - a grey zone between health and disease. And this ambiguous

state of being leads to clinical uncertainty concerning diagnosis, management and prognosis.

Clinical uncertainty has always been an inherent component of medical practice. The art of diagnosis consists of bringing order and meaning to a series of signs and symptoms. As discussed in chapter 4, the medical model that most clinician's use is based upon two basic assumptions. The first is that there exists an objective physical reality which medical and scientific knowledge can discover and second, signs and symptoms refer to some underlying physiological or chemical change the meaning of which can be established and agreed upon (Feinstein 1973, Mcghee et al. 1979) (12). In theory, this process is straightforward, however, in reality, it is complicated by the fact that the meanings of states of ill-health are forever changing. The history of medicine has been characterized by dynamic shifts in the way in which we understand the relationship between health and disease and the meanings of patho-clinical states (Foucault 1973, King 1982). In reality, clinicians are forced to make diagnoses based upon ever shifting and often ambiguous kinds of scientific knowledge.

In many cases, the elicitation of risk and its clinical assessment helps to bring certainty to the clinical diagnosis and management. For example, in assessing the information elicited during a physical exam and perhaps a mammogram, the assessment of risk factors helps the clinician decide whether or not to advise more invasive diagnostic procedures. A surgeon explained:

> I examine her and make sure that I don't feel any distinct mass in her breast, get mammograms, make sure that they're negative and that the woman gets followed. But it depends on family history, it depends on some of their risk factors. Under the age of 30 I'm a little less aggressive in terms of taking her right to the biopsy.

However, when faced with the everyday demands of clinical practice, the ambiguity in the meaning of risk factors often brings the clinician face to face with his or her own uncertainties concerning the ability to predict and control the outcome of breast conditions. Thus, in the practical world, clinicians tend to remove the ambiguity of risk by removing the physical condition itself.

When faced with managing a woman with a benign condition, clinicians experience personal lived risk in two senses. First, women diagnosed with benign conditions are at risk as they are thought to be more likely to develop breast cancer compared to women not diagnosed with the condition. Because of the uncertainty as to whether or not a woman with a benign condition will develop breast cancer, the condition comes to take on the double meaning of being both normal and premalignant at the same time. Clinicians must make clinical decisions based upon an ambiguous condition of uncertain outcome. Second, women and doctors are at risk for the failure to detect a small cancer hidden by a benign condition. Benign breast lumps can act to camouflage small cancers. Thus, clinicians experience lived risk as a uncertainty concerning the outcome of a currently benign condition and uncertainty concerning their ability to detect an existing but camouflaged cancer (see quotes on pages 123-126).

Objective risk and lived risk represent two dimensions of clinical risk experienced by medical practitioners. I have argued that clinicians translate objective risk into a clinical entity and then remove both objective risk and lived risk by removing the physical entity where risk resides.

6.3a Removing Risk Through Preventative Surgery:

An extreme example of this process is removal of risk through prophylactic mastectomy. At the time of this study, chronic fibrocystic disease combined with other risk factors, was being advocated by some clinicians as an indication for prophylactic mastectomy (McCarty et al. 1981). In 1982 an article appeared in the journal "Preventive Medicine" advocating prophylactic mastectomy to prevent breast cancer in women with a combination of fibrocystic disease a and family history of breast cancer (Mulvihill et al. 1982). The article is revealing for a number of reasons. First, the authors openly acknowledge the inability of clinical medicine to modify the risk factors for breast cancer through non-invasive means, and suggest that preventative surgery might be one way of removing risk.

> The major risk factors--age, prior breast disease, and a family history--can be identified but not changed. Efforts to modify minor risk factors, for example, by avoiding high fat diet, caffeine and oral contraceptives, are possible and not harmful in theory but are probably ineffective and surely unproven. Alternatives for control, then, would consist of an aggressive plan of surveillance in the hope of early diagnosis or prophylactic mastectomy (p:506).

Second, the authors have made a number of faulty assumptions about the epidemiologic meanings of the above risk factors. Concerning prior breast disease, they claim that "...a history of clinical or biopsy-proven fibrocystic disease is three to six times more frequent in breast cancer patients than in controls" (pp:503). From this data they assume that fibrocystic disease poses a risk factor for breast cancer, yet, as I have pointed out earlier in this thesis, the label of fibrocystic disease is ill-defined and can include many types of benign conditions. The relationships between these conditions and breast

cancer have yet to be clearly understood. There is little evidence to show that two of the minor risk factors, caffeine and oral contraceptives, raise a woman's risk of developing breast cancer (13). Not only do the authors select risk factors which are difficult to define within epidemiology but they make the assumption that the three risk factors which they select as being most important (age, prior history of fibrocystic breast disease and familial history), will have a multiplicative interaction.

> Calculated risk estimates for a woman with several risk factors will differ depending upon whether the factors are additive, multiplicative, synergistic in some other way or even antagonistic. Since few studies address the point we assume a multiplicative interaction of major factors and present the risk as 5-year probabilities (p:507).

Here, the authors clearly acknowledge that the current knowledge about how risk factors interact to produce breast cancer, is unknown. The authors then proceed to present "typical" case reports of women who elected to have prophylactic mastectomy based upon their calculated personal risks.

> Because of fibrocystic disease and family history of breast cancer, 29-year-old Patient 9 was advised by an oncologist to have a prophylactic mastectomy...Her relative risk was estimated to be 27, and her 5-year probability 3%...On follow-up, 7 months later, the patient was satisfied with the operation; however one breast became so painfully firm due to fibrous contraction that she had to cut a hole in her mattress in order to sleep prone. She finally found a surgeon familiar with this complication which he relieved by closed capsulotomy (pp:507-508).

The authors conclude their article by stating that:

> Despite areas of ignorance and controversy, a few firm conclusions emerge from this study and the literature:
> (a) Women are raising questions about their personal risk of breast cancer and routes for prevention and control;
> (b) A small number of demographic and epidemiologic features can account for the largest identifiable fraction of an individual's risk: sex, age, prior breast disease, and family history of histologically verified breast cancer;
> (c) For carefully counseled patients, prophylactic mastectomy may

be appropriate therapy (p:509).

I have devoted time to discussing this article as it illustrates several crucial points concerning trends in the clinical management of risk. While those who advocate prophylactic mastectomy to remove risk, take an extreme position, it does represent a mode of clinical thinking and practice that I would argue is becoming increasingly common. Some of the surgeons who I interviewed illustrated this mode of clinical thinking and practice. They spoke about the clinical management of risk under the guise of prevention, but prevention in terms of removing the the part of the body at risk rather than changing the conditions which give rise to the individual risk factors. One plastic surgeon explained:

> Surgeons who are concerned about breast disease have been trained...to handle curative surgery....None of us have been taught in medical school or in residency training about preventive surgery...There's preventive medicine all over but not preventive surgery. We are immunized against polio...you're immunized for tetanus. You don't wait until you get tetanus. All of these things are preventive types of procedures to prevent you from getting bad disease. Well, that's where, from a surgical philosophy, it is really very different. If you take a woman who has breast disease, proven breast disease by pathological tissue biopsy, if you then combine family history; if she's over the age of 40 and has not had children; if she's had mammograms that are changing in a suspicious way; if clinically she has breasts that are dense and difficult to follow; then that woman can be considered a candidate for prophylactic subcutaneous mastectomy.

Another surgeon explained:

> I certainly feel that probably anyone with a very risky family history is a candidate [for prophylactic mastectomy] or where you have patients with extremely difficult breasts to follow...and of course those who have more than one of those factors are definitely candidates.

Both surgeons are speaking of and failing to distinguish between two kinds of risk; the woman's risk of developing breast cancer and their own risk of being unable to detect an early cancer.

Finally, when speaking about prophylactic mastectomies, surgeons clearly articulated that it is the risk that they are removing; risk that resides as a sign of future disease within a particular organ of the body. Two surgeons explained:

> I feel that when properly done, you can clean out 95% of the breast tissue and in essence, you're reducing the risk factor by 95%.

> I've told maybe 10 women to have subcutaneous mastectomies and I don't do that lightly. But when I get to the point of saying, "My God! She's got these lumps all over the place and she's high risk; just get rid of them...get rid of as much risk as you can!.

The subject of when and how to perform a prophylactic mastectomy is a controversial one. Much uncertainty exists over how much breast tissue needs to be removed to reduce the risk significantly. As yet, no control studies have been completed that compare the rate of breast cancer among a group of women at risk who elect not to have the procedure, as compared to those who do. Thus, the belief that a reduction in a given percentage of breast tissue results in a similar reduction in risk is based largely upon the assumption that risk is evenly distributed throughout the breast. This assumption remains unproven. One surgeon expressed reservations with the procedure, as he explained:

> You always wonder if you do an 85% mastectomy, do you get rid of 85% of the risk or do you get rid of none of the risk. I'm not sure that risk factors alone would ever make me do a mastectomy.

As a part of this research, I regularly attended case conferences at the two hospitals over the period of a year. These special conferences were held to discuss particularly problematic cases and the issues of risk and patient management were common topics. The issue of risk and prophylactic mastectomy raised much debate among conference

participants and the following case study illustrates many of the dilemmas facing clinicians in the management of risk.

