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Illness and the Treatment Response: The Patient's View

Nina Patricia van Es
Portland State University

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COMMITTEE APPROVALS:

Joseph F. Jones, Chair

Kathryn A. Farr

Robert W. Shotola

Leslie McBride, Representative of the
Office of Graduate Studies

DEPARTMENT APPROVAL:

Robert W. Shotola, Department Chair

* *

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ABSTRACT

An abstract of the thesis of Nina Patricia van Es for the Master of
Science in Sociology presented May 6, 1994.

Title: Illness and the Treatment Response: The Patient's View.

In American society, where the biomedical profession is
institutionalized and its therapies dominate health care, a decision
to deviate from prevailing norms can be considered remarkable. Yet
research done by Eisenberg et al. (1993) found that unconventional or
alternative medicine had an "enormous presence" in U.S. health care
and that one in three persons had utilized an unconventional therapy
in 1990. The objective of this thesis was to explore this phenomenon.

Individuals who had used alternative and biomedical intervention
to treat a disorder were recruited through practitioners of
alternative therapies. Through semi-structured interviews, case
histories focusing on the illness trajectory and treatment choices
were obtained. These were analyzed following a method outlined by
Glaser and Strauss (1967) for generating grounded theory. The
specific purpose of this study was to examine the case histories for a
basic social process and to identify key variables which influenced
the utilization of both a biomedical and alternative intervention.

It was the position of this thesis that treatment responses
involved more than the decision to accept or decline a specific

therapy. Rather, choices were made by social actors embedded within unique social worlds which were differentiated by social variables (e.g., culture, ethnicity, social class) particular to the individual (see, among others, Brown 1989, Fitzpatrick 1989, Freund and McGuire 1991, Gerhardt 1989, Kleinman 1988, Mumford 1983). Treatment decisions were made within a framework of internalized patterns of interpretation and meaning, dynamically influenced by ongoing interactional and relational patterns; an individual's treatment response could be conceptualized as an emergent, multi-phased process (Pescosolido 1992).

Analysis of respondents' case histories supported the notion of a dynamic response process. Individuals described an evolving illness trajectory directed at achieving a desired state of wellness. Disparities between treatment outcomes and the desired goal prompted an evaluation and choice-making process. All respondents had developed a health care conceptualization in which biomedical and alternative therapies were either categorized as effective for specific conditions or occupied a particular place on a health care continuum, thereby perceiving a scope of treatment options beyond those available within biomedicine.

ILLNESS AND THE TREATMENT RESPONSE: THE PATIENT'S VIEW

by

NINA PATRICIA VAN ES

A thesis submitted in partial fulfillment of the
requirements for the degree of

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CHAPTER I

INTRODUCTION

The biomedical profession in the United States holds a position of exclusivity and dominance in health care that is unique in all the world (Payer 1988). A review of the establishment of biomedicine as a profession can assist in understanding how this profession came to wield such influence on social structures and institutions, in addition to individual's comprehension of disease and illness.

In The Health of Regionville, Earl Koos (1954, p. 54) describes the biomedical physician as having a professional "halo," earned or unearned, indicating that by possessing an M.D. the physician "automatically becomes a venerated person in the minds of many people." If the physician in the United States does indeed possess a halo, it may be due in part to the medical profession's success in developing and maintaining professional exclusivity through legislation regulating the licensure of those allowed to practice in the medical field, the enforcement of educational standards and by fighting a long battle with "quackery."

In the nineteenth century, practitioners of healing arts were numerous and functioned from diverse philosophical healing paradigms. Sharing the field with the biomedical physician were homeopathic and naturopathic physicians, barbers (who performed minor surgeries), midwives, bone setters, herbalists, and folk and religious healers

(Freund and McGuire 1991). Compared to naturopathy, in existence since the eighteenth century and homeopathy, developed in the early nineteenth century, the total body of biomedical knowledge was meager and diagnostic procedures were relatively undeveloped. The actual percentage of biomedical doctors practicing was small relative to the total number of persons practicing healing arts. Therapies utilized by the biomedical physician included bloodletting, blistering, purging, and vomiting. Other interventions utilized by biomedical doctors included treating disorders and illness ranging from depression and chest colds to venereal disease with patent drugs (a misnomer since most of these medicines were unpatented in order to keep the ingredients secret) such as opium, morphine and cocaine and poisons (e.g., arsenic). Although these nostrums were utilized without full knowledge of side effects or therapeutic properties, they did produce "forgetfulness of every ill" (Inciardi 1992, p. 2) and resulted in a lucrative patent medicine industry which contested medical physicians' efforts to gain popularity and control over the dispensation of "curatives." The public, understandably, was attracted to less dangerous forms of medicine (Freund and McGuire 1991, p. 220).

Few physicians actually graduated from medical schools. Often a person "simply read a few books, purchased a bagful of instruments, and hung out a shingle" (Coe 1978, p. 204). Complaints most frequently voiced by biomedical physicians during the late nineteen hundreds were about the "surplus of doctors, low income and low social

status of the profession" (Brown 1979, p. 67). Nonetheless, by the early part of the twentieth century, biomedicine was virtually the only therapy available and utilized to treat disease.

What transpired between the late nineteen hundreds and the early twentieth century was a carefully constructed reform and propaganda campaign conducted by an aggressive core of reform leaders within the biomedical profession aimed at "scientizing medicine," reducing the overcrowding in the profession, gaining control over medical education and courting public confidence (Brown 1979). Discussing the reform leaders' primary alliance seeking strategy, Brown (p. 70) writes:

> Leaders of the profession did not see their struggle as a grass roots campaign. . . . Active support would have to come from the already higher social classes. . . . Furthermore, political power increasingly rested in a new class in society--those capitalists who controlled great manufacturing and marketing enterprises. . . . It became clear to increasing number of physicians that the complete professionalization of medicine could come only when they developed an ideology and a practice that was consistent with the ideas and interests of socially and politically dominant groups in society. . . . The medical profession discovered an ideology [scientific medicine] that was compatible with the world view of, and politically and economically useful to, the capitalist class and the emerging managerial and professional stratum.

The American Medical Association (AMA) was established in 1847. Physicians within the AMA subscribed to a medical belief system that was characterized by invasive "heroic" therapies, the use of pharmaceuticals (drugs and poisons), and referred to themselves as "regular" or orthodox physicians (Freund and McGuire 1991, p. 220). The focus of the AMA was to create standardization and cohesion by establishing requirements for medical degrees and developing a

professional code of ethics. Discussing the AMA's efforts to raise

professional standards and develop a formalized collegial organization

which generated policies concerning medical practice and medical

education, Coe (1978, p. 205) writes the following:

> To protect their newly earned status, physicians gradually
> gained control over their own colleagues and established
> standards of practice designed to protect themselves from
> incompetent claimants to the field and, at the same time,
> prevent exploitation of lay people from unscrupulous
> practitioners.

At an American Medical Association convention in 1901, the

committee chartered with reorganization boldly announced their intent

"to foster scientific medicine and to make the medical profession a

power in the social and political life of the republic" (Brown, p.

138). Although the focus was to create cohesion and standardization,

the intent of the AMA was to exclude the "irregular" doctors from

their ranks and to eliminate incompetent claimants from the field. At

the time, the primary "irregular" competitors were homeopathic

physicians and the AMA's efforts were aimed at reducing the influence

of these practitioners (Freund and McGuire, p. 220). However,

campaigns to control homeopathic physicians' influence affected all

"irregular" practitioners. Curative bodies of knowledge (e.g.,

naturopathy, homeopathy, chiropractics and osteopathy), some

established for thousands of years (e.g., Chinese medicine--

acupuncture and herbology), were considered "irregular" by the AMA and

essentially marginalized along with "quacks" pedaling snake oil

medicine. The all-encompassing "quackery" designation process

employed by the AMA is described by Freund and McGuire (p. 221) in the

following passage:

> The AMA has, from its outset, been especially interested
> in exposing and prosecuting what it calls quackery, which
> is practically defined as all forms of medicating and
> healing outside the profession's control.

Legislative and political efforts were focused on licensing laws

which specified the quality of the education required to practice

medicine. In this way, the profession sought to control the

production and application of medical knowledge and skill. A very

aggressive reform movement, originating within the AMA and acting

under the standard of scientific medicine, spearheaded efforts to

control medical education. The most effective tool in the reform

campaign was the AMA's Council of Medical Education (CME) (Brown

1979). In 1905, to facilitate the cooperation of state licensing

boards, the SME invited licensing board members to a joint conference

at which standards for education and licensing were established,

beginning a merging of state and medical interests. Furthermore, at

the urging of the CME, local and state medical societies appointed

their own members to state licensing boards, eventually dominating

these organizations. Increasingly, licensing exams were geared toward

scientific curricula and only graduates from schools which provided

clinical experience and training in scientific medicine were allowed

to sit for licensing exams; such experience and training were also

crucial for passing the exams. In addition, to further differentiate

schools emphasizing scientific medicine from those which did not, the

Council of Medical Education, in 1905, inspected and rated all medical

schools. This effort, aided by the 1910 publication of the Flexner

Report, a highly critical study of the status of medical schools

commissioned by the Carnegie Foundation and supported by the

Rockefeller Institute, succeeded in rapidly reducing the number of

medical schools. By 1915, 92 of the 160 schools in existence in 1906

had closed their doors (Brown 1979, p. 154). The CME had gained

control over medical education and, ultimately, was highly successful

in reducing the "overcrowding" within their own ranks, in addition to

essentially eliminating competition from practitioners of other

healing therapies.

Not only did the strategy to control education and licensing

prove to be effective on a macro-level, it may also have precipitated

a typified treatment response on the individual level. By

establishing the biomedical physician as the principal health care

provider, the profession severely constrained the public's ability to

choose among healing therapies. Individuals were fundamentally

compelled to use biomedical physicians due to availability. This may

have facilitated a social process outlined by Berger and Luckmann

(1966) which begins with habituated actions and ends with typified

behavior becoming institutionalized. This process will be described

in detail in a later chapter. However, the following brief example

may help to illustrate the process. In the past, a mother may have

brought her sick child to either a homeopathic or a biomedical

physician. Due to licensing and education regulation, homeopathic

physicians were no longer readily available, therefore, the mother

brings the child to the medical physician. Each time the child is sick (sore throat, ear ache, chest cold), the mother brings the child to the medical doctor. The action has become habituated. Where the choice may have been conscious in the beginning (There are no homeopaths around anymore. I'll go to the medical doctor), in time it becomes unconscious (Sarah is sick. I'll take her to Dr. ___). "Sarah" is not aware that her mother initially made a conscious choice that involved weighing options. She learned: "If sick go to the biomedical doctor." For her, the action is typified. Berger and Luckmann (1966, p. 54) assert, "Typification is an institution," that is typified action has become a standardized pattern of behavior, an established order.

Of all the strategies employed by the AMA and the medical profession to gain exclusivity and public confidence, the single most influential in the establishment of the medical profession's dominance in the twentieth century was the profession's alignment with science and the "scientization" of the diagnostic procedures and therapies (Starr 1982). "Medical science rescued the medical profession, in particular the practitioners, from the widespread lack of confidence in their effectiveness" (Brown 1979, p. 77). Increase in credibility secured higher professional status and esteem, but perhaps more importantly, it furnished marketability. Addressing the benefit scientific medicine brought to the medical profession, Brown (p. 73) writes:

> Scientific medicine was utilized by professional leaders
> beyond merely increasing the technical effectiveness of

their practice. It became as well the *ideology of professionalization*, used to gain support from the dominant groups associated with industrial capitalism, to cement the dominance of health care by the medical profession, and to raise incomes and status of physicians as a group. (Emphasis in the original text.)

Technological advances and the aura of mystery surrounding scientific expertise helped wrap the physician in therapeutic effectiveness. The biomedical profession claimed that medicine was not a dogma or therapeutic art, but verifiable scientific theory and practice--a claim still common today, but criticized and discredited by practicing physicians within the profession (see among others, Mendelsohn 1979, Preston 1986)--thus making it "more effective" and "the only truly valid medicine" (Brown 1979, p. 78). On the basis of this claim, the medical profession asserted its right to a monopoly of practice. At the same time, even among the most active reformers, the limitations of scientific medicine were noted, albeit as an incidental concern. Commenting on John Shaw Billings, a leading medical reformer in the late nineteenth century, Brown (p. 79) writes the following:

Many quacks had effective cures where science failed, Billings admitted. But rather than giving him pause in his rejection of any but scientific medical methods, Billings saw it as a tactical problem of persuading the American public that it is (sic) in their interest to suppress this quackery.

Aided by the momentum of practical, tangible scientific and technological developments affecting the daily lives of nearly all citizens (e.g., automobiles, telephones), the ostensible scientization of medicine supported the profession's claims as "the only truly valid medicine." Awed by scientific achievements, the public eventually

acceded to the medical profession's stated right to authority and control over all healing methods.

The preceding brief review of the biomedical profession's rise to dominance portrays the intentionality of the campaign focused on the acquisition of political and social power. The AMA's intent to become a social and political power has, by all indications, been realized. The medical profession and the AMA have grown to wield considerable economic and political power. An examination of the medical profession's history illustrates how the profession's dominance was sought and, ultimately, constructed, how its ideologically based tenets about disease and treatment were propagandized and disseminated, influencing both social structures and individual interpretations of illness. Criticizing the medical profession, Ivan Illich (1976, p. 217) asserts that it has, in fact, created a "radical monopoly" and behaves as a "professional mafia." Given the profession's history of striving to establish and maintain biomedicine's status, as well as its battle to control competition and quackery, it is understandable that as a whole the medical profession is alarmed when non-medical (also labeled alternative or unconventional, terms used interchangeable denoting healing therapies/practices not considered part of the biomedical community) practitioners of healing arts administer therapies and remedies intended to cure disease.

In spite of the medical profession's efforts to maintain exclusivity, a recent study by Eisenberg et al. (1993), found that

alternative medicine "has an enormous presence in the U.S. health care system."

Eisenberg's study found that one in three respondents (34 percent) reported using at least one alternative therapy in the past year. Alternative therapies were defined as those "not in conformity with the medical community." Usage was the highest among nonblack persons from 25 to 49 years of age who had "relatively more education and higher incomes." Of those using unconventional therapies, 83 percent also sought treatment from medical doctors. Some of these findings were in contradiction with those of Koos' (1954, pp. 100-111) earlier study which found that use of non-medical personnel was significantly associated with lack of education and utilized predominately by "the poor people."

The results of Eisenberg's study may seem to some physicians as a call to arms against practitioners of quackery. Indeed, a physician (Campion 1993, p. 282), commenting in The New England Journal of Medicine on the study, wrote:

> Has the American public forsaken medicine for herbs and crystal healing . . . some of these treatments are probably quackery . . . patently unscientific and in direct competition with conventional medicine.