The case of a 36 year old woman was presented to conference members because the woman's clinician was uncertain about the clinical and pathological meanings of detected breast changes. The woman's surgeon, Dr. Smith, began by saying that the woman had been referred to him for a lump in her left breast. Upon a physical exam, he diagnosed the lump as a benign fibroadenoma but also recommended that she have a mammogram. The results of the mammogram had come back "suspicious with 3 clusters of calcifications." The surgeon then performed a biopsy which was diagnosed by the pathologist as "severe atypia" (13). At this point in the conference, the pathologist showed the clinicians slides of the woman's biopsy and said, "Here's a patient you'd think is a nice benign." He then showed the mammograms and said, "There are two lesions in the left breast, one benign and one less well defined." He then asked the clinicians what their diagnosis would be. "Carcinoma? Fat? Or scar tissue?" The pathologist then said, "What it actually represents is an area of duct hyperplasia." He then proceeded to describe the histories of 6 women with similar conditions who were seen at this hospital, several of whom (he did not cite the exact number) went on to develop carcinomas. He said, "My own personal feeling is to go after it. It is more likely to represent a carcinoma." At this point an argument took place between the clinicians as to whether or not the three calcifications on the mammogram represented further evidence of a possible carcinoma. One clinician cited studies which showed that 50% of all women will have at least one calcification and that three were not enough to warrant a diagnosis of carcinoma. Then

an open debate ensued concerning the controversy of prophylactic mastectomies for women with chronic fibrocystic disease. Various studies were cited in support of differing positions. After approximately 10 minutes of argument, the pathologist called for the need for a "management decision to be made." While no definitive decision was reached concerning the treatment or management of this woman's condition, the pathologist ended the presentation by saying to Dr. Smith, "Wouldn't you do a subcutaneous mastectomy for her? You won't let that drop will you? There are cases when you would with high risks."

This example illustrates several points. The clinicians all agreed that the present diagnosis was that of a benign condition, not a malignant one. However, it was unclear as to just how benign the condition was. In other words, was it very benign or was it premalignant? In fact, it was considered to be both benign and premalignant at different points thoughout the presentation. The meaning of the signs also shifted back and forth from that of a non-disease to that of disease. The ambiguity of the condition was clearly acknowledged and this led the clinicians to search for new knowledge as illustrated by the debate concerning the meaning of calcifications detected on the mammogram and the controversy over the prophylactic mastectomies. However, in the end, the pathologist chose to deal with the ambiguous meaning by recommending removal of the physical condition that gave rise to this ambiguity in the first place. The removal of the breast represents removal of risk, both the objective risk of the probability that the condition will become malignant and the lived risk of clinical uncertainty and error. The

result is the clinical creation of a physical condition over which the doctor now has control. Thus, the clinical management of risk can result in the physical manipulation of the body in order to create a more certain physical world.

6.4 LIVED RISK: LAY EXPERIENCES OF THE AMBIGUITIES OF NON-HEALTH:

For women, a diagnosis of benign breast disease often changes her perceptions of health and illness. For example, consider the following statements from women who have been diagnosed as having the risk factor of benign breast disease:

> I have very lumpy breasts. Nobody's sure if it's a disease or what the devil it is.
>
> I had some discomfort but I'd never had the thought that this was a disease!
>
> You know, one day you're walking down the street feeling wonderful and then all of a sudden somebody tells you that maybe you shouldn't feel so wonderful!

Risk for the lay woman becomes experienced as a symptom of a hidden or future illness and thus serves to further blur the already ambiguous distinction between experiences of health and experiences of illness (15). Women speak of risk in the same way that they speak of experiencing other symptoms of illness. Just as clinicians speak of risk as something that women suffer from, women speak of risk as an experienced state of being. Being at risk is a state between health and illness. Furthermore, women have little control over changing their risk experience and this can result in the additional risk of becoming either over or under medicalized.

In order to understand lay experiences of risk it is important to understand that the concept of risk for the laywomen is qualitatively different than risk as conceptualized by epidemiologists and medical

practitioners. Risk for women is lived risk. It is not objective or measured. It has its own terms of reference and thus, a different body of theoretical assumptions are needed in order to understand how risk is experienced by laywomen. A phenomenological approach towards understanding lived risk is most appropriate as it draws upon methodologies which are interpretative in nature and gives priority to understanding the lived experience of states of health. Such an approach is meaning-centered, the purpose of which is to ground explanations of ill-health in experience (Kestenbaum 1982).

To begin, it is useful to distinguish between scientific experiences of reality and everyday experiences of reality. Kestenbaum (1982) argues that for science, reality is the object as lived however, in everyday experience, reality is the experiencing of the object. Thus, for epidemiology and clinical medicine, risk is an object seen to reside within a population or in an individual. But for a woman, risk is the <u>experience</u> of "being at risk". This points to a fundamental gap that exists between a person's <u>experience</u> of a given reality and science's <u>explanation</u> of that same reality (Rosenkrantz 1976). A major difference between objective and lived risk is that the latter involves a good amount of unmeasurable uncertainty. Cassel (1976) argues that, "rational thought processes, at least as they are communicated, are useful only in handling material that is known and that can be converted into language" (Cassell 1976:36). Cassell's point is an important one as lived risk involves many factors that cannot be known, cannot be measured and thus cannot always be spoken about. Even when there is much information about individual risk, this information often has a high degree of ambiguity about it. Daniel Ellsberg has argued

that:

> Ambiguity may be high (and the confidence in any particular estimate of probabilities low) even where there is ample quantity of information, when there are questions of reliability and relevance of information, and particularly where there is "conflicting" opinion and evidence. This judgement of the ambiguity of one's information, of the over-all credibility of one's composite estimates, of one's confidence in them, cannot be expressed in terms of relative likelihoods or events (if it could, it would simply affect the final, compound probabilities) (1961:659).

For women, information about their own individual risk will always be highly ambiguous for several reasons. First, there exists much uncertainty within epidemiology concerning the significance of identified risk factors, Second, there exists much uncertainty within both epidemiology and other biomedical sciences concerning the mechanisms by which identified risk factors might act to produce breast cancer. Third, it is impossible to accurately translate population risk to individual risk. And fourth, it is impossible to know all the contextual factors and how they interact to determine risk for unique individuals. In sum, it is precisely because individuals are unique that we are unable to know all of the information needed to predict unique outcomes. Lived risk will always have as a central characteristic, an inherent quality of unmeasured uncertainty. Lived risk emerges from an individual's subjective feelings about the meaning of scientific and clinical risk mediated by the social and cultural contexts within which individuals live. Lived risk is not objective, cannot be quantified and is not static. Rather, lived risk must be understood as a dynamic experience of personal uncertainty about one's future. Lived risk represents the subjective experience of highly ambiguous states of health.

Within clinical medicine and public health, lived risk is often equated with objective clinical risk and with epidemiologically determined risk. Health practitioners often believe that if an individual fully understands the risks associated with the development of a particular disease, then they will take actions to reduce their risk. However, there is overwhelming evidence to show that individuals often ignore their risks and do nothing to change their style of life. Smoking behavior is a prime example. Concerning breast health, much attention has been given to the importance of monthly breast self examinations however, few women regularly engage in this practice (American Cancer Society 1973, Magarey, Todd and Blizard 1977). The most common explanations given for an individual's failure to recognize risk include psychological, social and structural factors which either inhibit communication, inhibit an individual's ability to understand the significance of information, or inhibit changes in bahavior. Decision-making theory and models are common approaches towards understanding how and why individuals make the decisions they do concerning risk and choice. However, these models are inadequate for understanding lay concepts of risk because they do not account for the fact that risk within epidemiology and clinical medicine is defined by different terms of reference (16). Lived risk has its own terms of reference and therefore, its own standards by which risks are assessed and evaluated. Thus, reasons why individuals often fail to take actions to reduce their risk of disease may in part be because they are acting on a concept of risk that is qualitatively different to that of epidemiological or clinical risk.

That these three types of risk are largely incommensurate often

goes unrecognized. Even when health practitioners acknowledge dimensions of lived risk, it is difficult for them to translate this in a practical way when counselling individuals. For example, a geneticist who counsels women concerning their personal risks for developing breast cancer explained that she likes to be able to "give women a number":

> Well, my approach is to find out from women what they think their risk is...and then I determine what their risks are. I talk to women about all the factors that can influence a woman's risk and then give them numbers; of how many women who have the condition, what the percent of risk is, what the age specific risk is. Whenever possible I give people a number, a risk number. For some things like stress, personality, diet, it's very difficult to put a number on those things.

Clearly this geneticist attempts to give women a risk as defined by the terms of reference within the confines of her profession. But how do women interpret epidemiological and clinical assessments of risk? First, risk for women represents potential changes in their experience of the relationship between one's current state of health and future state of health. In order for risk to have a personal reality, women must transform it from an objective entity to a subjective experience. Risk becomes internalized. One woman explained to me:

> I knew intellectually that I was at high risk but I didn't feel it inside. And then my mother died of cancer of the pancreas and that's the same time I turned 30 and as a combination of my mother's death and my turning 30, I started to really be in touch with my own mortality...I started to really internalized it, that yes, this could happen to me and I started getting a little bit scared.

In this research, women described their personal risk not in the language of objective knowing but rather in the language of the subjective senses (e.g. I sense, I feel, I think...) The following

quotes illustrate the language of lived risk:

> Well, now that I have fibrocystic disease I can't help but feel that I must have some sort of predisposition...but I don't really know if I'm at high risk now, more so than I would be if I didn't have this.

Another woman expresses her feelings about her low risk of breast cancer:

> I've wondered about the risk of getting breast cancer. The most part of me is fairly...I hate to say this, cocky is not the right word, positive is a better choice. I feel that for some reason, I'm here on this earth and I'm meant to be here...But then there is this tiny part of me that thinks, "Kid, it's happened to a lot of people and my God! It just might be you!

Because lived risk must be internalized in order to be experienced, it is difficult if not impossible for women to experience lived risk in terms of statistical probabilities. Irving Good (1975) has argued that the notion of subjective or personal probability is important for extending ordinary logic into useful everyday systems of reasoning. Using the metaphor of a "black box theory of probability and rationality", he argues that subjective probabilities consist of inequities between probabilities and that these inequities constitute a "body of beliefs" (1975:44). Thus, subjective probabilities are only partially ordered and refer largely to bodies of beliefs.

Kristin Luker (1975), has applied this notion of subjective probabilities to understanding why some women continue to take dangerous risks by failing to avoid unwanted pregancies. In her study of contraceptive risk taking and abortion, she argues that when deciding to use contraception, a woman must decide how "likely" it is that she will become pregnant and that often women discount future risks and focus instead upon the cost of present consequences. Discounting is a social process because it involves a woman's

interaction between her personal values and those of others. Risk taking emerges from a woman's subjective feelings about the costs of immediate consequences compared to those of uncertain futures.

The concept of subjective probability can be usefully applied to our understanding of women's experiences of lived risk and breast cancer. First, the women interviewed were well aware of the uncertainty that exists in clinical medicine concerning the meaning of identified risk factors and were faced with having to make a subjective decision concerning the meaning of these risk factors within the context of their own lives. While women may discount their risk of getting breast cancer, a diagnosis of benign breast disease can immediately act to bring personal meaning to risk. In this sense, a diagnosis of benign breast disease can be understood to symbolize a current state of ill-health. A woman diagnosed with benign breast disease is immediately thrown into a highly ambiguous state of being at risk, of being suddenly neither healthy nor ill. The discounting of risk until it comes to have personal meaning is illustrated with the following quotes:

> I always felt sure I would never get it 'cause I don't smoke, I don't do a lot of things that tend to cause people to get it. But since then, I consider it a real possibility.

> I read somewhere that women who don't have children before the age of 26 or don't breast feed are more likely to get it (breast cancer) but it doesn't seem like such a big thing....But I think my risks are higher now that I have fibrocystic breast disease.

> Now that I have fibrocystic breasts, I can't help but feel that I must have some sort of predisposition.

For women who have developed breast cancer, risk has resulted in certain unwanted and feared futures. What was once risk is now an experienced present. And here, risk loses much of its unmeasured

uncertainty. Risk is certain and rather than experiencing "being at risk", women experience "risk" as becoming the illness they feared. In the same sense that women "become ill", the onset of breast cancer can be understood as transforming a woman's experience of "being at risk" to "becoming risk". One women explained that not only was she at risk for a future cancer but that she had also become a risk statistic:

> After 5 years, if nothing has gone wrong, then you are free (of cancer). Then you don't have nothing to worry about. But I still have fear. The thing I do know is that I'm what you call a statistic and I am a cancer patient.

And another woman expressed similar feelings as she reflected upon why she had developed cancer:

> I had early menarchy and I had late cessation of my menses and the risk is higher statistically. I've had no children and that's another risk factor. I mean we're all just bodies and I'm going to fall into some statistic eventually.

These last two women express what is perhaps most important about lived risk and that is the issue of control. The uncertainties of risk present women with many dilemmas as there is presently little they can do to change their risk factors. Many of the women in the study expressed much frustration with this lack of personal control over risk. For example, when I asked a 26 year old woman if the doctors had told her of anything she could do to prevent further breast problems, she said:

> Well, you know, no coffee, no tea, no caffeine, none of which I do anyway. Which was a great let down to the doctors, which was another thing that frustrated me because they said, "Well, do you drink a lot of coffee?" I said no. I don't do any of that. And they would sigh, like, "Um, what is going on?" You know, "You really got a problem." So part of my frustration was feeling like I already do everything that I'm suppose to be doing.

Ironically, the search for personal control over risk often leads to further medicalization. Because women often feel helpless to do

anything to change their risk, they are left at the hands of the medical experts. One woman expressed her own frustrations by explaining:

> I always feel that Dr Smith is more in control than I am. Like I say, he's one of the few people that can intimidate me, and I don't think he does that, certainly not intentionally. But he does. I come out of there shaking all over. Now I have to wait until Wednesday to see if it's...Then we have to wait till the next time to see if that's it. But as he said, "What you have is serious and we have to watch it closely." Now I could walk away from it, sure. I could say, "It's been 2 years doctor, thank you very much for your help. I don't want to discuss it any more. I don't want to talk about it anymore." And maybe one day I will do that. But I am not ready to do that yet. I just simply am not ready to do that. He keeps asking me if I keep getting my periods. I keep thinking that maybe it's true that once your periods stop some of these lumps go away with it. You know, I have no control over that. Who knows. I'm not about to worry about something I have no control over. So for the time being, we will play it his way and see what happens. But if he tells me something I don't want, I don't know what I'll do.

This woman raises several important issues concerning lay risk. First, while it is clear that this woman does not have cancer, her doctor has diagnosed her as having a serious benign condition and she is therefore at risk for cancer. The doctor is not quite certain about the outcome of this condition and the woman is not quite certain if she is "supposed" to be healthy or ill. The doctor deals with his own uncertainty by retaining his surveillance over her condition until it either goes away or becomes cancer. The woman is left thinking that her menopause might cause her lumps to disappear but she has no control over when this might occur and it is not at all certain as to whether this will clear up the problem. Therefore, the woman is left feeling that she has no alternatives but to continue being medicalized. Faced with the fear of breast cancer as a possible outcome, knowing that there is no way to prevent the disease and that early diagnosis is a

woman's primary tactic for survival, this woman is caught in a bind of being healthy but of needing medical surveillance until her condition either becomes cancer or goes away. In her current state, can this woman ever walk away from her doctor and declare herself well? In a very real sense, being diagnosed at risk is itself a risk factor. It represents the risk of medicalization and the risk of losing control over the definition of one's own health.

Risk for women represents many uncertainties concerning the meanings of present health states and the possibilities of future ones. The loss of lay control over risk management stems from medical construction of risk. As I have argued, medical practitioners deal with risk by transforming it into a clinical entity, a sign of a present or future disease. Women are diagnosed as having risk factors in the same way that they are diagnosed with having disease. Within this context, women reconstruct these disease experiences into illness realities. Risk becomes experienced both as a symptom of future illness as well as a current illness. As doctors give risk a physical reality, so do women transform the unknown into an experienced abnormality in their current state of health. For example, one woman diagnosed with fibrocystic breat disease, clearly experienced her condition as an illness. She states:

> Since I know that your breasts can be filled with fluid and that it drains through these little lymph nodes, I have an image of everything building up and having no place to go and it makes my body like a waste heap. And if it does drain and I mean, the images are totally stupid! It's like, what I know of when they do mastectomies, that they sometimes have to take out those lymph nodes and so, I feel like it's poison. It's poison building up in my breasts with no place to go! I picture these other women with their great systems that just run the stuff through! And here's me, these strange clogs, you know?

What can women do to control their illness of risk? Some choose to deny that they might be at risk. They choose to create certainty by denying the existence of risk factors. However, this can sometimes lead to deadly consequences as the denial of risk results in the failure to take control over uncertain or unknown knowledge. As we have seen in Chapter 5, Molly was consistently told that her lump represented no danger and five years later was diagnosed with a late stage breast cancer. Molly did not have the knowledge to take control over uncertainty. She did not have the power to judge whether or not her doctors were making responsible decisions about her risk of cancer.

On the other hand, women may choose to remove the risk through removal of the physical condition where the risk resides. One young woman who I interviewed as a part of the large epidemiology project said to me:

> I don't know if I should tell this to you but I want to tell it to someone. I had a girlfriend die of breast cancer. It was terrible. Her death was worse than I imagined. The cancer went to her spine and liver. She was only 41 and had 3 little children. She had found the lump 2 years before and her doctor told her it was nothing to worry about and to come back and they would follow it. Well, she came back a year later and it was cancer. It had been cancer all along! With my lump, I was referred to Dr. Smith who I understand is a very good doctor. But he wanted to follow it. I wanted it out! Out of my body! There was no way I could live with that in me. I felt funny 'cause I had to insist on surgery. You normally don't do that. But I wanted it out! Out of there!

This woman, like clinicians, chose to remove the risk by removing the lump itself.

And in extreme situations, some women feel that they must control risk through prophylactic mastectomy. This extreme act to resolve the experiences of lived risk is very much influenced by the practitioner's attempt to remove clinical risk. In other words, inherent in lay risk,

is the clinical risk of being wrong, of failing to detect or predict a cancer. Lay risk incorporates women's lived experiences of their doctor's uncertainties. It represents a shifting of clinical responsibility for uncertainty to the woman. Rather than throwing this uncertainty back to the doctor, some women choose to resolve this conflict by allowing the doctor to remove that part of their body which makes both the doctor and the patient uncertain. But ironically, while the doctor is usually successful in removing his or her risk and regaining control over a physical condition about which he or she is now more certain, women suffer from the symptoms of a now certain illness: removal of their breasts. While doctors have treated and cured risk through physical removal of part of the body, risk for women has been transformed into a physical reality. For women, the ambiguities of health and illness are now made clear. While the woman thinks she has avoided breast cancer, she has brought about clear physical changes in her experiences of health.