Eisenberg's research, using a national telephone survey, focused on accumulating data on the prevalence, cost, and patterns of use of alternative therapies. The quantitative nature of the project did not lend itself to exploring why individuals would chose alternative therapies, and, if individuals were using both biomedical and alternative therapies, how they came to decide to do so. This project

endeavors to answer some of the questions raised by Eisenberg's study, seeking to understand the process by which people construct understandings of their health status and their medical care requirements. Specific focus of study is on individuals using both an alternative and a biomedical therapy, either complementarily or sequentially, to treat a physical condition. The scope of the research problem will be discussed in the next chapter.

CHAPTER II

THE PROBLEM

Although illness is generally associated with and precipitated

by a physical occurrence, the understanding and experience of illness

is highly influenced by social networks and ongoing interactional and

relationship patters (Fitzpatrick 1989, Kleinman 1988, Mishler 1981,

Pescosolido 1992, Williams 1984). In addition, response to illness is

shaped by cultural and social meanings, differentially affected by

social class, ethnicity, age and gender (Dutton 1986, Koos 1954, Zola

1973). Therefore, illness can be conceptualized as a sociobiophysical

phenomenon, a disturbance in the physical and social life of an

individual. Responding to the disturbance, the individual minimizes

the disruption by accommodating physically, personally and socially to

the symptoms (Zola 1973). Through accommodation the individual

normalizes life as nearly as possible to its pre-illness state. Thus,

the individual is not only concerned with alleviating the physical

disorder, but in dealing with upheaval in the social world as well.

Seeking treatment from a specific health care practitioner, be it

biomedical or alternative, can be seen as a purposive action by a

social actor, an action precipitated by a biological occurrence, the

product of an event-centered decision-making process embedded within

the individual's social context, aimed at accommodating and normalizing life.

Due to the biomedical profession's exclusivity and the social prevalence of this particular perspective and philosophy, the medical profession has influenced cultural and social definitions of health and illness. Given that the decision-making process is embedded in the individual's social context, persons living in the United States using both an alternative and a biomedical therapy are choosing to deviate from a generally accepted norm which recognizes the biomedical physician as the exclusive medical authority. Individuals, by challenging the exclusivity of biomedical authority with the inclusion of an alternative therapy, may encounter invalidation and negative sanctions from the biomedical physician involved in their care, as well as from people within their social networks. The use of a pluralistic treatment course in an environment dominated by the biomedical profession also raises questions about possible key variables which may have entered into and affected the decision-making process resulting in a shift away from the exclusive use of biomedical therapy. Moreover, the decision-making process may be further complicated by the individual's need to integrate potentially divergent therapeutic philosophies. Biomedical intervention tends to focus on physicality and pathology, functioning primarily on the assumption of mind-body dualism (Fitzpatrick 1984, Kleinman 1988, Preston 1986). In contrast, most alternative therapies subscribe to holistic principles that consider all aspects of a being: mind (the

thinking faculties that organize the physical, intellectual and perceptual life of the organism); spirit (the inner vitality or essence of the being which activates the mind and forms the outward expression of life--e.g., intensity of intellectual and emotional processes), and body (Beinfield and Korngold 1991). The social and natural world are viewed as integral variables in maintaining wellness, determining disease causality as well as important factors in the healing process.

Dissimilarity in healing paradigms may also affect perceptions about appropriate illness behavior. Kleinman (1988) notes that there are normal and anomalous ways of being ill. Expectations about how to be ill differ culturally, in different social situations (in the hospital or at home), and with individual social biographies. In addition, behavioral expectations, for both the practitioner and the patient, differ between alternative and biomedical theory. Freidson (1988, p. 510) argues that within the biomedical institution treatment is standardized and organized to minimize interference with routines, and further, to maximize convenience to staff. Furthermore, Freidson stated that in any single community illness is most likely to be managed by physicians utilizing the guidance-cooperation pattern, that is, the physician guides and the patient cooperates (p. 516). In contrast, in some alternative therapies such as Chinese medicine there can be as many treatment approaches as there are individuals (Beinfield and Korngold 1991, p. 35). Each person is viewed as having a unique social biography. Disease causality is conceptualized as

having not only biological origins, but also as being directly affected by factors present in the individual's social and natural world. Therefore, disease is the person's unique, physical expression of an imbalance between inner and outer worlds. The course of treatment is tailored to the individual and the practitioner/patient relationship is more of mutual participation in which the practitioner is a facilitator in the patient's healing process (Beinfield and Korngold, p.45).

This project seeks to understand how individuals organize potentially conflicting healing paradigms by exploring the individual's reported illness experience and the response to illness. In addition, the respondents' decision-making process will be examined for a basic social process and key variables which may have influenced the response to illness, leading to the utilization of both biomedical and alternative healing therapies. The following chapter is intended to place this exploration in a theoretical context.

CHAPTER III

THEORETICAL BACKGROUND

A comprehension of the process by which individuals internalize
social and cultural values and meanings is important in understanding
how person become social actors. In and of themselves biological
events carry no intrinsic meaning. However, teeth falling out at age
5 conveys a meaning significantly different from teeth falling out at
age 45. Nevertheless, both are similar biological events. How an
individual interprets, experiences and acts upon a physical occurrence
is the result of a cognitive process, a socialization into the values
and meanings of the individual's social group, culture and historical
time (Dingwall 1976, p. 61). Response to a biological event and
interpretation of that event as illness are, therefore, not solely the
musings or the discrete actions of an individual, but rather the acts
of an individual "self" that is a social product, defined and
developed in social interaction (Pescosolido 1992).

Berger and Luckmann and Schutz, phenomenological theorists, have
advanced explanations about various aspects of the complex social
process by which an individual becomes a social actor. These views
are crucial to the subsequent expositions and hence are surveyed here.
Berger and Luckmann analyzed the social construction of reality, more
specifically the foundation of "knowledge that guides conduct in

everyday life" (Berger and Luckmann 1966, p. 19). Albert Schutz examined consciousness and the reflective glance, presenting an explanation of the process by which experience becomes meaningful.

THE CONSTRUCTION OF REALITY

Concerned with common-sense interpretations of everyday life, Berger and Luckmann (1966, pp. 20-22) present a process by which knowledge becomes a socially established reality. The reality of everyday life is perceived by an individual as an ordered reality with prearranged patterns, in existence before the social actor arrives on the scene, seemingly independent, and appearing like an object apart from human actors. This ordered reality almost seems to be imposed on the social actor. The social world, however, is the product of human thoughts and actions. Furthermore, this world is maintained by thoughts and actions. "To understand the causes . . . for the emergence, maintenance and transmission of a social order one must undertake an analysis that eventuates in a theory of institutionalization" (Berger and Luckmann, p. 52).

The analysis of institutionalization begins with what Berger and Luckmann refer to as habituated action. Habituated action is a behavior that is repeated frequently and becomes cast in a pattern; all human activity can potentially become habituated (p. 51). Habituated and patterned action implies that this same action or behavior can be repeated under similar circumstances with the same effort and expected result. It frees the individual from redefining similar situations

anew each time they occur, providing a background in which human activity can proceed within an "undirected instinctual structure." Institutionalization arises when habituated action becomes reciprocally typified (p. 54).

For example, individual A lives alone in his part of the world. He learns that animals are out early in the morning. Therefore, to be insured of a better chance of killing food for the day, he too is out early in the morning. This behavior becomes a habit, a habituated action. Noticing his own habituated action, he says to himself, "Here I go again." In time, individual B comes to join A. B, seeing that A goes out early each morning and that it is a recurrent pattern, reflects "There he goes again." B assigns motives to the habituated action and typifies it into a role, reasoning all hunters get up early each morning or all men get up early every morning. Most likely B also has patterned behaviors. Perhaps B goes to the river at noon to collect water for the day. A notices the recurrent behavior, typifies it into a role, assigns motives and meaning (water is best collected at noon when it is warm or water carriers only go out at noon). "Thus a collection of reciprocally typified actions will emerge, habitualized for each in roles, some of which will be performed separately and some in common" (Berger and Luckmann, p. 56). A and B have constructed a background of habituated actions, a social order arranged around routinized roles relevant to their common situation. In the process of reciprocal typification, however, habituated actions performed by A or B are transformed from the personal habituated acts

of an individual to shared, objective, typical roles for a particular social group (hunters and water-carriers); reciprocal typification objectifies specific patterns of conduct and institutionalizes them (hunters get up early each morning, water-carriers collect water at noon). "Typification is an institution," assert Berger and Luckmann (p. 54). In other words, typified actions have become standardized behavioral patterns and often rule-bound established order.

Expanding the above scenario, suppose B is female, becomes mated to A, and they have children. Typifications existing in the lives of A and B will be passed on to their offspring. In conveying their institutional world to their children, the next generation, the objectivity of that world "thickens and hardens"; what was "Here he goes again" becomes "This is how it is done" (p. 57). Through transmission of the objective social world of social formations, A and B's children become socialized into institutionalized roles and behaviors; these become internalized as objective reality both by the off-spring and the transmitters, A and B (p. 57).

In brief, Berger and Luckmann (pp. 60-63) suggest that social reality is constructed through a three-stage dialectic process: (1) externalization, the expression of one's basic nature in activity; (2) objectivation, the transformation of human activity into a form that divorces the actor from himself; and (3) internalization, the process by which the objective world becomes embedded into individual consciousness. Further, the second stage of this dialectic process, objectivation, has dual aspects: habituation--the development of

strategies for facing recurring situations and institutionalization--
reciprocal typification generalizing actors' habituated actions. This
three-stage dialectic process is not a temporal sequence, but rather a
simultaneous occurrence (p. 129). Each stage cannot be analyzed
without the other two. The simultaneous nature of the process is true
for both an individual or a society; a social phenomenon is
simultaneously externalized and internalized as an objective reality.
The individual's experience of reality is the result of learned
patterns of actions and interpretation, thereby linking the subjective
experience to social structure (p. 130).

THE CONSTRUCTION OF MEANING

Objective reality, argue Berger and Luckmann (p. 131), is
mediated by significant others during primary socialization, that is,
an individual's "induction" into the objective reality of a society
(or a sector of it) is filtered by perspectives, "idiosyncratic
colorations," and biographical roots of those charged with primary
socialization. This raises the question: How do individuals
determine what is meaningful and significant?

Alfred Schutz (1967, p. 51) asserts that at the root of all
meaningful experience is the reflective glance. The stream of
experience is conceptualized by Schutz (p. 45) as a flow of duration--
a stream of conscious states, "a constant transition from a now-thus
to a new now-thus." Each now-thus runs into the next now-thus, is
shoved further back into the memory by each new moment, until finally,

after undergoing a process of "retentional modification" (diminution), this comet tail of memory-retention fades into imperceptibility. Experience becomes differentiated from this stream of duration through a directed glance of attention on a particular moment or portion of the stream. With the act of reflection, the experience is recollected, reconstructed and reproduced; the experience becomes discrete and is comprehended, thereby introducing meaning (p. 49-51). Schutz stressed that the act of reflection can only occur as a backward glance at already lived experiences. Reflection, he asserts (p. 52) is not possible while an individual is engaged and taking up a position within the flow of experience.

> Only from the point of view of the retrospective glance do (sic) there exist discrete experiences. Only the already experienced is meaningful, not that which is being experienced. For meaning is merely an operation of intentionality, which, however, only becomes visible to the reflective glance.

Schutz (p. 69) differentiated between life, which pertains to duration, and thought, which is the ego's regard on objects of the spatiotemporal world. Relating this conceptualization to the development of meaning, experience (life-duration) is not meaningful of itself, but becomes meaningful as a result of the "Ego's regard," the reflective glance, the attitude of the ego toward a portion of the flow of duration. Continuing with this analysis and applying it to behavior, the reflective glance endows past experiences with meaning. This provides a frame of interpretation for experiences in the present, an attitudinal act of the ego. Behavior is the result of an attitudinal act of the ego (p. 54), based on the interpretational

scheme produced by comprehension and understanding of past experience

by the ego's regard--the reflective glance (p. 57).

As an individual moves through time and accumulates more

experiences, they become synthesized and ordered into schemes or

context of meaning. Schutz (p. 82) writes:

> This means merely that the total configuration of our
> experiences is a synthesis of our already-lived-through
> experiences brought about by a step-by-step construction.
> . . . They are essential, therefore, to the Ego as it
> explicates what it has already lived through from the
> point of view of a later Here and Now.

The result of the synthesis of experience into schemes of

interpretation is a meaning-ladened framework for understanding the

Here and Now.

The explanation put forth by the preceding theorists provide a

basis for understanding how meaning is constructed, becomes

institutionalized and internalized by individuals, which can produce

patterns of interpretation influencing attitude and behavior, and,

recalling the focus of this thesis, response to illness.

CHAPTER IV

THE RESPONSE TO ILLNESS

Cultural differences in the types of illness considered to be
socially legitimate and the ethnic variations in the response to
illness and pain give evidence that sociocultural factors influence
the meaning construction of illness, how it is experienced and
interpreted, how it is diagnosed, and what treatment is sought and
administered. Furthermore, cultural differences practically and
graphically illustrate what Schutz (1967) called schemes of
interpretation, in addition to presenting examples of patterned
behavior--typification and institutionalization (Berger and Luckmann
1966).

Two examples, one from Latin America and another from the
Navajo, serve to illustrate this process. A medical sociologist,
Renee C. Fox (1989, p. 7-10) writes about research conducted by Rubel
and O'Nell involving a condition found throughout Latin America called
"susto" (the word means fright). Susto, considered a folk illness, is
said to have metaphysical causality, that is, it occurs when an
essential immaterial element (spirit) of the being is separated from
the body as a result of a frightening experience. The spirit is
allegedly wandering or held captive by supernatural forces which the
patient has purportedly disturbed. Although this illness is basically

metaphysical in nature, it exhibits many signs and symptoms of biological, organic disorder. The symptoms manifested by the individual, however similar they may be to authentic susto, are not legitimated as susto sickness unless the patient, the family and/or a healer attributes them to the detachment of the spirit from the body as a result of a fright. Healing from susto comes when the patient has atoned to the spirits for disturbing them.

Another instance related by Fox (pp. 7, 11), illustrating culturally different interpretations of illness, concerns a Navajo illness referred to as "standing near a tree when it is struck by lightening." In this case, the person is the intended victim of evil-producing witchcraft which was directed at the individual while standing near a tree. The individual develops psychic and somatic symptoms which are interpreted by the medicine man as signs of the above sickness. As is the case with susto, the sickness can only be diagnosed and treated by a folk healer, given that such a disease does not exist in Western biomedicine. Conversely, there is a disease that exists in biomedicine yet is not interpreted as a significant condition by the Navajos due to meanings associated with it. The Navajos have a high prevalence of congenital dislocation of the hip. This disorder, considered a serious condition in Western biomedicine, seems to be associated with the practice of strapping the infant with outstretched legs to a cradleboard. The Navajo people, however, do not consider this a significant disorder. Instead they seem to regard it somewhat like a blessing. Illness is interpreted as evil's attempt

to do damage to a family. A congenital hip dislocation is considered non-debilitating and not catastrophic by the Navajos. This benign interpretation coupled with the belief that evil is not likely to strike a family twice (the hip disorder representing one strike by evil) translates this disorder into a kind of talisman against and a triumph over evil.