The following case study illustrates this dilemma. As described in chapter 2, a large part of this research emerged from my experiences conducting structured interviews with women participating in an epidemiology project concerned with risk factors of benign breast disease and breast cancer. After each interview, I would teach women how to perform breast self-exams. One late afternoon, I interviewed Alice, a women in her late 30s who had elected to have a prophylactic mastectomy for a benign breast condition. After the interview was complete, I asked her if she wanted me to review with her breast self exams. She said that she did. I asked her to remove her blouse and she became upset, she was both angry and sad. Her story as she related

it to me is thus:

Alice had been seeing Dr Brown for 7 years because of lumpy breasts. Alice explained that she had had multiple lumps, had had 5 cysts aspirated and 2 previous biopsies. Dr Brown had told her that her mammograms had shown some calcification but not enough to indicate a cancer. However, because of her lumpy breasts and her suspicious mammogram, Dr Brown had recommended that she have subcutaneous bilateral mastectomies. Alice said that he told her that she had an 80% chance of developing nothing and a 20% chance of developing cancer. She went home and thought about her chances and decided that she didn't want "that 20% chance hanging over her head" so she did it. At this point, Alice told me that she was happy that she did it but that it was still painful. She said that she would rather live with the pain than with the 20% chance. She explained that when they did the mastectomy that her doctor told her that they had found "a tiny, tiny, the size of a pin, cell that was pre-cancerous." She said that it was good that they had done a mastectomy because the 20% had gone to 50%. At this point, Alice paused. She looked at me, looked down at her breasts and then close to tears she said "But it's hard getting use to something that is not your own." She explained that when she goes in to see her doctor, she tells him that she still has pain. "But he tells me that that I am fine. For him, the surgery was uncomplicated." She explains that since she has been able to resume her normal activities, that her doctor considers the operation a success. He tells Alice that he has done a beautiful job. But Alice explains:

> He does not know what I am feeling! I sit there and he nods his head and says that I am doing well and that I shouldn't worry. I feel like taking him and shaking him and saying "Listen to me!" I asked him if the mastectomy would affect my uterus and he said it

> would not, that the breasts were up here and the uterus and ovaries were down there and that they were two separate systems. But any woman knows that they are not. Around your period, your breasts hurt and when you're pregnant, your breasts fill up. Any woman knows that they are connected. I asked him if it would affect my periods. He said no but the month after the operation, I skipped a period. I felt miserable but he said that it wasn't connected. Even now my breasts hurt around my period but he said that they shouldn't because he removed most of the tissue.

Alice then told me that she had a friend who had a hysterectomy but who still knows when she is suppose to menstruate. Alice continued to explain:

> I feel like asking him, "Are you married? Why don't you go ask your wife!" My new breasts feel like stones on my chest, like big weights. But you know, the silicone was light, I held it. Why should it feel so heavy? When I lie down they feel like they're falling to the side but when I look at them, they are not. Why do they feel like that? He [her doctor] tells me that it is normal but it is not! I have no sensation in them at all but he says it will come back.

Finally, Alice said:

> I went ahead and did it because Dr Brown is retiring soon and he has seen me all these years and I wanted it done before that so that I wouldn't have to worry about it.

How many women like Alice, choose to remove their risk in this manner not knowing the consequences that they must live with? The medical treatment of risk through surgical procedures represents a dangerous trend in medical and lay thinking and action. In my interviews with surgeons, I concluded by asking them how they would solve the whole breast health controversy if they had the power to do so. Only one surgeon spoke of inventing non-invasive preventative measures while all the others spoke of new treatment procedures. It is alarming to contrast the following surgeon's response with Alice's story:

> I'd have a crystal ball! I'd look in the crystal ball for each patient to determine whether or not she's going to get cancer and then if I found that she's going to get cancer, I'd know exactly

what to do. That's real easy, 'cause then I could say, "Don't worry at all, you don't need any surgery for the rest of your life, 'cause you're not going to get cancer." And "Yes, you're going to get it in 4 years or 2 years and we want to save your life!" 'Cause that's what subcutaneous mastectomies are all about. If you do it on the right patient, you can prevent her from getting breast cancer. You can have an effect on their life span! That's what it's all about. Let me tell you a very interesting thing. Probably the bottom line for you and your study here. Breast cancer is the most common cancer in the female body. 26 % of all carcinomas in the female body are breast. Over 110 or 115 thousand women every year get breast cancer in the United States. About 35 thousand women every year die of breast cancer in the United States. Those are pretty awesome figures. OK? In spite of all the advancement of mammograms and in needle aspiration and in all the modern techniques of surgery and all these things we've evolved in the last 15, 20 years, the most interesting thing is that there's still an increase. We're finding more breast cancer,...perhaps our diagnostic techniques are improving. But in spite of all the improvement in technique, the mortality rate for breast cancer over the last 40 years,...these figures are from the National Cancer Institute, the mortality rate has stayed almost flat! Almost the same! So in other words, even though we're being more aware of it...and we have all kinds of medical research going on, all the various things, we still have not had a significant effect at lowering the mortality rate. So that's where the concern and perhaps the philosophy if you will, of subcutaneous mastectomy comes into play. If in fact you can take women that are at truly, I mean without any question,...you eliminate the ones that there is a question on, truly at high risk, and meet all the criteria, and if you can operate on them and lower their risk factor from 40% to 2%, then you will have an effect over the long term on the mortality rate of breast cancer. And that's where subcutaneous mastectomy has it's hope!

Finally, Fiona, (see chapter 5) was diagnosed with mammary dysplasia and it was recommended that she have a prophylactic mastectomy in order to reduce her risk of developing an invasive carcinoma. Fiona refused and she explained:

> One does not just go lopping pieces of one's body off at will. . I mean what do you cut next? One has to be wondering! One has to live as one wants to live. I think living is very nice. I'm not opposed to dying but I think you have to live the way you want to live and you can't live in pieces and parts. At least that's the way I feel about it. I'm sure I would feel that way if it were my little finger...I just think that there has to be something else besides lopping things off. Men don't lop their private parts off when they have cancer. They simply don't do that. They find another way around it...I do believe that the

> medical profession seems to look, particularly at breasts as something that is not essential to living, breathing, moving and all of these various things. And they're right. But neither are testicles. They don't go lopping those off. They can do without that whole bottom part and get along very well. But they don't do that. They don't do that because it does something psychologically and they understand it from that point of view. But they seem to find it really rather ridiculous that a woman would think that that's important. I think the same thing is even true with hysterectomies. "It's disease, lets just cut it out and then we won't have to worry about it anymore." Pardon me but it was put there for a purpose and I would like to leave it there until they really understand why we're going to have to do something. I mean, if you have brain cancer, and it's a very sad thing to have, there is no question but they don't cut your head off! They have to think of something else to do if they can.

Thus, we find the cultural creation of a new disease/illness entity. It is in this sense that the medicalization of risk might be understood as a culture bound syndrome. Being at risk or having risk factors represents a state of health that expresses a belief in cause and effect without the "proof". It expresses an illness state and a disease entity that arises from anxieties and uncertainties about our ability to control future states of health. Risk then, transforms an unpredictable future into a present state of being that can be diagnosed, treated and controlled. It transforms possible future states of ill health into a present liminal state of being that is between health and illness.

6.5 NOTES TO CHAPER 6

1. Although I have spoken of risk in terms of degrees of uncertainty, I could have spoken of risk as degrees of certainty. I have focused on risk as measures of uncertainty because it more accurately reflects the dilemmas that arise in clinical practice.
2. For a brief but well written description of the historical relationships between the rise of scientific thought, biology and medicine see Capra 1982, pp 97-117.
3. The Henle-Koch postulates state that in order for an agent to have a causal effect, that agent must:
   1. Always be found with the disease
   2. not be found with any other disease
   3. must be able to be isolated from the one who has the disease and be cultured through several generations and produce the diseases within experimental animals (Susser 1973).
4. Many early scientists recognized the limitations of the reductionist, mechanistic models, however, these models seemed to have the greatest explanatory power and utility. For example, Pasteur recognized the complexity of disease causation and the many factors in the natural world which contributed to states of health. In his study of the diseases of silkworms, Pasteur openly advocated an ecological approach. More generally, he emphasized the importance of factors in both the host and environment and recognized the important role that mental attitude played in host

resistance (Capra 1982, Dubos 1959).

5. I am basing my arguments concerning paradigm shifts on Kuhn's ideas of scientific revolutions. Kuhn argues that puzzles that resist solution are seen as anomalies rather than as falsifications of a particular paradigm and that the existence of a number of unsolved puzzles does not necessarily lead to a crisis. Scientific revolutions occur when competing paradigms are created and when more and more members of the scientific community adopt the new paradigm. Kuhn compares scientific revolutions to political revolutions in that choices between old and new political institutions or scientific paradigms represent choices between incompatible modes of community life. Thus, the shift from one paradigm to another is not one based upon logical argument, rather it is one based upon persuasion. This is why Kuhn argues that competing paradigms are incommensurable. The concept of risk and its use within epidemiology and clinical medicine points to a number of anomalies within the current biomedical paradigm. My argument is that the meaning and use of risk does not represent a shift to a new paradigm, but rather an attempt to explain emerging anomalies within the current paradigm. For a more in-depth discussion of Kuhn's ideas and the the philosophy of science see Chalmers (1978).

6. Few epidemiologists have openly advocated a change in epidemiological thinking itself nor have they seriously considered the epistemiological assumptions upon which epidemiological logic rests. Michael Marmot's article, "Facts, Opinions and Affaires Du Coeur, published in the American Journal of Epidemiology (1976)

represents a notable exception to this trend. Other exceptions to the traditional modes of thought are found in the implicit assumptions of general susceptibility theory. The advocates of this theory argue that instead of focusing upon causes of disease in those who are ill, the emphasis should shift to understanding why healthy people do not get sick. In one sense, this shift could be understood as the search for causes of health, however, it can also be understood as a shift away from causal modes of thinking. Complex causal models may be inappropriate for thinking about health in the first place. This would obviously lead to new models or ways of thinking about health, disease and illness. Berkman 1981, Berkman and Syme 1979, and Najman 1980 have presented discussions concerning this new theoretical model.

7. Lilienfeld and Lilienfeld argue that "a causal relationship would be recognized to exist whenever evidence indicates that the factors form a part of the complex of circumstances that increases the probability of the occurrence of disease and that a diminution of one or more of these factors decreases the frequency of that disease". (Lilienfeld and Lilienfeld 1980:295)

8. In their text on the fundamentals of epidemiology Lilienfeld and Lilienfeld argue that "...in diagramming the natural history of a chronic disease, we can replace "etiological factor"...with "risk factor" (1980:259-260).

9. Much has been written upon how different kinds of risk are to be defined and calculated within epidemiology. I am not concerned here with particular kinds of epidemiological risks but rather with the more general concept of risk. Although epidemiologists

have gone to great lengths to precisely define different types of risk (e.g. relative risk, attributable risk, etc.), few have considered the meaning of the concept itself. A definition of risk and probability as given in the Dictionary of Epidemiological Concepts (Last 1983) lends some interesting insights into the epidemiological belief in the concept of risk. Probability is defined as "...a basic concept that may be considered undefinable, expressing "degree of belief." Risk then, expresses the degree of belief we have concerning the probability that an event will occur" (Last 1983).

10. It is interesting to note that most epidemiologists and clinicians share basic training in medicine. Most epidemiologists in the United States, and virtually all qualified epidemiologists in Australia and England are first trained in medicine. Epidemiology is often referred to as a branch of medicine and there has been much controversy between Schools of Public Health in the United States concerning admitting non-medical scientists to epidemiology programs. Thus, most epidemiologists begin their training within the dominant medical model of thinking and practice.

11. Gorovitz and Macintyre argue that "...where there is scientific activity, there is partial ignorance--the ignorance that exists as a precondition for scientific progress...This ignorance of what is not yet known is the permanent state of all science and a source of error even when all the internal norms of science are fully respected" (1976:53). Epidemiology shares this quest for unknown knowledge.

12. The use here of the terms signs and symptoms is consistent with

the definitions given by Stedman's Medical Dictionary (1976). A sign is defined as "any abnormality indicative of disease, discoverable by the physician at his examination of the patient; a sign is an objective symptom of a disease: a symptom is a subjective sign of disease." Symptom then is defined as "any morbid phenomenon or departure from the normal in function, appearance, or sensation, experienced by the patient and indicative of disease." Good discussions concerning the history of the concepts of signs and symptoms are provided by King (1982) and Foucault (1975).

13. Some studies have shown that caffeine is associated with benign conditions however other studies have not confirmed this relationship. Caffeine has not been shown to be associated with breast cancer. The epidemiological evidence concerning oral contraceptives is just as difficult. Oral contraceptives appear to be protective against benign breast conditions and if one assumes that the risk factors for benign conditions and breast cancer are similar, then oral contraceptives might in fact, be protective against breast cancer. The point here is that the epidemiological evidence of risk is highly ambiguous.

14. Severe atypia is not a malignant condition but is thought to be strongly associated with the development of breast cancer.

15. I am using the terms illness as opposed to disease to distinguish lay from biomedical concepts of states of health. See Chapter 4, page 95 for a discussion concerning the use of these terms. Disease is the biomedical and scientific construction of ill-health while illness represents lay experiences of ill-health.

Symptoms and signs of ill-health have corresponding relationships. Symptoms are what the patient suffers, they are the subjective experiences of illness. Signs are what the doctor observes, they are the objective manifestations of disease. Much has been written concerning the different dimensions of lay and biomedical experiences and explanations of ill-health, one of the important points being that while the clinician operates within a biomedical model where he or she elicits signs leading to diagnosis, treatment and cure of disease, this approach may not heal a patient's illness. The patient's experience of ill-health often goes beyond the clinical encounter. The subjective experience of ill-health is embedded within a social and cultural context. Much has been written concerning biomedical and lay constructions and experiences of ill-health. See for example the work by Eisenberg 1977, Engel 1977, Engelhardt 1975, Good and DelVecchio Good 1981, Kleinman, Eisenberg and Good 1979, Rawlinson 1982, Treacher and Wright 1982, Young 1978.

16. I have drawn upon ideas concerning risk assessment and standard setting within occupational health and safety. In a report concerning the assessment of risk and the protection of workers' health and safety, Mathews argues the assessment of risk and standard setting is a two stage process. "The first is the stage of conceptual evaluation and measurement and clinical and epidemiological research, culminating in the establishment of quantitative links between exposure and its health effects. This is the province of the technical experts....The second stage involves evaluating the risk consequent upon any particular level

of exposure. The process of evaluation is a social process - it means looking at the likely extent of pain and suffering....The first stage of risk assessment is properly the province of technical experts; the second is properly the province of laypersons, including workers who actually run the risks." (Mathews et al., 1984:25)

CHAPTER 7: CONCLUSION

7.1 SUMMARY

In this research, I have been concerned with exploring how women and doctors experience and understand "risk" for breast cancer. I have focused specifically on the process of diagnosis and the problems that women and their doctors face when translating uncertain or ambiguous information to have clinical significance. Uncertainty will always form an inherent part of medical practice and as such, clinicians will never be free of the risk of medical fallibility. While the development of new technologies and new kinds of knowledge may decrease uncertainty in some areas, these developments will in turn produce new kinds of clinical uncertainty. Thus, clinical fallibility will continue to exist along with advances in the production of medical knowledge and technology.

I have argued that the concept of "risk" is coming to play a central role in medical models of health and disease. Risk has come to condense multiple meanings of uncertainty about health, illness and disease. For epidemiologists, the concept of risk has emerged from attempts to predict and explain the etiology and distribution of chronic disease. In this sense, it is a scientific concept; a concept that measures the possible associations of various factors to a particular disease within large populations. The language of risk then, is quantifiable and objective.

But for the clinician, risk becomes more than just a scientific concept. It takes on a subjective, unmeasurable dimension. The clinician is faced with translating epidemiologic risk to have

relevance for the diagnosis and management of a specific patient. But because a clinician can never have perfect knowledge about a specific individual, clinical risk takes on the added dimension of the risk of being wrong. Inherent in clinical risk, is the patient's risk of developing disease and the clinician's risk of making a wrong diagnosis or prognosis. Within this context, clinicians come to think about risk not so much as a theoretical concept, but rather, in the same way that they think of other disease entities. Risk becomes understood, spoken about and treated as a sign of a current or future disease. Risk factors become understood, spoken about and treated as if they were a disease entity. Thus, clinicians tend to diagnose patients "at risk" in the same way they diagnose other disease states. And once diagnosed, clinicians often treat patients for risk by removing the tissue where risk is seen to reside. Removal of risk is carried out though the prescription of drugs, biopsies and in the extreme case, though prophylactic mastectomy. However, these procedures do not remove the risk of breast cancer from the patient, but rather, they remove the clinician's personal risk of making a wrong diagnosis or prognosis.

For women, being diagnosed "at risk" is a distressing and confusing experience. Being diagnosed with risk factors often leads to greater medical surveillance. Risk takes on the added dimension of a woman's own personal risk of developing breast cancer. However, there is always a dimension of "unmeasurable uncertainty" in personal risk. A woman's risk also includes her clinician's risk of being wrong and the risks introduced with increased medical surviellance and intervention. The fact that these different dimensions of risk have

gone unrecognized has resulted in the inability of women to take back control over their health. Often, they feel that the only thing they can do is to follow their doctors advice. For women, being diagnosed at risk changes her perceptions of her health and her body. "Being at risk" is being somewhere between health and illness. This process I have referred to as the medicalization of risk. Being diagnosed with risk throws a "patient" into a liminal space between health and disease.

The medicalization of risk is a process that is becoming more common for other chronic diseases. The number one killer in the industralized world is cardiovascular disease. Cancer is the number two killer and these diseases together account for 67 per cent of all mortality (World Health 1984). The incidence and prevalence of these diseases are strongly associated with socio-environmental risk factors (Berkman, 1981, Berkman and Syme 1979, Lindheim and Syme 1983). Yet, it has been difficult for medical scientists, public health professionals and policy makers to translate epidemiologic understandings of these diseases into preventive public health approaches.

One of the dilemmas is how to apply information about what keeps <u>populations</u> healthy or what makes them sick to understanding what keeps <u>individuals</u> healthy or what makes them sick (Rose 1985). The primary approach towards the prevention of chronic disease has been directed towards individuals and the medical establishment has begun to put more emphasis on the practice of preventive medicine. Yet, while enormous levels of resources have been allocated to medicine, it has had little impact upon improving the health of general populations (Haggerty 1972,

Knowles 1977).

Major activity in the field of preventive medicine concerns routine screening of patients for diseases such as cancer, hypertension and diabetes. Screening involves the elicitation of risk factors and treatment for those patients found to be at high risk. Treatment typically involves the perscription of exercise, modifications in diet, and drug therapy. While treatment for risk may or may not be successful for individual patients, it does not change the wider socio-environmental and political contexts that produce risk and ill health.

Why then, has the emphasis upon intervention in individual risk factors gained so much attention? First, the dominant research model, that of the experimental approach is best suited to studying interactions and effects on the individual and sub-individual level. The biomedical model has historically ignored environmental and social factors. Second, the cultural values of industrialized societies place a major emphasis upon the individual. Individuals are seen to be responsible for their own well-being and approaches that emphasize individual responsibility and self-control are dominant (Wallack 1984). The dominant biomedical model and cultural values define the way in which problems of "cause" and "prevention" are understood.

Both the dominant biomedical model which focuses upon diagnoses, treatment and cure and our cultural values which emphasize the importance of individual responsibility shape the way in which doctors think about and treat "risk". In a context where doctors are expected to able to dis-cover underlying patho-physiological changes and to be certain about the meanings of these changes, the medical management of

risk becomes a particularly difficult problem. The very concept of prevention embodies contradictions as prevention implies the current absence of an undesirable physical or psychological condition. Prevention requires that the doctor extend his or her control to ensure the absence of these future disease states. Doctors must control what does not yet exist. The future of these states is always uncertain and are thus transformed into present states of ill health. Risk then, symbolically condenses what is unknowable and uncontrollable into a "real" disease category. What emerges is the cultural creation of a new disease and illness categories.