It is important to note a similar progression in the illness experience regardless of source of causality or socioculture environment, a sort of trans-cultural typified process. As is true in most cases in Western culture, the individual first recognizes symptoms, attributes them to an illness, seeks confirmation and help. A disease (either somatic or psychic) or a metaphysical condition is diagnosed by an authoritative person and legitimized as a sickness. Treatment is accepted by the individual from the practitioner considered competent in healing the disorder. Three terms appear repeatedly: disease, illness, and sickness. These terms, often used interchangeably, in fact represent significantly different concepts in medical sociology. Each of these sociological concepts is seen as identifying a particular way of viewing signs and symptoms of physical disruption in the life of an individual. Before continuing with a discussion about response to illness, it is important to differentiate between these three concepts as used in medical sociology.

DISEASE: A DEFINITION

Disease is a concept of biological science; it is associated with specific biological processes, pathological entities and physical abnormalities. Disease represents, quoting Engel, a "deviation from the norm of measurable biological (somatic) variables." Diagnosis of a disease is made by associating signs of discernible deviations in the body with established theories of disorder.

The biomedical physician, through schooling and medical training, has been socialized to view the physical complaints of the individual through the theoretical lens of his or her profession. It is the job of the physician, as an agent of the profession, to recast physical signs and complaints into terms of theories of disorder, technical diagnostics and treatment issues--a socialized reaction to a biological deviance (Coe 1978, Freidson 1988, Kleinman 1988). For example, an individual complains of chest pain. The physician translates and reduces broad subjective symptoms (arm pain, heaviness in the chest, inability to breathe) into the most likely biological cause--cardiovascular processes such as blocked arteries or heart failure; actions will be focused on confirming impressions diagnostically and improving the physical conditions. The individual suffering from chest pain, however, may be experiencing more than a cardiovascular event, as is indicated below.

ILLNESS: A SOCIOBIOPHYSICAL PHENOMENON

Illness is a subjective experience (Coe 1978, Cockerham 1992),
a disruption or disorder in the physical and social life of an
individual (Zola 1973). Encompassing all the individual thinks and
feels--understandings and meanings associated with illness, responses
to manifestations of symptoms, and accommodation and normalization
strategies--an illness experience involves both the individual and the
surrounding social networks such as family, friends, and work
relationships (Freund and McGuire 1991, p. 154).

It is significant to recognize that an individual can feel ill,
in fact, be incapacitated by illness, without the presence of
biological manifestations or pathological causality of disease. This
is true, although not necessarily, of mental illness such as
depression. Conversely, it is also possible for an individual to have
disease and not feel ill, as is true of some cancers which do not
manifest with signs or symptoms until the later stages of the disease'
progress. In all cases, however, an individual feeling ill perceives
an altered state of self (Coe 1978, p. 101) and most often, the
recognition of illness is the result of physical signs of biological
disorder or disruption.

Comparing the concepts of illness and disease and relating these
to the chest pain example introduced above, the individual, in
addition to suffering from a biological disturbance--chest pain, may
also be experiencing a sense of frustration and fear about the loss of
ability to function, concerns about finances and work, and the

family's anxiety, all social matters. In contrast to the physician whose object of attention is biological (the disease, the disease process and the controlling thereof), the individual's focus is biosocial, centering around adapting, accommodating and normalizing the effects of the illness, physically and socially.

Freidson (1988, p. 517) argues that the different perspectives of the physician and the individual results in an inherent conflict in the patient/physician relationship. The physician, as an agent of the profession, has no alternative but to handle the case according to professional norms and conventional treatment. The patient, on the other hand, "will be struggling to determine whether or not he is the exception to the conventional rules." Furthermore, the patient will often be trying to retain individuality, managing illness in a way that is more fitting personally, regardless of the demands of the medical system as a whole. The physician/patient interaction in treatment, then, can be seen as a social negotiation of separate conditions and separate understandings (Freund and McGuire 1991, Freidson 1988). Generally, the end result of this negotiation process is the legitimization of the individual's illness by the physician and the individual's acceptance of the physician's proposed course of treatment.

Should the individual's illness impair the ability to function in pre-illness roles, either temporarily or permanently, the individual assumes, sometimes involuntarily, a new social role: that of sick person.

SICKNESS: A ROLE AND A SOCIAL LABEL

Standards that determine health are social products and, as
stated earlier, differ culturally and historically (Coe 1978,
Cockerham 1992, Freund and McGuire 1991). Sickness refers to a social
state, legitimized by an authoritative person who confirms the
presence of socially sanctioned sickness criteria, which exempts an
individual from performing normal social obligations. The sick role
is a description of social expectations and, according to Parsons
(1951), entails certain responsibilities, as well as privileges.
Parsons outlines the responsibilities and privileges of the sick role
as follows:

1.   The sick person is exempt from "normal" social roles.

2.   The sick person is not responsible for his or her
     condition.

3.   The sick person should try to get well.

4.   The sick person should seek technically competent help and
     cooperate with the physician.

While Parson's conceptualization of sickness as a social state
(specifically a state of deviance) is well known and somewhat of a
standard, it is important to note that this essentially functional
typification has many critics (see among others, Freidson 1988, Glaser
and Strauss 1965, West 1984). The most frequent arguments are with
the sick role labeled as deviant, the rigidity of the roles assigned
to the physician and patient and the inherent difference in
interactional purpose (one diagnostic, technical and treatment
oriented, the other primarily social in nature focusing on

relinquishing and/or resuming a particular social role) which could
potentially lead to a clash in the perspectives of the actors. Most
critics suggest that the physician/patient roles are more negotiated,
meanings and perspectives modified, and actual situations less
functional and more interactional.

For the purpose of this thesis, however, the fine points of the
sick role need not be argued. It is sufficient to make the distinc-
tion between illness and sickness. To summarize, sickness is essen-
tially a social state (considered by some theorists to be a type of
deviance), having particular role expectations, legitimized by those
who have the authority to determine who can be admitted to the sick
role (Cockerham 1992, Coe 1978, Freund and McGuire 1991, West 1984).

PSYCHOLOGICAL MODELS OF HELP-SEEKING BEHAVIOR

The three concepts defined above, disease, illness, sickness,
are most clearly depicted as part of a process in Suchman's (1965)
psychosocial model of The Stages of the Illness Experience (Figure 1).
Suchman's model is significant in that it acknowledges and incorpo-
rates the influences of cultural, social and psychological factors
(Coe 1970, p. 115), making it a versatile model and applicable cross-
culturally. At every stage the individual weighs various responses
(e.g., action, denial, flight into health) to the manifestations of
the physical disorder with consequences within the social world.

At the first stage, symptom experience, the individual
recognizes manifestations of physical disorder, evaluates the physical

changes, and chooses to accept or reject the validity and importance
of the symptoms. At this point, if symptoms are recognized as
significant, the individual begins to experience illness. In the
second stage, assumption of the sick role, the illness becomes social
and the person begins to relinquish normal roles. However, the person

	I Symptom Experience	II Assumption of the Sick Role	III Medical Care Contact	IV Dependent-Patient Role	V Recovery and Rehabilitation
Decision	Something is wrong	Relinquish normal roles	Seek professional advise	Accept professional treatment	Relinquish sick role
Behaviors	Application of folk medicine, self-medication	Request provisional validation for sick role from members of lay referral system-- continue lay remedies	Seek authoritative legitimation for six role- -negotiate treatment procedures	Undergo treatment procedures for illness-- follow regimen	Resume normal roles
Outcomes	Denial (flight into health) ↓ Delay ↓ Acceptance	Denial ↓ ↓ ↓ Acceptance	Denial ↓ Shopping ↓ Confirmation	Rejection ↓ Secondary gain ↓ Acceptance	Refusal (chronic sick role) ↓ Malingerer ↓ Acceptance

Figure 1. Suchman's stages of illness experience (Coe, Rodney. 1970, 1978. Sociology of Medicine. New York: McGraw-Hill Inc.), p. 108.

can still negotiate the meaning and experience of illness, reject the
sick role, in spite of continued physical symptoms, and return to
stage one or move into denial and take flight into health. Medical
contact and legitimation of the sick role are made at the third stage.
Again, the individual negotiates both the treatment procedures and the
sick role. Here the divergent perspectives of physician and

individual (patient) converge and the separate meaning of illness and disease are negotiated into a treatment plan. The process continues through a fourth stage, dependent-patient role, and a fifth stage, the recovery-rehabilitation role.

At each stage the individual makes decisions about the symptoms, how to proceed in the illness experience, and has the option of denial and taking flight into health. At each stage the person is influenced in the decision-making process by others, family and friends. As irrational as it may seem to deny the existence of physical symptoms and to take flight into health, in Koos' study, respondents frequently denied obviously disturbing physical problems (chronic backaches, swollen ankles), reasoning that these were normal or not significant, again illustrating the influence of interpretation in the recognition of illness.

Another psychosocial model provides some insight into why an individual could choose to deny illness or take flight into health. The Health Belief Model (Becker 1974) examines the social factors that influence an individual to take a recommended action either to prevent illness or to restore health (Figure 2).

Designed primarily to account for ways people seek to avoid disease, this model can also be used to understand the response to illness. The pivotal variable in this model is the individual's perception of the threat of disease "X." Several categories of psychosocial factors modify the perceived threat of disease: (1) demographic, structural and sociopsychological variables, (2) the

perception of susceptibility, (3) perceived barriers to action (e.g., the given action may be defined as too painful, too inconvenient, too expensive), (4) cues to action--from the media, newspapers, magazines, and others--family members, friends, and physician or dentist (Cockerham 1992, p. 94).
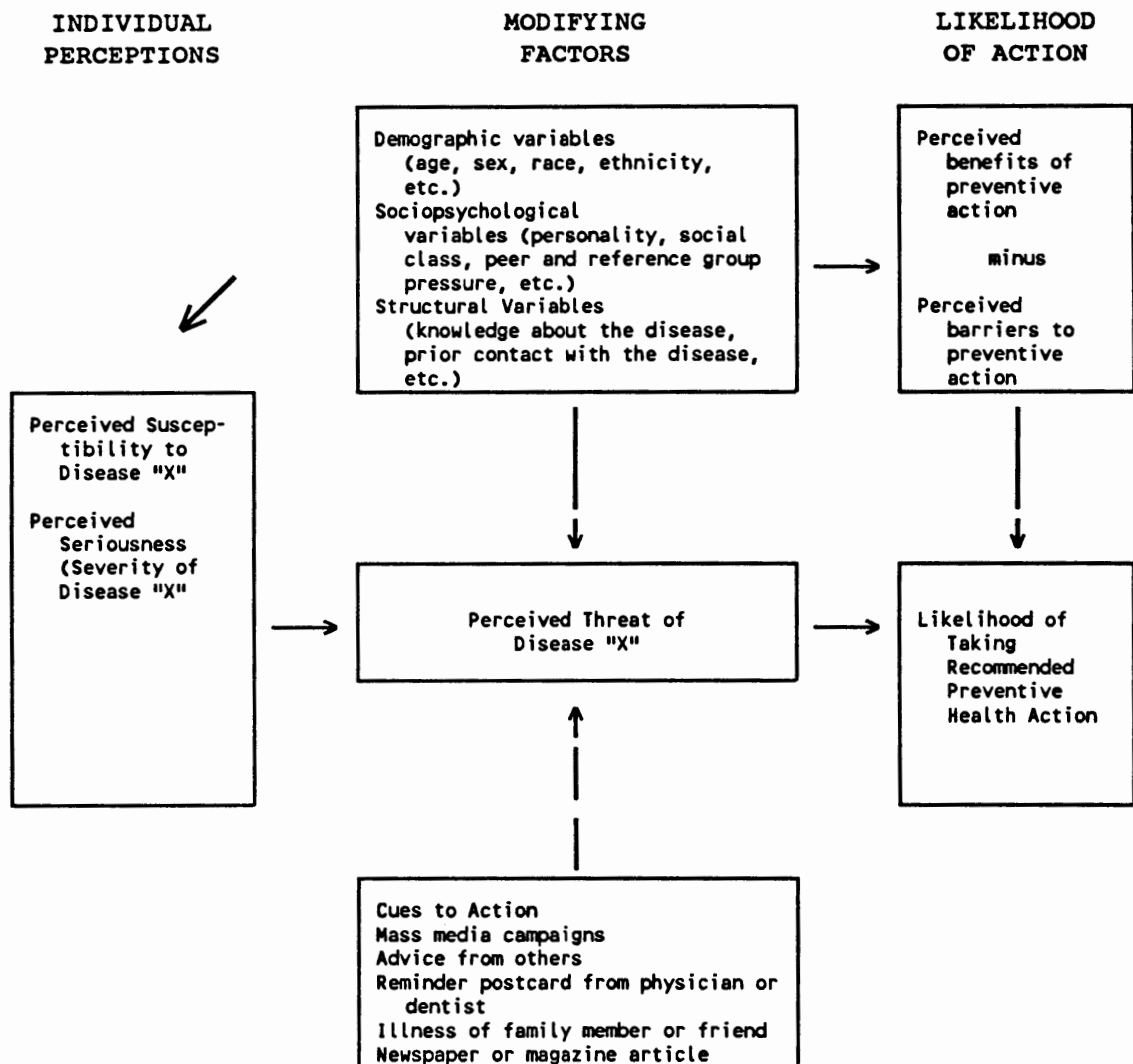

Figure 2. The health belief model (Becker, Marshall. 1974. The Health Belief Model and Personal Health Behavior. San Francisco, CA: Society for Public Health Education), p. 334.

According to the Health Belief Model, the individual, before taking the recommended action, weighs the perceived benefits against the perceived barriers. The influence of the modifying factors on the perceived threat of disease "X" explain how an individual can recognize symptoms as an illness, yet not take action because the perceived barriers to or the disadvantages of the action are too high.

Like the Health Belief Model, the Social Organization Strategy (SOS) framework developed by Bernice Pescosolido (1992), focuses on the help seeking process in the illness experience. In developing her SOS framework, which incorporates aspects of rational choice models, symbolic interactionist tradition and network theory, Pescosolido argues for a multidiscipline approach to understanding decision making. Constructed on the premise that the individual is funda-mentally social by nature, developed and defined through social inter-action, the SOS framework asserts that help-seeking decisions during an illness are made on the basis of "four basic, related building blocks" (p. 1103). First, decisions are made by social and pragmatic actors, ever-consciously rational, not "social dopes or social dupes." Second, given the social nature of the individual, choices are made embedded in patterned interaction with other individuals. Third, interactional patterns are ongoing and relationally dynamic, a social network that allows for both improvising and routinizing. Fourth, the individual and the structure in which the individual exists are intertwined and "cannot be understood apart from each other or from the social networks that shaped them" (p. 1104). The SOS framework

analysis shifts the focus away from the specific help-seeking action
to viewing help seeking as an emergent multi-phased decision-making
process, "mounted on the back of an ongoing social process." The
decision-making process, precipitated by a biological event, is
conceptualized as an individual and network mechanism intended to cope
with an uncertainty, and therefore, this process can be conceptualized
as a network phenomenon (p. 1105).

VARIATIONS IN RESPONSE TO ILLNESS AND DISEASE

Psychological models provide conceptual frameworks and
explanations for the variations in responses to illness. Stressing
that response to illness is largely a result of social interactions
which develop around the emergence of a phenomenon, Coe (1978, p. 112)
describes comprehension and evaluations made about particular symptoms
as part of a process of defining the situation, a process influenced
and affected by multiple sociocultural factors. The following studies
demonstrate the affect of social variables on the interpretation and
the response to illness, and again, provide examples of differentiated
schemes of interpretation (Schutz 1967) and patterned behavior (Berger
and Luckmann 1966).

A significant amount of sociological research (see among
others, Dutton 1986, Koos 1954, Zborowski 1969, Zola 1973) has been
directed at examining the influence of culture, ethnicity, social
class and group membership on understandings about illness,
perceptions of pain, and help-seeking behavior. Among the earliest

studies is research done by Koos (1954) which demonstrates the effect
of class membership on illness behavior. Although economic conditions
have changed and increased availability of government-sponsored health
care programs and Medicare have influenced illness behavior among
members of lower social classes (Coe 1978, p. 122), Koos' research
remains a significant demonstration of the influence of social class
membership on illness behavior.

His findings indicated that utilization of medical care,
knowledge and beliefs about illness and disease were different for
upper and lower classes. Knowledge and belief played an important
role in obtaining treatment. On a very basic level, lower class
respondents in Koos' study found sickness hard to define. One
respondent (p. 36) states:

> I wish I really knew what you mean about being sick.
> Sometimes I've felt so bad I could curl up and die, but
> had to go on because the kids had to be taken care of, and
> besides, we didn't have the money to spend on a doctor--
> how could I be sick?

Not only was sickness hard to define, health proved to be an equally
difficult concept to establish. Another respondent talked openly
about her cold and her husband's hernia, but failed to be concerned
about her badly swollen ankles, although she showed the interviewer
how badly the ankles were pitted from the edema. The respondent was
short of breath and grew very fatigued doing minor activities. All
these (ankle edema, shortness of breath, and exertional dyspnea) are
symptoms of heart disease. However, the respondent did not indicate
any concern about the condition, stating that her mother had shortness

of breath and swollen ankles. Her mother, who had since died, had not found it necessary to have a doctor treat the ankles, therefore, neither did she. The respondent recognized her cold and her husband's hernia as illnesses that required medical treatment, but the far more serious symptoms were not interpreted as illness or even considered significant enough to warrant concern.

Attitude toward illness varied between classes. Several interpretations can be offered for this difference; among the relevant variables may be educational achievement, variation in experiences, financial ability to purchase medical care and group belief (Koos 1954, p. 34). The following respondent illustrates the importance of group belief in determining the need for treatment.

> There is a lot of these things I know you're supposed to
> do something about, but there's a lot of reasons why you
> don't. . . . I'd look silly wouldn't I, going to see a
> doctor for a backache. My mother always had a backache,
> as long as I can remember, and didn't do anything about
> it. It didn't kill her either. . . . If I went to the
> doctor for that, my friends would hoot me out of town.

The study also indicated that the threshold over which one stepped to become ill was highly variable. Several factors influenced the willingness to accept and acknowledge illness. Among them were fear, cost, need for treatment, and perceived urgency for need of treatment. The question of need for treatment was tied to the value system of the individual and the family (p. 37). "If something was wrong with my husband, we'd get it fixed right away. He earns the money, we can't have him stop work" (p. 35).

There is considerable literature examining cultural differences in response to illness, both on a societal and individual level. Kleinman (1988, p. 23), writing about the cultural difference attached to the meaning of symptoms, states that in Chinese communities weakness connotes loss of vital energy *(qi)*. *Qi* is essential to the health and a central principle in Chinese medicine.

> Excessive loss of semen, through masturbation or an overly active conjugal sex life has always generated marked anxiety among Chinese because semen contains *jing*, or the essence of *qi*, which in turn is lost when semen is lost. This makes semen loss a potentially life-threatening illness.

In American culture, the power of meaning attached to illness can be illustrated when considering the response to hearing the following statements: she has coronary heart disease; she has breast cancer; and he has AIDS. Each diagnosis encases the individual in a "visible exoskeleton of powerful peculiar meanings that the patient must deal with, as must those of us around the patient" (Kleinman 1988, p. 22). Hear disease seems to implicate the tensions and stress of daily life. Cancer, a seemingly random, largely uncontrollable problem threatens a twentieth century notion that technology and science can manage and ultimately control disease. The uncertainty of cancer "forces us to confront our lack of control over our own or others' death" (Kleinman, p. 22). AIDS is shrouded with moral judgments, discrimination against homosexuals, the stigma of self-earned illness (Kleinman, p. 22). Kleinman argues that the exoskeleton of culturally marked illness, once applied to a person, radically affects the individual's identify and is not easily removed.

The influence of group affiliation and cultural identify was demonstrated in Zborowski's (1969) research which compared the response of Jewish, Italian, Irish and "Old American" patients to pain. The results of his findings showed that Italians and Jews tended to overreact to pain; they were very emotional and sensitive, tending to exaggerate (Coe 1978, Wolff and Langley 1968). "Old Americans," on the other hand, reported pain but showed little emotion, withdrawing socially.

Zola (1973) did a similar study and also found that response to illness varied among ethnic groups. After reviewing the literature and finding it replete with studies attempting to understand why person delayed getting treatment, Zola focused his research on understanding why persons would seek treatment now (p. 224), interviewing new patients in the Out-Patient Clinics of the Massachusetts General Hospital while they waited to see their physicians. The respondents were divided into cultural reference groups, Italians, Irish-Catholics and Anglo-Saxon Protestants.

The results of the study showed that Italians were more likely to define their symptoms in more generalized terms. "I have a constant headache . . . it lasts all day" (p. 230). The Irish tended to be particular, locating the locus of symptoms in the eye, the ear, the nose--a sense organ. "I can't see to thread a needle or read the paper." This not only reported the experience of physical disorder but the perception of a social disturbance was well. Italians who did have eye, ear, nose and throat problems did not necessarily localize

their chief complaints. For Italians, pain was more often the major part of their problem. The Irish did not merely "say they had no pain," but rather utilized a kind of denial statement: "No, I wouldn't call it pain, rather a discomfort" (p. 228).

In addition, Zola's research explicated patterns of personal motivation which triggered the decision to seek medical help. Five distinct nonphysiological patterns which triggered the decision to seek medical aid emerged out of his research. They were: (1) the occurrence of an inter-personal crisis; (2) the perceived interference with social or personal relations; (3) sanctioning; (4) the perceived interference with vocational or physical activity; and (5) temporalization of symptoms.

Italians were most likely to rely on the first two patterns, interpersonal crisis and perceived interference with social or personal relations. The following is an example of how these patterns triggered the decision to seek treatment. For over a year, an 18-year-old male had been experiencing recurring headaches over his left eye and pain in and around his right artificial eye. Symptoms were worse in the early evening. Since the problem began he had avoided meeting friends in the evening. While walking down the hall at school, he saw a poster for the upcoming senior prom which began at 8:00 p.m. "He noticed the starting time of 8 p.m. and went immediately to the school nurse who in turn referred him to the Massachusetts Eye and Ear Infirmary" (p. 232).

The third pattern, sanctioning, one individual taking the responsibility for seeking medical assistance for someone else, was most often used by the Irish. Anglo-Saxon Protestants were most likely to use the fourth pattern, perceived interference with work or physical functioning as the reason for seeking treatment. Zola comments that this is almost "straight out of the Protestant ethic" (p. 233), giving an example of a man who had multiple sclerosis; despite falling down and losing his balance in many places, he did nothing until he fell at work. The man then perceived that falling might affect his ability to continue to work. The fifth pattern, temporalization of symptomology, was the Anglo-Saxons' secondary pattern. Zola notes that this might be the most rational mode of decision making. This pattern involves setting an external time limit (if it isn't better in three days, if this happens one more time, I'm going to wait until Monday, etc.).

Zola's research illustrates the persistence of culturally characteristic behaviors. He suggests (p. 235) that these:

> . . . may well be general modes of handling anxiety, sort of culturally prescribed defense mechanisms and probably transmitted from generation to generation in the way that much learning takes place, almost on an unconscious level.

The preceding studies demonstrate that health and illness are not narrow and limited concepts. These concepts instead have multiple interpretations and aspects, psychological, biological and sociological. The experience of illness is a social phenomenon and is socially constructed. Zola (p. 236) argues that the issue is not only if one has disease or if one is a medical case, but also "how does one

become a case and since of the many eligible, so few are chosen, what does it mean to be a case." To this it might be added that research examining the response to illness should not be limited to investigating how an individual arrives at accepting treatment, but should also include examining what kind of treatment the individual chooses and why. Research, assuming use or non-use of biomedical interventions to be the only available choices, does not adequately reflect the actualities of the contemporary health care environment. As maintained by Pescosolido (1992, p. 1113), illness is an evolving and emerging process of coping with a condition. The current health care marketplace contains a wide array of therapy options, "lay, professional, and semiprofessional." Conceivably an individual could continue to revise treatment plans, changing courses of action, developing personalized pluralistic therapy approaches until "the situation is resolved or options are exhausted" (Pescosolido, p. 1113). This research explores the illness experience of individuals who have chosen to use alternative therapies and biomedical intervention to treat their physical conditions, thereby developing for themselves a pluralistic treatment approach. In the next chapter the methods used in this exploration are explained.

CHAPTER V

METHODOLOGY

Given its purpose and focus, the phenomenological approach was

deemed the most appropriate orientation for this research. Through

semi-structured interviews the individuals' stories of the illness

trajectory and treatment choices, essentially case histories, were

obtained. The focus of a case history is a story--an event or a

particular temporal span in the social life of the individual.

Research utilizing the case history as the central social unit of

analysis examines the story for its own sake. This differs from case

studies in which the focus is "on analytical abstraction and

construction for the purposes of description, or verification and/or

generation of theory" (Glazer and Strauss 1965, p. 183). In other

words, the story is subordinate to the abstract purpose. The case

histories in this study provided "readable imagery for sociological

theory" (Glaser and Strauss 1970, p. 185), a story that could be

explained and interpreted with theory. Arguing for the use of case

histories, Glaser and Strauss (p. 185) write:

> From the history, people can gain much understanding of
> general phenomena through its theoretical interpretation
> and explanation. This task of doing a case history is at
> one end of the continuum of abstraction. . . . At the
> other end is the generation of theory by multiple case
> studies and comparative analysis. . . . The fullest
> understandings of social phenomenon come, we believe, from
> dense case histories on one end of the continuum and from

densely generated grounded theories on the other end of
the continuum.

With applied sociological theory, the researcher can explain and
interpret a single case history, or link and integrate multiple
histories. Analysis of a case history can show a type, an exemplary
case or a basic social process.

The notion of a common process or a basic social process is not
new to sociological research. It is similar to Max Weber's concept of
"ideal type." Glaser and Strauss referred to common processes while
doing grounded theory research. Simply stated, a basic social process
is an organization of social behavior that reflects and integrates the
psychosocial (micro) and social context (macro) of the individual's
world (Bigus et al. 1982). The findings in research done by Williams
(1984) and Glaser and Strauss (1970), utilizing case histories,
presented a basic social process and demonstrated the generation of
grounded theory in a substantive area of study.

The research methodology in this project was patterned after
work done by Williams (1984) and Glaser and Strauss (1970). Williams
(p. 268) examined chronic illness--"how and why people come to see
their illness as originating in a certain way, and how people account
for the disruption disablement has wrought in their lives." Analysis
of interviews he obtained from people with rheumatoid arthritis
revealed a basic social process, specifically a narrative
reconstruction. In this process, the individuals personalized the
clinical view of their disease, translating it into a more substantive
biographical interpretation, thereby transforming the meaning of the

disease. Williams (p. 268) argued that although his findings were not representative in the statistical sense, they "symbolize, portray, and represent something important about the experience of illness." Williams' work illustrates the integration of multiple case histories which were linked together with the application of his narrative reconstruction theory.

Glaser and Strauss (1970) used a single case history to analyze the dying trajectory of a hospitalized patient. They assert that through their study of the single dying trajectory they were able to explicate basic social processes utilized by the medical staff and the patient to organize work, manage pain, and develop expectation about dying. In addition, the authors were able to generate substantive theory about pain control, awareness contexts and the dying trajectory, thereby gaining understanding of general phenomena.

This research project was based on the preceding methodological rationale and utilized a variation of the research design put forth by Williams and Glaser and Strauss.

SAMPLING PROCEDURE

Sampling was purposive. The event--illness, a very broad designation given its conceptualization as a sociobiophysical phenomenon, was limited to physical occurrences, thereby excluding conditions such as mental illness. Respondents were recruited through alternative practitioners. Because there is a wide array of practitioners administering what can be called alternative therapies ranging from aroma-

therapists and shamanic healers to homeopathic physicians and Chinese doctors, it was necessary to establish defining criteria for alternative practitioners. Alternative practitioners are defined in this study as those who have completed a course of study which qualifies them to administer therapies that belong to a body of knowledge which is free-standing, that is, has its own methods for diagnosing and treating physical disorders. In other words, the practitioner must be trained and the healing modality should not rely on another body of knowledge to determine treatment (e.g., a massage therapist cannot diagnose and often relies on the expertise of a chiropractor or a physical therapist). In addition, the practitioner must be licensed by the state of Oregon, thereby eliminating practitioners such as aromatherapists and shamanic healers. Osteopathic physicians were not considered alternative in this study. Although osteopathy was considered very similar to chiropractics by the biomedical community in the late nineteenth century, it has essentially be appropriated by biomedicine today. Describing the current practice of osteopathic medicine Miller and Keane (1978, p. 731) write:

> Many changes have been made in the practice of osteopathy,
> bringing it closely in line with conventional medical
> practices . . . recognize that . . . chemical and
> nutritional factors influence the state of health and that
> medicines and surgery are necessary . . . manipulation may
> or may not be used as an adjunct to other treatments.

Osteopathic physicians perform surgeries, diagnostic procedures, prescribe pharmaceuticals and are, in many ways, indistinguishable from biomedical physicians.