Within this framework, it is relevant to question the principles of health promotion. Ratcliffe et al. (1984) have argued that a basic conflict exists between health promotion and health protection. Health promotion is based on educating individuals about how to remove themselves from risk whereas health protection is policy-oriented and aimed at removing risk from the environment. Health promotion is clearly linked to the privatization of medicine and the rise of the medical practitioner as the policy-maker in Western medicine. The uncritical acceptance of an objective, scientific meaning of risk as conceptualized within epidemiology has resulted in greater control on the part of the medical profession over the diagnosis and treatment of risk in individuals. It has diverted attention away from translating epidemiologic knowledge into population level interventions and has allowed the focus to be directed towards the medicalization of risk within individuals.

7.2 TOWARDS AN ANTHROPOLOGY OF RISK:

The study of risk has until recently been the domaine of

psychologists, epidemiologists, economists, and decision making theorists. Only one anthropologist has directly addressed risk from an anthropological view. Douglas and Wildvasky (1982) have explored how cultural values and beliefs shape the ways in which societies select risks they deem to be important. Yet they fail to address the cultural creation of the concept itself.

The concept of risk symbolizes contradictions in deeply held values of our society. Risk forms a constellation of formal and popular beliefs about the possibility of unwanted future states. As a cultural concept, it represents our society's attempt to give reality and to take control over a complex and abstract future. But it also expresses a fundamental cultural dis-ease with being unable to understand the increasing complexity of our world. Risk emerges from and points to widening gaps in our current explanations and understandings about our relationships between past and present to future events. It brings meaning to and therefore legitimizes the liminal states between current and future states of health.

In one sense, risk might be understood as a culture bound illness in that it symbolizes a growing dis-ease in our society's core meanings and behavioral norms about sickness (Carr 1978, Kleinman 1980). First, risk speaks of a "belief" in cause without the concrete evidence. It gives reality to ambiguous causal agents such as stress, migration, diet, personality type, and exercise. Second, risk allows us to apply traditional and culturally "appropriate" approaches of prevention to new disease entities. It embodies deeply held cultural values of personal responsibility for health. And finally, risk allows us to perpetuate our cultural myths about our ability to conquer and

control disease. Risk has become a core cultural symbol expressing illusions of control over an increasingly chaotic world.

While risk, as a cultural symbol, expresses meanings about control over future states of ill-health, the very acceptance of the concept as a part of our taken-for-granted world, has in fact transformed it into an instrument of control. Here, a subtle shift in meaning has occurred in that risk, which once expressed our very lack of control over the future, has become transformed into an entity which, if controlled, can change our future. The cultural belief in risk as something which resides in individuals, as something which individuals are responsible for and as something that can be removed through medical intervention and patient compliance, has resulted in greater medicalization of our lives.

In conclusion, the anthropological study of risk can help point to a number of possible courses for thought and action that might reduce the medicalization of risk for breast cancer and other chronic conditions. First, medical scientists, clinicians and lay women need to recognize the limits of knowledge. It is important that uncertainty in health science, medical practice and lay health be accepted as legitimate, resulting from knoweldge that changes and evloves along with the advances in research.

Second, clinicians need to recognize the difficulities of translating epidemiologic risk into clinical practice. While epidemiologic studies are invaluable in terms of pointing to specific risk factors strongly associated with the onset of a particular disease, clinicians need to assess the relative importance of these risk factors in the context of each individual patient. Clinicians

must understand and accept that the translation of epidemiologic and other scientific knowledge into the management of an individual patient will always be fraught with uncertainty. It is simply not possible to predict with certainty, disease outcomes within individuals.

It is important that women learn to accept that their doctors are unable to diagnose many conditions with any certainty and must themselves accept responsibility for their own state of risk. Often, patients want their doctors to tell them what to do, and an essential part of this relationship consists of the trust the patient must develop with their doctor. The sharing of clinical uncertainty should not be seen to threaten this bond of trust. Rather, the discussion of uncertainty should be seen to stregthen this bond of trust by allowing patient and doctor to achieve a mutual understanding about the limits of knowledge. This mutual understanding legitimizes different kinds of knowing. A mutual sharing of uncertainty can result in a more equitable relationship between doctor and patient leading to greater patient participation for decision making.

And here lies an important caveat for medical anthropologists who are working within the discipline of epidemiology. Many of us have been concerned with applying our anthropological understandings to epidemiologically defined social and cultural risk factors. And while our contribution is greatly needed, we should be wary that social and cultural processes do not become reduced to factors which are translated only into risk reduction within individuals. Rather, we must ensure that our understandings are more general in application and have relevance to health protection research and health policy issues. It is here that our strength as medical anthropologists lie in that the

appliction of our knowledge needs to be directed primarily towards socio-cultural solutions rather than medical interventions.

Finally, breast cancer kills approximately 30,000 women in the United States each year. While emphasis upon mass screening, self breast examination, early detection and better treatment procedures is vital, none of these procedures prevent the disease. The problem of breast cancer will not be solved through the development of better detection and treatment techniques. The ultimate solution lies in understanding the etiology of breast cancer. Although more research directed towards understanding how the disease can be prevented is certainly needed, it is unlikely that such research will provide substantial results in the near future. The reality of the situation is that breast cancer is a serious health threat that currently cannot be prevented. Treatment is painful and not always successful. As with many chronic diseases, the understanding and treatment of breast cancer is fraught with many uncertainties. These uncertainties represent risks. And the dimensions of risk as conceptualizecd within epidemiology, medical science, clinical practice and lay health are qualitatively different. The interpretation of risk from one dimension to another requires a transformation in meaning, and until the different dimensions of risk are fully recognized and made legitimate, clinical control over uncertainty through the medicalization of risk will only increase.

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APPENDIX A: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF WOMEN INTERVIEWED

DISTRIBUTION OF WOMEN BY MARITAL STATUS AND BY BREAST CONDITION

Marital Status / Br cond	Married	Divorced	Widowed	Separated	Never Married
Benign	11 (37%)	6 (20%)	0	1	12 (40%)
Malignant	4 (27%)	2 (13%)	1	0	8 (53%)

TOTAL = 45

Question asked:

What is your present marital status?

1. married
2. divorced
3. widowed
4. separated
5. single (never married)

DISTRIBUTION OF WOMEN BY RACE/ETHNIC BACKGROUND

AND BY BREAST CONDITION

Race / Br Cond	White	Black	Latin American
Benign	28 (93%)	1	1
Malignant	13 (87%)	1	1

TOTAL = 45

Question asked:

What is your race or ethnic background?

DISTRIBUTION OF WOMEN BY AGE AND BY BREAST CONDITION

Age / Br Cond	20-29	30-39	40-49	50-59	60-69
Benign	9 (30%)	16 (50%)	5 (17%)	0	0
Malignant	1	3 (20%)	5 (33%)	4 (27%)	2

TOTAL = 45

DISTRIBUTION OF WOMEN BY COMBINED YEARLY FAMILY INCOME

AND BY BREAST CONDITION

Income / Br Cond	< 10,000	10-19,000	20-29,000	30-49,000	> 50,000
Benign	9 (30%)	5 (17%)	4 (13%)	7 (23%)	5 (17%)
Malignant	1	4 (27%)	3 (20%)	5 (33%)	2 (13%)

TOTAL = 45

Question asked:

Please tell me which of the following categories contains the best approximation of the combined yearly income (before taxes) that is received by you and other members of your family living in your household?

1. under $10,000
2. $10,000 - 19,000
3. $20,000 - 29,000
4. $30,000 - 39,000
5. over $50,000

DISTRIBUTION OF WOMEN BY LEVEL OF EDUCATION AND BY BREAST CONDITION

Education / Br Cond	Did not complete high school	Completed high school	College/ other post high	Post grad school
Benign	1	1	18 (60%)	10 (33%)
Malignant	0	1	9 (60%)	5 (33%)

Question asked:

What was the highest grade in school you completed?

00 06
01 07 College/Other Post High School
02 08 13
03 09 14
04 10 15
05 11 16
12 Postgraduate School
17
18
19
20 or more

FREQUENCY OF BREAST SELF EXAM PRACTICED BY WOMEN OVER THE LAST 5 YEARS BY BREAST CONDITION

Frequency of BSE / Br Cond	Never	> than once a month	Once a month	Once every 2-6 months	< than once every 6 months
Benign	5 (17%)	5 (17%)	9 (30%)	10 (33%)	1
Malignant	4 (27%)	2 (13%)	3 (20%)	5 (33%)	1

TOTAL = 45

Question asked:

In the last 5 year, have you practiced breast self-eximantion?

1. no
2. yes

How often do you examine your breasts?

1. more than once a month
2. about once every month
3. about once every 2-6 months
4. less than once every 6 months

FREQUENCY OF BREAST SELF EXAM PRACTICED BY WOMEN OVER THE LAST 5 YEARS BY AGE

Frequency of BSE / Age	Never	> than once a month	Once a month	Once every 2-6 months	< than once every 6 months
20-29	3	0	3	4	0
30-39	2	3	8	5	1
40-49	2	2	1	4	1
50-59	0	2	0	2	0
60-69	2	0	0	0	0

TOTAL = 45

Question asked:

In the last 5 years, have you practiced breast self-examination?

1. no
2. yes

How often do you examine your breasts?

1. more than once a month
2. about once every month
3. about once every 2-6 months
4. less than once every 6 months

DISTRIBUTION OF WOMEN BY METHOD OF DISCOVERY

AND BY BREAST CONDITION

Method of discovery / Br cond	Self exam	Physical exam by medical practitioner	Mammogram
Benign	18 (60%)	12 (40%)	0
Malignant	7 (47%)	4 (27.5%)	4 (27.5%)

TOTAL = 45

Question asked:

How did you <u>first</u> become aware of your current breast problem?