Practitioners who met these criteria, education and licensure, were homeopaths, naturopaths, and practitioners of Chinese medicine-- acupuncture and herbology. Initial contact made with practitioners in the alternative health care community was quite favorable. However only five of those who had originally expressed interest in providing referrals for this project agreed to the terms of the study which included making first contact with potential respondents, presenting a brief explanation about the research and providing the client with the researcher's name and telephone number. Most preferred providing a client's name, with the researcher making the initial contact and presenting all project information. Practitioner-initiated recruitment, which left the follow-up to the client, proved to be problematic and a less than fruitful method for obtaining respondents. Practitioners reported having more clients using multiple therapies than contacted the researcher. In all, six referrals came from alternative practitioners--one naturopath and two acupuncturists. Of those six, three did not keep interview appointments. Five other subjects were obtained through snowball referrals.

SAMPLE CHARACTERISTIC

A total of eight subjects agreed to submit to semi-structured interviews. Of the eight individuals, two were males and six were females. Except for one Eurasian, all were Caucasian. The ages ranged from 32 to 54. Educational levels attained by respondents were relatively high. All subjects had at least two years of college, one

had a doctoral degree, another was a doctoral candidate. Five of the individuals interviewed had utilized biomedicine and an alternative therapy sequentially, three simultaneously. Of the three who had used therapies simultaneously, two interrupted simultaneous use, incorporating a period(s) of exclusive usage of either (biomedical or alternative) therapy, thereby engaging in an alternating pattern of utilization (i.e., serial utilization). Chinese medicine--acupuncture and herbs--was used by six respondents, naturopathy by two.

ACQUISITION AND HANDLING OF THE DATA

As stated, eight subjects participated in the study. The purpose of the project and the role of the subject were described again when individuals referred by practitioners contacted the researcher. Those subjects who were snowball referrals were given very detailed explanations at the initial contact. In conversations with all subjects, the voluntary nature of participation was emphasized. If the subject agreed to be interviewed, a meeting time and place was arranged. These meetings occurred during the evening or on weekends, most often at the individual's home, sometimes in restaurants. At the start of each interview, the study was briefly reviewed and a consent form was signed (see Appendix A).

Interviews were semi-structured. Conversations were taped and supplemented by brief notes made during the meeting. The interview, guided by some general questions, was primarily open ended. The focus was on the individual's description of the illness trajectory and the

treatment decision-making process. Sessions lasted from between 35
minutes to 2 hours.

The first four interviews occurred in a two-week time frame.
These interviews were entirely transcribed. Depending on the length
of the conversation, transcription took between 1.5 to 3 hours.
Analysis of the data relied heavily on the work of Glaser and Strauss
and the process they put forth in generating grounded theory.
Following this method, after transcription, each interview was
analyzed using a technique referred to by Strauss and Corbin (1990) as
"open-coding" and "axial coding." A similar method was described by
Tesch (1990) as "decontextualization and recontextualization." This
process involved examining the transcript text for "significant pools
of meaning" (Tesch, p. 118) or relevant passages, then labeling the
phenomenon, in essence conceptualizing the data. (For example, the
phrase "It wasn't working" was determined to be significant and
labeled "disparity.") After the transcripts had undergone "open-
coding" or were "decontextualized," an arduous process, which took
approximately two weeks, was undertaken in which identified concepts
were grouped and categorized or "recontextualized." This reduced the
number of units of analysis, producing core categories and subcate-
gories. Two core categories emerged: acknowledgment of illness and
response to illness. Subcategories were then linked to core cate-
gories through relationships, context, action strategies and conse-
quences (Strauss and Corbin, p. 99). Subcategories, such as evalua-
tion and choice, and properties of these subcategories (e.g,

dissonance and disparity) appeared at least once, sometimes repeatedly, in each respondent's story; cyclical patterns of action strategies became evident and a basic social process surfaced. Following the Glaser and Strauss method, emerging patterns and processes were confirmed through theoretical sampling (Glaser and Strauss, pp. 45-49, Strauss and Corbin 1990, pp. 177-179), that is sampling on the basis of evolving theoretical relevance which is focused on density and saturation of the categories. Sample groups were identified according to treatment trajectory and therapy utilization: initial use of biomedicine transitioning to an alternative therapy, initial use of an alternative therapy transitioning to biomedicine, sequential use, simultaneous use, and serial use of therapies. It was determined that gender and race might be factors influencing utilization, therefore it was crucial that both genders and a non-Caucasian respondent (preferably one of Asian heritage given the predominant use of Chinese medicine among the subjects) be included. Recruitment of respondents representing the sample groups took an additional two months. Each interview was entirely transcribed and analyzed utilizing the method previously outlined. Respondents described a process like that of the initial four respondents, used similar language, verbalized comparable sequence of events and described like concerns, thereby confirming the process, the core categories and the subcategories.

The purpose of generating grounded theory pertinent to a substantive area is to generate conceptual categories and/or their properties, as well as relevant theoretical abstractions related to

the area of study (Glaser and Strauss, p. 23), in this case the ill-

ness trajectory and decision-making process of individuals utilizing

biomedical and alternative therapies. Describing the purpose and

function of generating grounded theory Glaser and Strauss (p. 30)

write:

> Discovery gives us a theory that "fits or works" in a
> substantive or formal area (though further testing,
> clarification, or reformulation is still necessary) since
> the theory has been derived from data, not deduced from
> logical assumptions.
>
> Since accurate evidence is not so crucial for
> generating theory, the kind of evidence, as well as the
> number of case, is also not so crucial. A single case can
> indicate a general conceptual category or property; a few
> more cases can confirm the indication. . . . [The
> sociologist] is . . . to develop a theory that accounts
> for much of the relevant behavior . . . generate
> categories and their properties for general and specific
> situations and problems.

Analysis of the data did reveal a basic social process and confirmed

the existence of core concepts consistent among the sample population,

therefore affording an explanation for behavior and opening a "running

theoretical discussion . . . a theory in process" (Glaser and Strauss,

p. 32). The intent of this project was to acquire an understanding of

meaning constructions and subjective realities experienced by

individuals employing both an alternative and biomedical therapy. The

findings satisfied this purpose. A process similar to one outlined by

Glaser and Strauss for generating grounded theory had been followed;

all groups in the theoretical sample were represented. Considering

these outcomes, it was deemed that there were enough data to conclude

interviewing. The results of the above process are considered next.

CHAPTER VI

FINDINGS

THE ACKNOWLEDGMENT OF PHYSICAL DISORDER

An analysis of the illness trajectory and response to illness

begins with the individual's acknowledgment of physical disorder.

This is essentially the threshold of the illness experience. Without

the recognition of physical disturbance, the illness phenomenon is not

experienced by the individual. As was discussed earlier, recognition

of illness is highly embedded in cultural and social interpretations,

making individual definitions and perceptions of disorder varied.

Further confounding the process of acknowledgment is the option of

denial or flight into health. At any point on the illness trajectory,

even at the threshold, the individual has the option of taking flight

into health or denial as depicted in Suchman's (1965) psychosocial

model of the illness experience and demonstrated in the findings of

Koos' (1954) and Zola's (1973) research. The absence of

acknowledgment, however, does not mean disease--defined in biomedical

terms as the presence of physiological pathology or abnormality--does

not exist; it means the biosocial phenomenon, illness, has not begun,

is not being experienced by the individual. Conversely, the

perception of disorder is not bound to the presence of signs and

symptoms (Goffman 1961, p. 329) of physical disturbance.

Among the respondents of this study comprehensions of disorder were diverse, affected by social variables (e.g., the beliefs and values of the individual, significant persons in the individual's social networks, economic conditions) and experiences such as prior illness, all influencing the formation of the individual's subjective interpretations. Presenting disorders ranged from subtle, progressive subacute conditions--"I just wasn't feeling myself; I wanted to sit in the corner and cry" to distinct, precipitously acute indispositions-- "My horse stepped on my hand and broke the bones in it." For those experiencing abrupt breaches in normal physical states, such as broken bones, recognition of physical disorder was rapid and relatively uncomplicated. However, some conditions, those progressing gradually or possessing potentially catastrophic ramifications, were more difficult to recognize and acknowledge. Even in the limited sample of this study, the denial response was present.

Digressing briefly, denial is a much debated psychological process. According to Lazarus (1985), denial, a defense mechanism focused on adapting to distressing external realities, is a strategy used to maintain psychological homeostasis. Conceptualizing the notion of psychological homeostasis in a model, Selye (1980, p. 142), described stress as existing on a continuum on which eustress (good stress) and distress (bad stress) occupy opposite poles. Individuals who perceive severe threats to their reality through catastrophic events such as a potentially fatal disease experience a state of hyperstress in which denial may be one of many forms of adaption.

Denial, however, is most often a tentative construction, not a static state or a stable interpretation (Lazarus, p. 162). People are constantly striving to comprehend what is happening, therefore denial is a dynamic state responsive to changes in external and internal conditions, a tentative suspension of belief and an on-going process rather than an entrenched fixed state of mind.

The following case demonstrated the denial mechanism, as well as the subjectivity of the acknowledgment process. A female respondent, educated (Ph.D. candidate) and actively involved in dispensing cancer therapies, ignored her own continual vaginal bleeding (a cardinal sign of uterine cancer) for three months, stating "I don't need someone to hit me over the head with a baseball bat do I? After three months, I just couldn't ignore it anymore." This respondent had already experienced and overcome more than one debilitating illness: polio and breast cancer; the latter resulted in a right mastectomy. Admitting that her vaginal bleeding was abnormal also entailed acknowledging that she was again ill; moreover that her cancer might be back. Her training and knowledge about cancer, objective understandings, did not make admission (highly affected by her previous experiences) of the present disorder easier. In fact, understanding the potentially unpleasant and uncomfortable consequences her particular signs of disorder were heralding produced fear and, most likely, a state of hyperstress which negatively influenced her ability to acknowledge disorder. However, as Lazarus affirmed, denial was temporary. The persistence of her symptoms

forced the reality of her condition into her awareness, compelling

acknowledgment of disorder. After recognizing the acuity of her

condition, the respondent was able to mobilize support from her social

network to help her cope with her distressing situation and assist her

in formulating a very comprehensive treatment plan.

Gradually escalating disorders were difficult for individuals to

recognize as illness primarily due to unclear personal determinants of

health and illness and the boundary that exists between these two

spheres. The most frequent factor confusing the distinction was

stress. Respondents were willing to accept physical discomfort if

they thought the malady was due to stress, reasoning that stress was a

given part of modern life, somewhat self induced and controllable,

therefore physical discomfort was not a disorder but a personal coping

problem. This dilemma was expressed in the following statement:

> I'd been under so much stress. I didn't know if I just
> wasn't coping as well as everyone else. . . . I didn't
> know if my body was trying to shut down . . . is there
> actually something wrong with me or is it just in my mind.

Even without the presence of stress, some found it troublesome to

decide where acceptable discomfort ended and abnormal pain began.

> It began as a cold. But it just got worse and worse.
> It was getting hard to breathe . . . didn't think I could
> go on.

> At first I thought I might have overworked the muscles.
> Then when it didn't go away I got worried. When I work up
> and couldn't lift my arm I thought, this is wrong!

RESPONSE TO ILLNESS: A PROJECT AND A STRATEGY TO NORMALIZE LIFE

Once physical disorder was recognized and illness acknowledged,
the individual moved into the response phase of the illness
experience.   In this phase, health status was evaluated (How ill am I?
How is this going to affect my life?) and a course of action
determined.   All those interviewed sought help from authoritative
individuals as the first step in determining a course of action.
Authoritative individuals can be anyone the individual perceives as
having knowledge or experience managing the particular ailment.
Therefore, an individual may choose to seek help from the professional
referral system—licensed and trained person such as biomedical
physicians or naturopathic practitioners—or from anyone within their
lay referral system.   A lay referral system is described by Freidson
(1970, p. 290) as a system comprised of agents thought to have
knowledge of health and health agents.   (This would include a neighbor
who has experienced a similar disorder.)   Persons within the lay
referral system have primarily a strict advice-giving function,
directing or referring the individual to a particular practitioner.
Two of the respondents in this study utilized alternative therapies as
a result of advice received from someone in their lay referral system.

Most research exploring the response to illness has examined
when or why individuals sought out treatment (see among others,
Dutton 1986, Koos 1954, Zola 1973) or how individuals responded to
physical manifestation of pain and discomfort (Zborowski 1969, Zola
1973).   The response to illness was presented as somewhat one

dimensional in that persons either sought treatment or did not. Treatment was most often assumed to be biomedical intervention. Examination of the case histories in this research revealed that a response to illness was more like an evolving strategy focused on normalizing the physical status--achieving a state of wellness or wholeness as nearly as possible to pre-illness condition--an undertaking with an envisioned goal, a project, rather than a single fixed decision to seek treatment from a particular practitioner. The action, seeking out the initial authoritative person, was one of many actions, comprising a grand strategy, the beginning of a process rather than the end. The wellness goal was envisioned in varying degrees of clarity--vague or detailed--and changed as new information became available or treatment outcomes modified expectations.

To clarify the conceptualization of response to illness as a strategy and a project, it is important to differentiate between the sociological concepts "act" and "action." A conscious act is an act of the memory containing intentions and expectations derived from interpretive schemes acquired from experience, "the referral of the unknown to the known" (Schutz 1967, p. 84). The individual constructs an act out of values and understandings learned in the everyday world. The act contains intentions and expectations which are projected into the future by the individual, creating an anticipated outcomes, a goal. Actions are components of the act, specific steps executed in order to realize a particular goal or outcome. Schutz (p. 60) writes:

> What is projected is the act, which is the goal of the
> action and which is brought into being by the action.

. . . The act is the goal of the action. . . . What is
visible to the mind is the completed act, not the ongoing
process that constitutes it.

Most actions performed by individuals in the course of a day
constitute steps in one or more overarching acts. The goals are
implied in the actions, a part of everyday stock of knowledge which is
understood by participants. For example, a mother declares, "I am
going to the store." She has announced the decision to execute an
act. Implied in that statement is the notion that she is going to the
store for something, presumably an item. The end goal is most likely
not arrival at the store, but some activity that will take place in
the store. Involved in the process of arriving at the store are
various steps--actions (e.g., procuring some means of transportation,
bringing funds to pay for purchases, knowing the directions to the
store). At various points in the process, arrival at the store and
securing the intended goods can be interrupted or totally obstructed,
preventing completion of the act or requiring modification and
redirection (e.g., the car is out of gas, there are no checks in the
checkbook, the directions to the store are wrong). The simple
statement, "I am going to the store," is in actuality a project, an
undertaking intent on achieving a certain goal. In recollection,
however, the multi-action process involved in arriving at the store
and obtaining the particular item will be unified and collapsed into a
single act, "I went to the store."

Response to illness--an act--unfolds much like the act of going
to the store. It is a project, requiring multiple actions to achieve

a certain goal. However, it differs in that the act and the actions are more deliberately arranged, sometimes step by step. The act and actions are, most often, not routinized or spontaneous activity rising out of everyday common knowledge. The choice of practitioner is purposeful, affected by various concerns (economic, naturalistic, social). The course of treatment is planned. A goal is envisioned and specific means are adopted to achieve that goal. Furthermore, unlike going to the store, the sequence of actions needed to complete the act are not always known at the onset. Subsequent actions are influenced by the outcomes of preceding action (e.g., results of tests or therapies). Furthermore, like any multi-action project, the strategy can be unpredictably interrupted or obstructed, requiring reevaluation, adoption of other means or modification of the goal.

Individuals in this study clearly described a goal-oriented process when discussing their illness experience and treatment course. Implicit in their explanations for seeking help was their wellness goal. "I wasn't my normal self," implying the goal was to again become the "normal self." "I couldn't work without becoming exhausted," suggesting the goal was to be able to work without exhaustion. "My foot hurt so bad I couldn't even bear weight on it," intimating that the goal was to be able to again walk normally on the foot. Who to contact for help and treatment was a decision filtered through overlapping frames of reference: economic consideration, social networks, understanding about the risks of the condition and consequences of the generally prescribed treatment. As one might

suspect, each individual weighed variables differently. For some economic factors, the ability to pay for medical services and insurance overage were most important. "I had to use a biomedical doctor. It was the only thing my insurance covered." For others, naturalistic concerns such as avoiding the ingestion of perceived physical pollutants--drugs and chemicals--were most important. "I don't like to use chemicals more than I have to; I just don't want them in my body." Even after the decision to seek a particular practitioner and to undergo treatment was made, respondents sometimes associated a temporal qualifier to their choices, suggesting that this action was one in an evolving series and supporting the notion of illness response as a project or a strategy. "I thought I'd try this first." "I knew I had to have the surgery. After that was over I'd see what I needed to get strong again."

Not only did the addition of temporality imply the existence of a scheme, it also implied the treatment course and outcomes would be evaluated. All those interviewed engaged in some type of evaluation during their illness experience; some evaluated more frequently than others. Evaluations involved a kind of map-consulting that is a comparison of the therapy outcomes with the anticipated goal. These evaluations consumed varying degrees of attention and lengths of time. For some, evaluations occurred much like spontaneous realizations. "It dawned on me why this wasn't going away." Others put a great deal of attention and rational decision making in their evaluations. This happened most frequently when individuals were invested in making a

particular therapy work, repeatedly trying a treatment in the hope that it would deliver the desired outcome. All the respondents, at one point or another, perceived a disparity between their current treatment outcomes and their anticipated goal. The most frequent phrase used to describe this disparity was "It wasn't working." The perception of disparity presented a critical juncture in the therapy course, a potential bifurcation in the road to wellness. Individuals were presented with an acknowledged discontinuity requiring a decision and a choice. If the individual chose to continue with the present treatment course, the anticipated goal would need to be modified and expectations changed. If this was not an acceptable option, the individual would have to explore other therapy options.

At this junction all social variables which came to bear on the original decision—what and whom to contact for help—again came into play. Individuals proceeded with choosing much as they did with evaluating. Like evaluation, choice involved projection. Based on past experiences, cognitive comprehensions gathered from study, and information garnered from social networks, individuals projected likely treatment plans and outcomes into the future, again "the referral of the unknown to the known" (Schutz 1967, p. 84). From these hypothetical representations, individuals chose that which was most likely to achieve their desired outcome.

I'd had success with it before. So I figured I'd try it again.

My partner uses alternative medicine all the time. And I've seen amazing things happen.

Here two pivotal variables emerge which heavily influenced choice and the use of alternative therapies--lay referral systems or social networks and financial access. Only one of the respondents had experience with and exposure to alternative therapies in childhood. All other respondents learned about alternative therapies from associates and friends, their secondary circles of socialization and lay referral systems. Conceivably, had the initial introduction to alternative therapy been less than credible, individuals would not have considered it a viable treatment option. Respondents in this study were sufficiently impressed with the initial introduction to invest time into acquiring more in-depth understandings and to risk trying the alternative therapy themselves. It is significant to note that four of the eight respondents were health care professionals. (This high number was most likely influenced by the snowball sampling technique, in addition to individuals' willingness to participate in the study out of scholarly and/or professional interest in the subject matter.) Hence, their introduction to non-biomedical therapies and their subsequent experience with them were notable enough to undermine professional socialization and the biomedical profession's claim to exclusivity in health care.

Two of the respondents had no experience with alternative therapy prior to utilizing it to treat their presenting condition. These individuals made their decisions based solely on the information received from persons within their lay referral networks and incidental reading they had done to familiarize themselves with the

therapy. With the exception of the two respondents who were new to

the use of alternative therapies, all others interviewed had utilized

non-biomedical therapies to attend to their health care needs with

varying degrees of consistency, fluctuating between biomedical and

unconventional intervention as medical condition and financial status

dictated. This leads to the second variable--access. All those

interviewed were professional people with at least two years of

college education. They had careers and occupations that provided

them with incomes at the national median or above. These variables,

education and income, would suggest that the respondents occupied a

middle-class position in society. In other words, they had financial

access to alternative treatments which are not reimbursed by medical

insurance. Still, one respondent reported she was not able to

continue with her alternative therapy due to cost. From this, one

could hypothesize that the use of alternative therapy can be

financially prohibitive and not a viable option for some segments of

the population. This raises a further question: If the exclusivity

of biomedicine were not so firmly institutionalized and entangled in

economic structures would more people be inclined to use alternative

therapies to treat their illness?

To some it may seem that the path to choosing multiple therapies

is somewhat erratic, and at times even capricious. Those interviewed

did not perceive their treatment decisions as erratic. Response to

illness, the intentional act, the project, was guided by the wellness

goal, not a particular healing modality. The strategy was to arrive

as nearly as possible at the envisioned goal. The treatment course incorporating the sequential or simultaneous use of various healing therapies was perceived as one by the individual. The intention and goal was one of wellness, not loyalty or commitment to a particular healing modality. The notion of dissonance or conflict between healing philosophies and therapy paradigms did not arise in this context. In reflection, the individual saw the act as unified, albeit an articulated unity of more than one healing modality. All actions were bound together by the overarching intentional act.

Moreover, those interviewed did not distinguish one healing philosophy as more valid or credible than another. As one respondent stated, "They act differently. They do different things." Healing modalities were conceptualized as existing on a continuum or as effective only for specific categories of disorder, therefore making unique contributions to health care as a whole. Biomedicine was seen as the therapy of choice for acute conditions. "If you have a gall bladder that is going to explode, I think you should have it taken out." However, respondents found biomedicine limiting when treating subacute conditions or conditions that did not have obvious pathology or causality.

> If you don't fit in their molds, they don't know what to do.

> Why bother telling the doctor, he'll just give you another pill to try.

> There was just the one choice--the steroid shot. That was all he had to offer.

Alternative therapies, on the other hand, were considered effective in treating subacute conditions (stress, low back pain, sinus problems, and headaches), as well as contributing positively in the management of chronic disorders.

Individuals used multiple treatment modalities to augment or replace what they perceived to be lacking in their overall therapeutic journey to their wellness goal. The decision to explore and utilize more than one healing therapy was perceived as rational and logical, as is illustrated by the following case. The respondent was riding her horse when she fell off; the animal stepped on her hand. The horse broke several bones in her right hand, requiring immediate surgery. Her hand was immobilized and placed in a cast for several weeks. After the cast was removed, she discovered that she was not able to extend the last three fingers of her hand. They were contracted in a curled state, much like a claw. Not only was the use of her fingers severely limited, she was experiencing pain in her hand. The biomedical doctor prescribed a systemic analgesic (Vicodin). She was ingesting the maximum amount prescribed by the doctor in an attempt to control the pain. "It wasn't touching it. And I couldn't work because it made me so dopey." Desperate, she decided to try an acupuncturist, at the suggestion of a friend. "I had to do something. The doctor said there wasn't anything else he could do for me. I didn't have anything to lose. I couldn't take Vicodin all my life." The choice was rational. After evaluating and projecting the present course of treatment into the future, she

arrived at a conclusion--remaining in her present state was not acceptable. Because she "couldn't take Vicodin all her life" and the M.D. had not offered other options for pain control, she had to "do something" else. This "something" else was the exploration of the alternative therapy (specifically acupuncture) suggested by her friend, a rational choice resulting from a logical process of elimination. The acupuncturist was successful in gradually eliminating the pain in her hand. "It felt better right away. With each treatment the pain got less and less." Furthermore, with massage and physical therapy administered by the acupuncturist, the fingers began to relax their claw-like position and the ability to intentionally extend the fingers partially returned.

Individuals engage in periodic evaluations and choice-making throughout the response phase of their illness experience. If treatment outcomes were consistent with expectations, the therapy was uneventful and continued uninterrupted. If treatment outcomes did not meet expectations but other factors such as preference for a particular healing modality or financial concerns outweighed the outcome shortfall (i.e., disparity is reconciled by secondary gains), therapy continued. It was only when disparity between the desired goal and the treatment outcome became irreconcilable that individuals began to explore the choices available to them. Some persons began the response phase using an alternative therapy and substituted biomedical intervention. Among those interviewed, the reverse trajectory (biomedicine then alternative) was most frequent. Others

used alterative therapies and biomedicine simultaneously with the intention of augmenting what they perceived to be lacking in each healing modality. Two respondents with extended illness trajectories alternated between simultaneous use of multiple therapies and singular use of a specific therapy, engaging in a pattern of serial utilization. Most often, however, therapies were used sequentially. The length of the response phase varied according to the condition. Hypothetically, this phase continues until the individual perceives the condition has reached an optimal level of wellness. In the worse case, the response phase could continue until all treatment options are exhausted; ultimately, this would be at death since one could hypothesize that until death occurs some type of treatment can be administered (albeit it palliative) and the individual still has options available.

Not all of the presenting conditions were resolved. In some cases, individuals were forced to modify their wellness goals based on the treatment outcomes, as was the case with the female suffering from uterine cancer. Although the tumor was benign and the surgery considered successful, her convalescence was slow and painful. Original goals, to be back at work in weeks ("I thought I'd get my pins [legs] under me again in a few weeks."), had to be radically modified. Other cases in which the original wellness goal was modified will be presented later in this chapter.

To summarize, respondents in this study moved through the process that began with the acknowledgment of disorder. After

disorder was recognized, the individual moved into the response phase in the illness experience. This phase can be conceptualized as the undertaking and execution of an intentional act, a project or strategy to achieve wellness and normalize life. Response to illness was a multi-action, intentional act that could continue until the illness was resolved, options were exhausted and/or death occurred. Throughout the response act individuals intermittently conducted evaluations or map-consultations during which the goal and the treatment outcomes were compared. All individuals in this study, at some point, perceived insurmountable disparities between their treatment outcome and their wellness goals, prompting them into an evaluation and choice-making process which led to some alteration in their therapy course. This alteration was either a complete substitution of one therapeutic modality for another (sequential use of therapies) or the addition of another mode of intervention to the existing therapy (simultaneous use of multiple healing therapies). An alternating type of therapy utilization (serial utilization) in which the individual fluctuated between simultaneous use of multiple therapies and singular use of a particular therapy was also noted. The total length of the response phase was determined by the severity of the condition. Although some individuals, at the time of the interview, had been undergoing therapy for an extended period (as long as 16 months and 2 years), the original presenting condition had not been resolved as they had desired or anticipated.

CASE HISTORIES

The four case histories (names are fictitious) presented in this section illustrate the process, consisting of two phases (the core categories)--acknowledgment of disorder and response to illness, outlined in the preceding section. These specific cases were selected because they represent all aspects of the theoretical sample: variations in the response trajectories, female and male respondents, a non-Caucasian (Asian) racial extraction, as well as a health care professional. Each trajectory demonstrates the subject's unique interpretation and use of the basic components (subcategories) of the response process, making the trajectories distinct. In the first two, presenting conditions resolved according to the subjects' expectations. In the last two, the conditions did not and the respondents were forced to modify the initial wellness goal.

Sally: Alternative Therapy as a Practical Option

Sally is a working mother of four children, ages range from 3 to 13. She was introduced to alternative therapy, specifically herbology, through an acquaintance.

> A teacher at [son's] school. [Son] used to get these ear
> infections and we had him taking these antibiotics. . . .
> Every time he was off the medicine he kept getting an ear
> infection all over again. We couldn't figure it out.
> . . . She [the teacher] was saying . . . replace the
> blood cells that need to fight the infection off. It made
> sense. . . . So the next time I found acidophilus cap-
> sules and began giving it to him. He ended up finishing
> the ear infection and with the medicine . . . it didn't
> come back.

Although the teacher did not give a particularly technical explanation, perhaps not even accurate, in Sally's eyes she represented a credible and educated person. Her subsequent positive experience with herbs encouraged her to find a naturopathic physician and further explore herbal remedies.

> So it's like, well I'll try it one more time to see if
> it really was that . . . my allergies were getting really
> bad and I was pregnant. . . . I decided I'd try something
> different because I didn't want to use drugs while I was
> pregnant. And so I went . . .

Despite continued positive outcomes with herbs, Sally's use of herbal remedies was inconsistent, a secondary intervention. Her primary intervention was biomedical. She had a long-standing relationship with the family's primary care physician, the physician's care was covered by insurance and his office geographically convenient.

Sally's presenting condition began innocuously. She became aware of growing lethargy and depression. "Nothing was getting done." The depression evolved and intensified, consuming more and more of her attention as she struggled to try to understand her moods.

> I didn't know . . . I was shaky. I was depressed. I
> couldn't get out of my depressed funk. And I thought my
> memory was bad. I was just in a daze all the time.

While her "depressed funk" was clearly uncomfortable for her, she did not recognize it as an illness and doubted that it was actually a disorder.

> Yeah, because we were going through such stressful times
> that I figured it was just my nerves at first. . . . I
> just kind of passed it off . . . is there something
> actually physically wrong with me or is it just in my

mind. Am I not handling the situation properly or as well
as other people. I have the tendency to do that. . . .
[depression] can be nerve related, some people can say
that did it.

Nevertheless, her depression continued to grow. "It seemed like nothing was right in my life. It just didn't seem normal." With this phrase, Sally acknowledged disorder and moved into the response phase of the illness experience. During a scheduled wellness exam, she told her biomedical doctor about her depression. He ordered blood tests which indicated a hyperthyroid, "my thyroid was high," and an elevated cholesterol level. The physician prescribed Thyroxine.

I really didn't want to take the medicine at first. [But]
I didn't want it to go any further . . . so I opted to go
the quick route. . . . I'd done the herbs before and
stuff and it worked. And most medicines have had adverse
reactions with me . . . or maybe its just mental. . . . I
just don't want any chemicals inside me.

At the onset of her treatment course, Sally was aware of dissonance between her desired treatment and the prescribed treatment. However, the desired goal was clear. "I didn't want it to go any further." In her experience with herbs she had noticed that herbs acted slowly. "It took twice as long as an antibiotic would, but it worked." Therefore, opting for the "convenient" and "the quick route" she began the therapy.