1. self-exam
2. physician/nurse physical exam
3. mammogram

INTERVIEW THEMES FOR WOMEN

1. How did you first become aware of your breast condition?

    a. Describe how you first found it
    b. What did you think it was?
    c. Who did you talk about it with?
    d. What had you heard/read about breast conditions?
    e. What are/were your worries, fears or concerns?
    f. What did you do about your breast condition?

2. Describe your experience with your doctor.

    a. Why did you seek medical treatment?
    b. What did your doctor do?
    c. Did you understand what was being done? How did you feel about it?
    d. What did your doctor tell you? Did you understand?
    e. Did you have questions to ask your doctor? What were they?
    f. Did he/she answer your questions? Did you understand?
    g. Were you satisfied with your treatment? Why or why not?

3. Questions to help elicit explanatory models:

    a. What do you feel is the underlying cause of your breast condition?
    B. Why do you think it started when it did?
    c. Can you tell me what image you have in your mind about how this condition works? What do you think your condition does to you? What does it look like? How does it work?
    d. What kinds of treatment (both medical and folk) do you think would be helpful?

4. What do you think about breast self exams (BSE)?

    a. Do you know how to do one? Describe how.
    b. What kind of things are you looking for? What would a change feel like?
    c. Have you been taught how to do a BSE? By whom; describe how you were taught.
    d. Do you practice a BSE?
    e. Do you think that it is a helpful thing to do?

5. Have you ever worried about getting breast cancer? Why?

    a. What are some of the most important causes of this illness?
    b. What can you do to keep from getting this illness?
    c. What can you do to take care of breast cancer once you have it?
    d. What kinds of things have you read/heard about breast cancer?
    e. Probe for their understanding of the concept of <u>risk</u>, <u>chance</u>.
    f. If you found out you had breast cancer, what would you do?
    g. What would you most fear?

INTERVIEW THEMES FOR MEDICAL PRACTITIONERS

1. Please describe your practice for me.

2. What are the most common kinds of conditions you see?

3. Which are the most difficult kinds of cases or problems that you deal with?

4. How do you view benign breast conditions?

5. What do women want from you? What kinds of questions do they ask?

6. Probe for the practitioner's concept of risk.

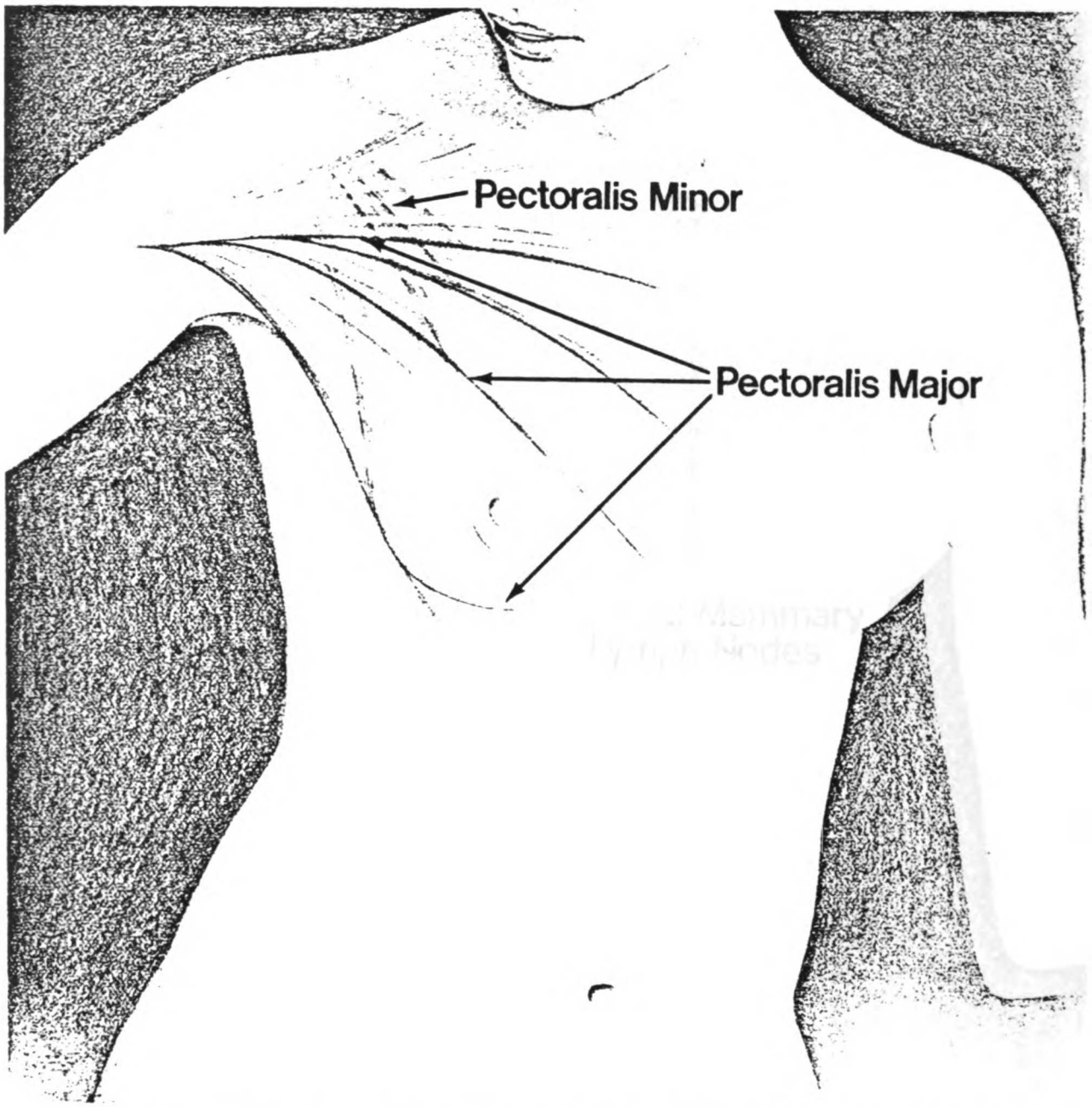
7. How useful are epidemiological studies to your practice of medicine?

8. Which areas in your practice of medicine are you most uncertain about?

9. Probe for opinions on the legal aspects of risk, clinical practice and malpractice.

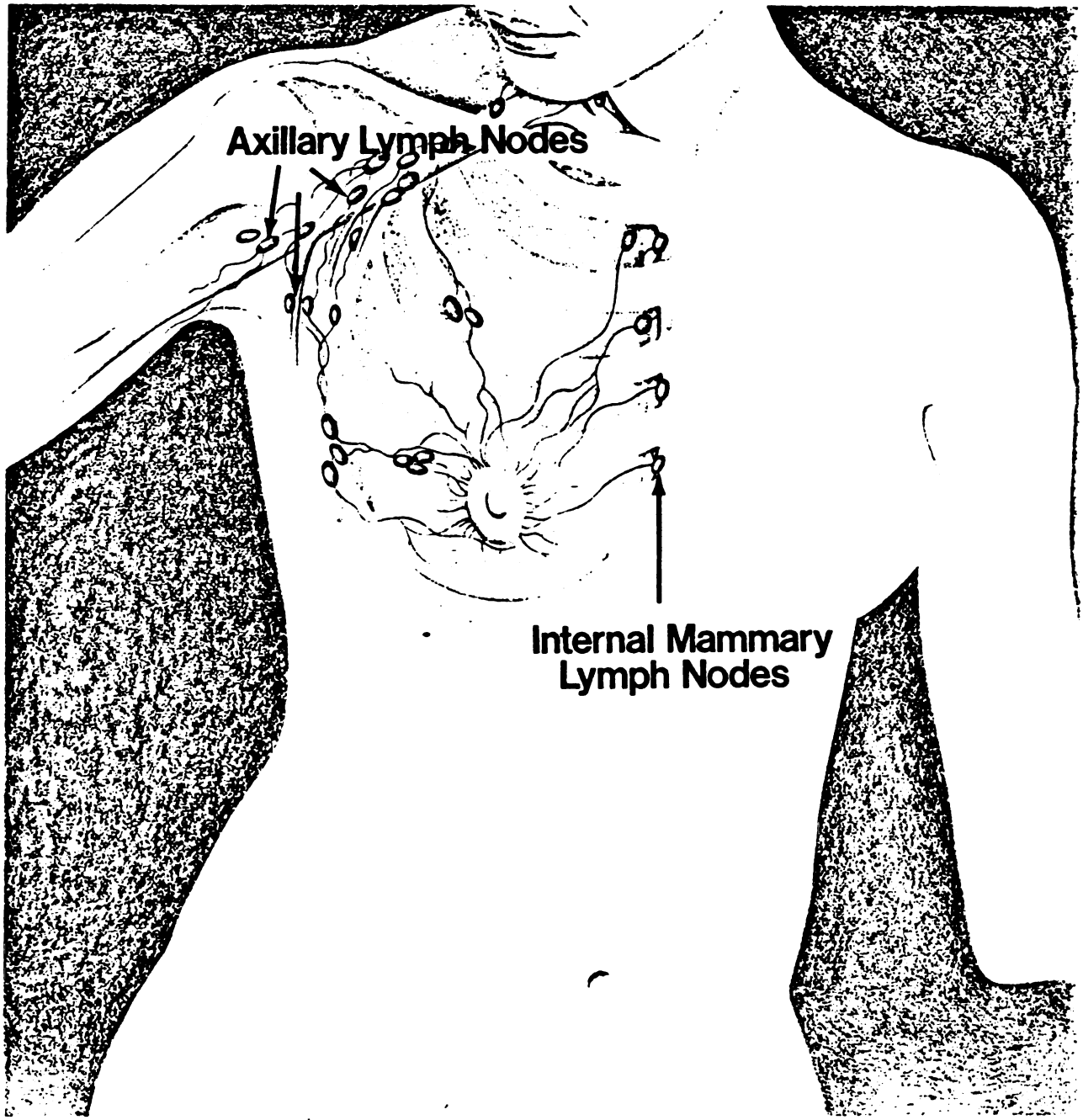
10. What do you think about fine needle biopsies?

APPENDIX C.: ANATOMY OF THE BREAST

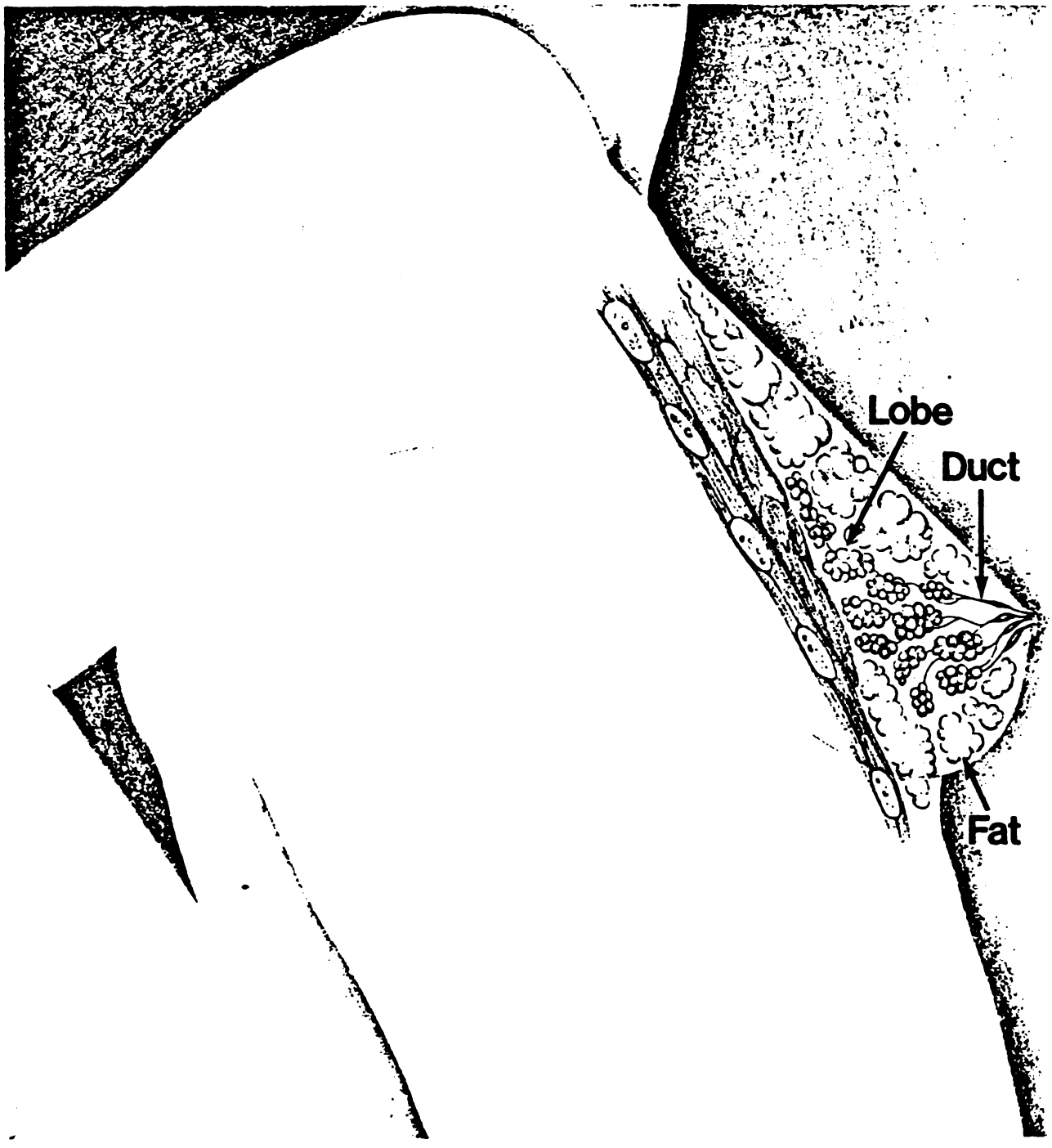


Two muscles, the pectoralis major and the pectoralis minor, lie underneath the breast tissue, cover the ribs, and aid arm movement. The Cooper's ligaments, which hold the breasts in position, are attached to the breast tissue and skin.

From: The Breast Cancer Digest. National Institute of Health 1980



The lymphatic system removes wastes excreted from all body tissues and carries the fluid of the immune system throughout the body. Each breast contains a network of lymphatic vessels that drains either into the lymph nodes of the armpit or into the internal mammary lymph nodes.



Approximately 20 lobes are arranged within each breast; the lobes are subdivided into lobules and end in milk-producing bulbs called acini. A complex network of ducts connects the lobes, lobules, and acini to the nipple.

Appendix D—Classification System of Breast Carcinoma

The following classification system, prepared by the American Joint Committee for Cancer Staging and End Results Reporting, describes the tumor, the condition of the lymph nodes, and the presence of metastasis individually and then combines that information to classify breast cancer into four stages. Under the AJC system, tumors (T) and nodes (N) are described both pre- and postsurgically, because after pathological study their condition may change.[221]

Clinical Classification of Primary Tumor (Presurgery)

TX Tumor cannot be assessed

TO No evidence of primary tumor

TIS Paget's disease of the nipple with no demonstrable tumor. (Paget's disease with a demonstrable tumor is classified according to size of the tumor.)

T1* Tumor 2 cm or less in greatest dimension

T1a: No fixation to underlying pectoral fascia or muscle

T1b: Fixation to underlying pectoral fascia and/or muscle

T2* Tumor more than 2 cm but not more than 5 cm in its greatest dimension

T2a: No fixation to underlying pectoral fascia and/or muscle

T2b: Fixation to underlying pectoral fascia and/or muscle

*Dimpling of the skin, nipple retraction, or any other skin changes except those in T4b may occur in T1, T2, or T3 without the classification.

T3* Tumor more than 5 cm in its greatest dimension

T3a: No fixation to underlying pectoral fascia and/or muscle

T3b: Fixation to underlying pectoral fascia and/or muscle

T4 Tumor of any size with direct extension to chest wall or skin. (Chest wall includes ribs, intercostal muscles, and serratus anterior muscle, but not pectoral muscle.)

T4a: Fixation to chest wall

T4b: Edema, including peau d'orange (orange peel skin), ulceration of the skin of the breast, or satellite skin nodules confined to the same breast

T4c: Both of the above

T4d: Inflammatory carcinoma

Pathologic Classification of Primary Tumor (Postsurgery)

TIS Preinvasive carcinoma (carcinoma in situ, noninfiltrating intraductal carcinoma, or Paget's disease of nipple.)

Postsurgical TX, TO, T1a and b, T2a and b, T3a and b, T4a, b, c, and d are the same as clinical classification (presurgery).

Clinical Classification of Lymph Nodes (Presurgery)

The following information is used to describe the condition of the regional lymph nodes (N):

NX Regional lymph nodes cannot be assessed clinically

NO No palpable homolateral axillary nodes

N1 Movable homolateral axillary nodes

N1a: Nodes not considered to contain growth

N1b: Nodes considered to contain growth

N2 Homolateral axillary nodes considered to contain growth and fixed to one another or to other structures

N3 Homolateral supraclavicular or infraclavicular nodes considered to contain growth or edema of the arm

Pathologic Classification of Lymph Nodes (Postsurgery)

NX Regional lymph nodes cannot be assessed clinically

NO No metastatic homolateral axillary nodes

N1 Movable homolateral axillary metastatic nodes not fixed to one another or other structures

N1b Lymph nodes with only histologic metastatic growth

N1a Gross metastatic carcinoma in lymph nodes

N1bi: Micrometastasis smaller than 0.2 cm
N1bii: Metastasis (larger than 0.2 cm) to 1 to 3 lymph nodes
N1biii: Metastasis to 4 or more lymph nodes
N1biv: Extension of metastasis beyond node capsule
N1bv: Any positive node greater than 2 cm in diameter

N2 Homolateral axillary nodes containing metastatic tumor and fixed to one another or to other structures

N3 Same as for clinical classification

Classification of Metastasis

Metastasis (M) is classified:

MX Metastasis not assessed

MO No (known) distant metastasis

M1 Distant metastasis present, specify site

When all the information about the tumor, nodes, and metastasis has been assessed and combined, that information will provide the physician with the stage of disease. Disease stages are described as:

Stage I

A tumor less than 5 cm with minor skin involvement, either affixed or not affixed to the chest wall, muscle, or fascia; nodes not considered to contain growth; no evidence of metastasis

Classified:	T1a	No, N1a	MO
	T1b	No, N1a	MO

Stage II

A tumor less than 5 cm with possible muscle or chest wall fixation; nodes are movable, but may or may not contain growth; no evidence of metastasis

Classified:	TO	N1b	MO
	T1a	N1b	MO
	T2a, T2b	NO, N1a, N1b	MO

Stage III

A tumor larger than 5 cm with or without fixation or extension to fascia and chest wall; any amount of nodal involvement; no evidence of metastasis

Classified:	Any T3	N1 or N2	MO

Stage IV

A tumor of any size with extension to chest wall and skin; any amount of nodal involvement; evidence of metastasis

Classified:	T4	Any N	Any M
	Any T	N3	Any M
	Any T	Any N	M1

From: The Breast Cancer Digest. National Institute of Health 1980.