I took it [Thyroxine] for about two weeks. I didn't
notice what it was doing to me. There was just so much
stress in the family at that time. I was starting to get
really itchy. I thought it was nerves or something and
didn't pay attention to it. Until when I got so busy, I
totally forgot to take the Thyroxine. I realized that the
itchy stuff had gone away.

This realization disturbed her. Now there was more than dissonance between her desired and prescribed treatment, there was a disparity. Itching was not part of her desired outcome, prompting a very careful process of evaluation.

> I thought maybe it was something I was eating. . . . You now, then I had to figure out what I was eating. And then, when I started taking the medicine again, I realized that I was starting to get itchy again. To confirm that it was the drug I looked in one of my herb books . . . one of the side effects of those drugs was itchiness and rashes.

The new information presented Sally with choices: continue the therapy, consult the doctor or try another treatment intervention. Projecting her choices, Sally decided continued itchiness was not a good option. "I was going to cut off my nails. I was doing it in my sleep. I was scratching. I was noticing the rash on my stomach and my arms." She discontinued the medication, "I just stopped it," elected not to consult the physician, "He'd just give me another pill," and pursued an herbal remedy. Her practitioner recommended an herbal compound which did not produce side effects. Sally reported, "It helps when I take it. . . . If I'm consistent, I'm less depressed."

In hindsight, Sally wished "I had taken the herbs first." However, given similar circumstances, it is likely that she will again choose to use her biomedical physician first. Her decision was highly influenced by her desired goal, a rapid resolution of her disorder. In addition, the social factors that affected her initial decision, insurance coverage, proximity and her long-standing relationship with

her physician continue to carry great weight in her health care decisions. For Sally, herbal remedies provided a second option when biomedicine didn't work, as well as a therapy that can augment biomedical interventions. "If I couldn't shake the headache, I would take the Tylenol and wait a couple of hours. Then, I'd take my [herbal] allergy medicine." She did not verbalize awareness of potential conflict between healing philosophies; rather Sally's concerns were practical: geographical access, insurance coverage and the resolution of her disorder. In her description of health care, biomedicine and naturopathy--herbal remedies--provided specific services and therapies that were appropriate at certain times and inappropriate at other times. Therefore, the utilization of multiple healing modalities to treat disorder was practical.

Mary: Alternative Therapy as the Primary Health Care Intervention

Mary became interested in "herbs as medicine" during her college years. To increase her knowledge of herbs and related therapies such as aromatherapy, she took classes and used herbs and tinctures to treat minor conditions. "I learned that they [herbs] were very effective." Although she has used biomedical intervention throughout her life, she describes her experiences with biomedical doctors as follows:

> I've not had any fun experiences with M.D. type of doctors. . . . I haven't met an M.D. in my experience of going to clinics that didn't feel kind of cold, didn't feel detached. You were sort of a number. Oh, here is another vulva.

However, it was not until she became pregnant with her daughter that
she actively pursued contact with other types of practitioners. More
discriminating than most individuals, Mary interviewed several health
care professionals, among them naturopathic practitioners and
biomedical physicians, before deciding who would care for her during
her pregnancy and delivery. She chose a naturopathic doctor.

> I feel much more comfortable with the naturopath than I do
> the M.D. . . . I would say it is a wonderful relationship
> in that it encompasses all the aspects of life and all the
> body-mind-soul type connection and how that all inter-
> relates in your total health. So it's not just, gee where
> is the pain? . . . But, what are you going through? What
> is your stress level? What are you eating? . . . It is
> all-encompassing treatment . . . more balanced . . . more
> inclusive, more holistic.

Her preferred healing modality became naturopathy, particularly
homeopathic remedies. "I'd much rather use the homeopathy."

Gradually progressing, Mary's presenting condition was
troublesome for her to discern as illness.

> Well, I am a smoker so I'm used to when I have a cold
> to have it go into my chest very quickly and developing a
> cough . . . I've had bronchitis in the past. . . . I had
> what I thought was a cold. And it turned into a chest
> thing, with the cough and the typical cold symptoms. . . .
> It just kept getting worse and worse. More and more
> congestion, more and more pressure, worse and worse cough
> as I'd be trying to sleep.

It was difficulty sleeping ("It was very difficult for me to breathe
when I was laying down at night") that prompted her to acknowledge
disorder ("It felt very serious to me") and seek treatment from the
naturopathic practitioner, her preferred provider. "I went to the
naturopath and they recommended some homeopathy for me. . . . I've
used homeopathy in the past and it has been effective on me." This

time the remedies were not effective. "I tried that and it didn't

work. Things kept getting worse." Mary's first evaluation after

accepting treatment revealed a distinct shortcoming in expected

outcome and presented her with a choice--continue treatment or explore

other treatment options. Steadfast and committed to her belief that

homeopathy could work, she returned to her practitioner for new

remedies twice in a three-week period. Each time her treatment

outcomes were the same.

> I tried another remedy and it didn't help, things kept
> getting worse. I believe I tried three different remedies
> over a period of three weeks and things just kept getting
> worse and worse. Finally they sent me in for a chest x-
> ray.

Her chest x-ray was clear, but her culture specimen was positive

for bacterial growth. The diagnosis was a type of "walking

pneumonia." This new information changed the situation for Mary and

crystallized her wellness goal.

> This is not right. There is something drastically
> wrong here. . . . This was like nothing I'd ever
> experienced and it wasn't familiar to me. It scared me
> very, very much. Because that is a life and death type of
> thing. You know if you stop breathing you're not around
> much longer. I didn't want to fool with it beyond a
> certain point, not take a risk.

Mary felt danger. The disparity between treatment outcomes and

her wellness goal could no longer be reconciled by her conviction that

homeopathic remedies would work in time. She perceived her condition

had progressed to a stage of acuity where rapid resolution was cru-

cial. Mary's somewhat vague wellness goal changed from "nip it in the

bud and take care of it" to a clear and urgent goal to "get rid of

bud and take care of it" to a clear and urgent goal to "get rid of it." She decided to seek a doctor and use a pharmaceutical, an antibiotic.

> So that is when I made the choice. I need to get well here. This is the more important thing. And if it take the standard medicine to do that, that is what I am going to do. It took me three rounds of antibiotics to do that.

"Walking pneumonia" did not dampen Mary's belief in naturopathy or homeopathic remedies. Rather, she blames her own lifestyle for the remedies' ineffectiveness.

> I think what the difference was this time was that I was under tremendous stress. And I was also drinking alcohol . . . and coffee. And when you do those three things . . . the homeopathy will not be effective. The homeopathy is counteracted by all that . . . I believe truly that if I had not been drinking alcohol, smoking cigarettes, and under tremendous amounts of stress that the homeopathy probably would have worked, nipped it in the bud and taken care of it.

Illustrated in Mary's illness experience is a similarity in the response phase regardless of treatment trajectory (alternative to biomedical). The response phase was guided by the overarching intentional act—the wellness goal—and involved patterns of evaluating and choice making. However, personal investment in the efficacy of her chosen alternative therapy may have influenced the number of times Mary was willing to reconcile the disparity between treatment outcomes and her wellness goal. Nevertheless, when she perceived her life to be in danger, this investment did not stop her from utilizing what she deemed to be a less desirable form of intervention—biomedicine—in order to achieve her desired outcome to "get rid of it."

<u>Evan: Alternative Therapy as "Something to Fall Back On"</u>

Evan, an Eurasian man, was the only respondent with childhood

experience of alternative medicine.

> We had it when we were growing up. Yeah, I guess when we
> were growing up. . . . We kind of lean that way. . . .
> There is a belief in it. . . . You know that there is
> something else you can fall back on.

His personal experience with alternative therapies was extraordinary

and left positive impressions.

> Even my father believed in it when he had stomach cancer.
> He took something weird. Anyway, they made it into a tea.
> It worked. The doctor said he would probably get stomach
> cancer back. And he never did get stomach cancer back.
> He never did.

Evan describes Eastern medicine (acupuncture, herbology,

acupressure) and biomedicine as functioning "differently, totally

different."

> The medical one was very scientific. There was only
> one proven means of corrective action. And this was it.
> This is what I prescribe and this is what you get. . . .
> The medical doctor takes care of the specific. You go
> there for something specific. I have a broken finger, a
> hurt shoulder, something in my eye . . . like an
> emergency. . . . The other [Eastern medicine] was a
> totally different approach. It was more . . . the whole
> person, the total being . . . more preventive, not only
> preventive but also recuperative.

In his family--wife and children--the primary health care

intervention was biomedical. For his own health care needs, he used

Eastern medicine to treat non-acute or subacute conditions (to stop

smoking, relief of lower back pain, stress management) and biomedicine

for acute disorders (cuts that require stitches, broken bones). Evan

had determined what he perceived to be the limits of his two primary

health care modalities, categorized them, and utilized them
accordingly.

Evan's presenting condition occurred precipitously.

I got the condition from a car accident. My body moved
forward and my shoulder didn't. I hurt my shoulder. It
was all messed up. Ligaments and muscles . . . everything
got out of joint . . . in the wrong place.

Acknowledgment of disorder was immediate. "I hurt my shoulder."
The choice to use biomedical therapy was automatic based on
conceptualized therapeutic efficacy and insurance protocol. "I needed
to follow the insurance deal." Recounting his subsequent experiences
he sounded much like someone reciting insurance protocol. "I went to
the emergency room . . . they referred me to my regular doctor . . .
he referred me to a specialist . . . the specialist . . . had x-rays
and all that stuff." Although Evan thought that biomedical
intervention was the therapy of choice, early into his prescribed
treatment course he became uncomfortable with this therapy, perceiving
serious deficiencies in his biomedical treatment and dissonance
between expectations and treatment reality.

No therapy, no anything. He just said don't lift
anything, don't do anything strenuous. Keep your range of
motion down to a minimum. . . . He put me on a regime of
cortisone shots for inflammation or pain or whatever.
. . . I didn't like the idea of cortisone shots to begin
with . . . it did help but only for a day or a day and a
half. And like, wow, when it was gone, my body ached and
that was it. . . . What bothered me was that there was no
therapy. There was nothing. There was come get your
shot.

Evan followed physician's orders, "Come see me in two weeks," for two
rounds of cortisone shots (approximately a month). Persistent in his

belief that biomedicine was the appropriate therapy for "specific" and "emergency" disorders, he was committed to try "what [his] general practitioner wanted . . . and recommended," enduring his discomfort in the meantime. "It was like this ache all the time. And you feel it, something is wrong." Further exacerbated by stress from his job, the continuous aching in his shoulder became intolerable. He could not ignore the disparity between his wellness goal--"I just wanted it to go away"--and his treatment outcomes any longer.

> I mean I couldn't use it. . . . You know when its wrong
> when it isn't working right. . . . When it didn't work I
> knew I had to do something else.

Evan's evaluation was somewhat protracted, beginning with his reluctant use of cortisone and displeasure at having "no therapy." When his shoulder pain compelled him to "do something," choosing between available options--continue with the present treatment or explore other treatment options--was relatively quick. Continuing with the biomedical intervention was not acceptable. "So then I went to . .. a naturopathic acupuncturist," a therapeutic modality he was familiar with; he "fell back" on Eastern medicine.

The acupuncturist was successful in resolving Evan's acute shoulder pain. Moreover, he received what he perceived was lacking in biomedical intervention--"therapy."

> First he gave me a general massage. . . . Then he used
> acupuncture . . . which felt great. It seemed like the
> needles were in the exact right spot of the hurt. . . .
> He prescribed for me a whole regime of vitamins and herbs
> for stress . . . that helped a lot with the amplification
> [of the shoulder pain] while sitting behind a keyboard or
> drafting. . . . I did that twice a week. . . . Each time

> I went back it [the treatment] lasted. . . . And
> progressively it got better. It worked pretty good.

However, the therapy was only partially successful in achieving
Evan's initial wellness goal--"I just wanted it to go away." His
injury did not completely go away. "He [the acupuncturist] said it
would never be the same. And he was right. . . . I still have the
stretched ligaments in my shoulder. When you move it in the right
direction, it's still not right. It just [grinds] when you move it."
When presented with a discrepancy between the outcome and the wellness
goal, the individual can continue to seek out other treatment options
or modify the goal. Evan chose to modify his goal, accepting the
function and status of his shoulder as the most optimal. He recast
his persistent shoulder weakness in a positive, somewhat advantageous
light. Noticing that his shoulder ached when stress became excessive
or overwhelming, he determined it could be a personal stress
barometer.

> On one hand it is good . . . when you have a lot of
> stress, you know . . . you have a point where you know
> right away. You can pinpoint it is time to go out and get
> some time to breathe. So it works really good.

Evan was confident the therapeutic sequence in his response to
illness was correct. Biomedical intervention was for "emergency" dis-
orders. He felt strongly that he needed "to follow what his general
practitioner wanted" him to do. "So I went and did it." Equally as
logical was his decision to shift his therapy to the acupuncturist.
"But when it didn't work, I knew I had to do something else." For
Evan, response to illness was a strategy guided somewhat by protocol.

In the final analysis, however, the overarching intention of the act--make it "go away"--did not preclude utilizing a therapy not sanctioned by his general practitioner or his insurance company.

Lani: Biomedicine as the Institutionalized Health Care Provider

As a nurse providing direct patient care in an institutional setting, Lani had a clear understanding of disease and disease processes. She became interested in alternative therapies, specifically "Eastern medicine," through a significant other who used this form of treatment almost exclusively. "My first real experience with Eastern medicine was three and a half years ago. . . . And I've seen amazing things happen." She describes her concept of the association and relationship between Eastern and Western therapies in the following statement.

> I think that they [Eastern and Western medicine] can work
> together. I think they should work together. But I don't
> think its 50-50. My primary would always be Eastern with
> a smattering of Western, it would be more like 80-20 . . .
> I've seen herbs work right away . . . For a headache, for
> sinus, you put rosemary on and its gone. . . . You take a
> drug for that sinus headache and it affects you
> systemically. And it doesn't necessarily work that well.
> It affects your whole being. . . . Western does have its
> place, like for people that are dying and need big pain
> control. I've seen people work really hard trying to
> manage pain with herbs and it just wasn't as effective as
> Morphine. . . . So I think they have a place together.
> But I think primary is Eastern.

Illness occurred suddenly for Lani.

> I went into the tub room to talk to one of the CNA's. She
> was cleaning the tub with . . . an agent that has a 23
> percent hydrochloric base. They say that it is in salt,
> so it shouldn't be caustic. . . . She sprayed that at the
> foot of the tub, I was standing at the foot of the tub, I

breathed in. It [the cleaning agent] was propelled by
warm water and the fumes went into my lungs.

The fumes caused a reaction similar to anaphylaxis. "I started
shutting down; my throat was closing. I was coughing." Although she
knew that the fumes had affected her breathing, acknowledgment of
disorder was not immediate. Another nurse convinced her she needed to
go to the hospital. "I was having a real hard time breathing. As
time went on it got worse. Eventually I went to the emergency room."
Lani spent a day in the Intensive Care Unit, followed by two days on a
hospital ward. After her hospital discharge she was given high doses
of Prednisone, a steroid, to control inflammation and the constriction
in her throat. Consistent with her belief that Eastern was primary,
Lani also initiated treatment with her acupuncturist. "She started me
on herbs and did a little acupuncture on me." Although, she states,
"It did help," Lani did not continue to use the acupuncturist. At
this early and still acute stage in her illness ("I was still reacting
a lot and still very ill"), Lani engaged in the first of many cycles
of evaluating and choice-making. She decided that the acuity of her
condition did not lend itself to herbal remedies and acupuncture. In
addition, the financial burden she would have incurred utilizing
Eastern medicine was prohibitive. "I didn't stay with the
acupuncturist because . . . the workman's compensation company
wouldn't recognize the Eastern medicine. They wouldn't pay for it.
And so for me to go and do only Eastern medicine would have been far
too expensive. I could never have afforded it."

Unable to work for three months after the inhalation injury, Lani struggled within the biomedical system to recuperate from her illness. Fully aware of the side effects of long-term steroid use, she became concerned about the length of time she'd been on Prednisone, at this point close to four months. She evaluated her situation. "I stayed on that dose for months. I had Cushings Syndrome and everything that went with that--weight gain." The side effects of the drug were frightening and unacceptable. "I finally told the doctor that I could not stand to be on this drug anymore." The physician was willing to comply with her decision and prescribed a gradual tapering dose to wean her off the drug. "I tried twice to get off and was unsuccessful, my reactions would reoccur pretty strong." Again, she evaluated her situation. She considered her decision to wean herself from steroid use as still valid and determined that the physician's tapering regime was too rapid for her system. Discarding her physician's suggestions, she informed him that she would wean herself off using her own tapering doses. "He said it was okay for me to try . . . And finally the third time I weaned myself off. . . . I went down . . . really slow to get off it. Then I was able to get off of that drug." Successfully weaning herself from the steroid was one desired treatment outcome; it was not the wellness goal which was "heal myself." Her condition, still unresolved today, is exacerbated by "pollutants." "I still react around cigarette smoke. I still react around any kind of chemical smells. The copy machine at work is in a small room. If I walk by in the hall when they've made lots of

copies, I start coughing almost immediately." Throughout the
interview, Lani described the multiple ways she had attempted to
normalize her life and heal from the inhalation injury.

> I continue to take my Tagamet and when I react I take my
> inhalers or cough syrup with codeine or both depending on
> where I am or what I am doing, or nothing if I'm driving a
> long way. . . . I have some patients where I've used the
> inhaler before I got to their home and they make me shake.
> The caregivers . . . one in particular, it makes her
> nervous that I have breathing difficulties. . . . The
> physician I am seeing is an allergist . . . wants to know
> if I'm reacting from gastric acid rather than . . . this
> original injury . . . they are going to put an NG
> [nasogastric] tube down with a Ph tester on the end of it,
> leave it in for 24 hours and test when I have reflux.
> . . . I'm switching over to another physician. I saw him
> for a consult. He said he thought I had vocal cord
> asthma. He said if I had vocal cord asthma I could
> retrain my vocal cords.

In the 16 months since her initial injury, Lani has utilized the
services of several physicians (a primary care doctor, at least two
allergists and a pulmonologist). In addition, she has explored a
workman's compensation settlement in an attempt to get money to "buy
property away." "I thought that if I could get out where I could
breathe . . . I feel like I can heal myself away from the city . . .
in my own way." This demonstrates clearly the project and strategy
aspect of the response phase. Lani's wellness goal, "heal myself,"
drives her to explore all avenues she thinks are available to her
within the biomedical system to which she has felt bound due to
insurance coverage ("Absolutely, that is the only reason I stayed with
it"), although she thinks it has failed her ("I was really let down by
this medicine again"), as well as options within the legal system.
Lani's response phase contained repeated cycles of evaluating and

choice-making that left her trying to reconcile disparities between treatment outcomes and her wellness goal.

After a visit to the acupuncturist for an unrelated condition, "I had severe pain under my right scapula," she again began considering the use of acupuncture to treat her inhalation injury, the need to heal herself overriding her financial concerns.

> She again said let's address the lung issue. I've had two treatments. And I think I'll go back for some more, because I cannot wait for Western medicine anymore. I need to just pay for it myself. It's expensive but it's my lungs.

Although unsuccessful attempts to bring about her desired "healing" have forced Lani to accommodate to her illness, modify her immediate expectations and reconsider previously limiting perceptions (insurance coverage and financial inaccessibility of alternative treatments), the long range wellness goal was never modified. Therapy utilization began with simultaneous use of biomedical treatment and acupuncture, was consolidated to a single healing modality-- biomedicine, then after numerous unsatisfactory treatment outcomes again expanded to include acupuncture (simultaneous use). This alternation between therapy application patterns illustrates a type of serial utilization. Lani's relentless and creative efforts to achieve her desired outcome demonstrate the scope of treatment options perceived viable by an individual in a response phase, some completely non-medical. Furthermore, the notion that the response phase is dynamic, open-ended and active until all options are exhausted, is

supported by the length of Lani's response phase and persistent efforts to seek out new avenues to "heal" herself.

CONCLUSION

The preceding case histories illustrate the process that emerged out of analysis done following the method outlined by Glaser and Strauss for generating grounded theory. The process presented provides an explanation for actions and choices made by individuals using both an alterative and a biomedical intervention to treat a particular condition. Moreover, the findings give insight into the subject's conceptualization and understanding of the interrelation and relationship of various healing modalities and suggests that particular social variables--lay referral systems, social networks and financial access--influence the use of alternative therapies. Echoing Williams (1984, p. 268), the findings of this study are not meant to be "representative in the statistical sense." The purpose of the research was to gain understanding of a significant (according to the results of Eisenberg's research) phenomenon--the use of alternative therapies--which is occurring in a health care environment that is dominated by the biomedical profession. The process presented here illustrates a type of response to illness, can be seen as "a theory in process" (Glaser and Strauss, p. 32), and the beginning of a theoretical discussion, not the end.

The findings suggest that the illness trajectory and response to illness involves more than merely accepting professional treatment.

Rather, the response phase described by respondents was an intentional act or a project comprised of multiple actions aimed at achieving a particular wellness state. Unlike Suchman's model--The Stages of the Illness Experience--which gives the patient the choice of accepting or rejecting a dependent-patient role after negotiating the treatment procedure, the subjects in this study described engaging in a relatively independent and active patient role, involving a vigilant process of ongoing evaluating (map-consulting) and choice-making after the acceptance of treatment. Furthermore, they reported augmenting and substituting therapies. These therapy choices were directed by their wellness goal and based on the outcomes of their treatment evaluations.

In order to present a visual representation, Suchman's psychosocial model of the illness experience was adapted to illustrate the process reported by respondents. Suchman's general framework (entry into illness, seeking professional help, and recovery) remains in the Illness Trajectory model (Figure 3) in a modified form. The primary alterations were the incorporation of an evaluation and choice-making stage into the process, thereby giving the individual the ability to assess, adapt and alter a treatment course.

To review, the illness trajectory was comprised of two phases. In the first phase--acknowledgment of disorder, the threshold of the illness experience, individuals recognized the existence of a disruption in their physical and/or social life. Recognition of disorder was sometimes complicated by unclear personal determinants of
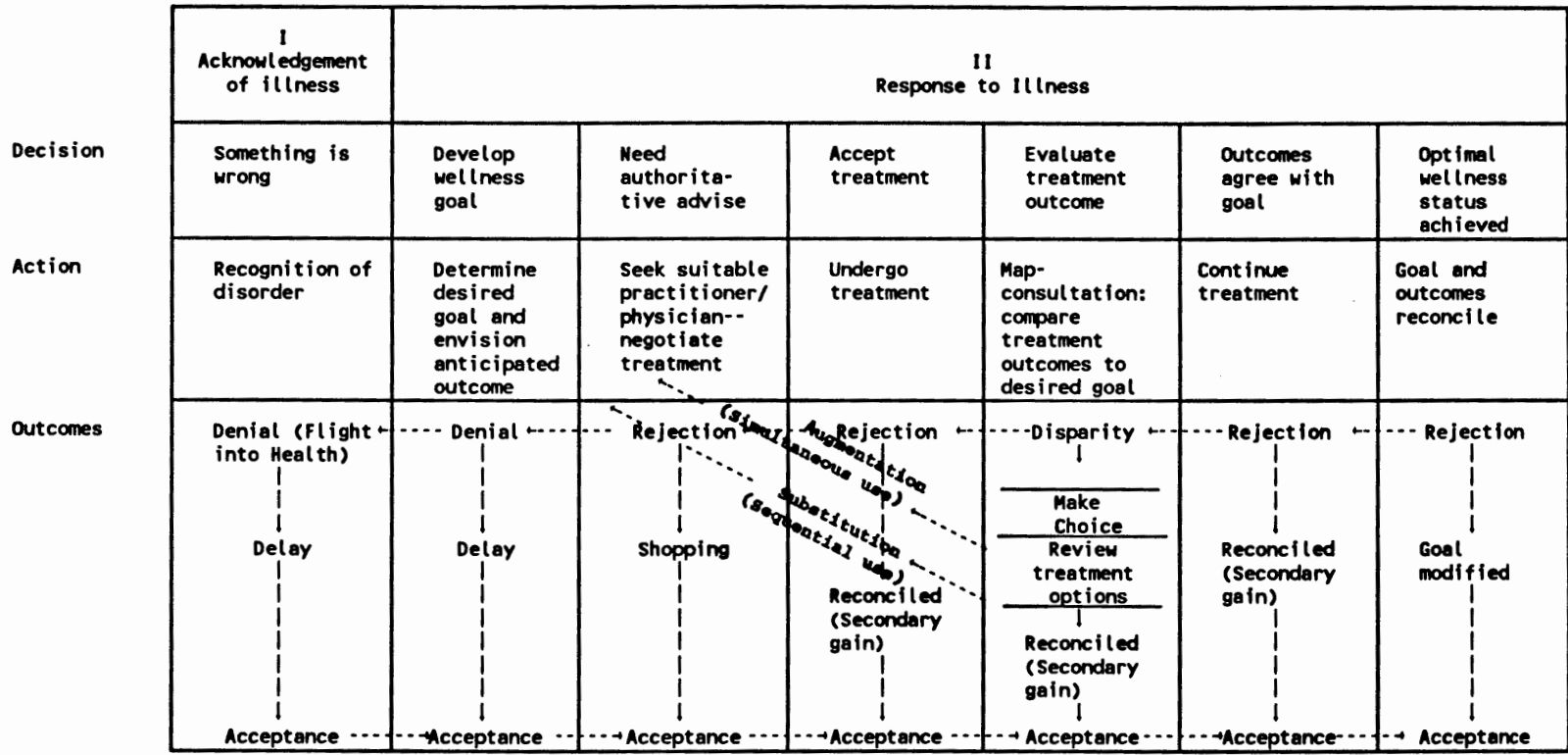
	I Acknowledgement of illness	II Response to Illness					
Decision	Something is wrong	Develop wellness goal	Need authorita- tive advise	Accept treatment	Evaluate treatment outcome	Outcomes agree with goal	Optimal wellness status achieved
Action	Recognition of disorder	Determine desired goal and envision anticipated outcome	Seek suitable practitioner/ physician-- negotiate treatment	Undergo treatment	Map- consultation: compare treatment outcomes to desired goal	Continue treatment	Goal and outcomes reconcile
Outcomes	Denial (Flight into Health) ⏐ ⏐ Delay ⏐ ⏐ ⏐ Acceptance	Denial ⏐ ⏐ Delay ⏐ ⏐ ⏐ Acceptance	Rejection ⏐ ⏐ Shopping ⏐ ⏐ ⏐ Acceptance	Rejection *(simultaneous use) Augmentation (sequential use) Substitution* Reconciled (Secondary gain) ⏐ Acceptance	Disparity ⏐ ———— Make Choice Review treatment options ⏐ Reconciled (Secondary gain) ⏐ Acceptance	Rejection ⏐ ⏐ Reconciled (Secondary gain) ⏐ ⏐ Acceptance	Rejection ⏐ ⏐ Goal modified ⏐ ⏐ ⏐ Acceptance

Figure 3. The illness trajectory (revision of Suchman's States of Illness Experience) (Coe, Rodney. 1970, 1978. Sociology of Medicine. New York, NY: McGraw-Hill Inc.), p. 108.

health and illness, particularly troublesome in gradually escalating disorders and in situations of chronic stress and denial. Once disorder was acknowledged, the individual moved into the second phase, the response phase of the illness trajectory, undertaking the wellness project—an overarching intentional act comprised of multiple actions focus on achieving a particular wellness goal. The first task in the response project was to evaluate the health status (How sick am I?), determine a course of action and develop a desired outcome. This was most often a straightforward comprehension. ("I sprained my ankle and couldn't bear weight on it. I went to the doctor to get it taken care of.") The second action was to seek the advice of an authoritative person and negotiate a course of treatment, followed by the third action, the acceptance of treatment. Up to this point the response phase of the illness trajectory was very similar to the stages outlined by Suchman in his model of the illness experience. Here, however, the illness trajectory described by subjects departs from Suchman's model with the inclusion of the evaluation and choice-making cycle(s). Evaluations entailed a type of map consulting which compared the treatment outcomes with the desired wellness goal. Some of the respondents entered into their treatment course with misgivings about proposed therapies (i.e., dissonance), but secondary gains such as financial considerations and commitment to particular conceptualization of appropriate or preferred interventions prompted individuals to reconcile the dissonance and proceed. If evaluations revealed treatment outcomes to be consistent with expectations,

therapies continued uninterrupted. An irreconcilable disparity between outcome and goal produced a choice-making predicament in which the individual chose whether to continue the present therapy, modify the wellness goal or explore other options. Individuals who chose to explore other treatment options again had to seek out authoritative individuals and find a suitable practitioner or physician. Three variations in utilization patterns existed among the respondents: (1) complete substitution of one therapy for another--sequential use; (2) augmentation of a perceived lack in the existing therapy with another--simultaneous use; and (3) alternation between exclusive use of a particular therapy and simultaneous use--serial utilization.

The illness trajectory and response to illness described by the respondents were general and not specifically bound to the use of alternative medicine. It would not be difficult to imagine an individual who does not consider alternative treatments credible utilizing a process of evaluation to assess whether treatments are achieving the desired results, and if not, embarking on a search for a physician to give a second opinion or another course of therapy. What makes the subjects in this study different is that they perceived alterative therapies as credible and viable treatment options. Two variables (properties of the subcategories evaluation and choice), lay referral systems and/or social networks and financial access, heavily influenced the use of alternative therapies. The perceived viability of healing modalities other than biomedicine induced individuals to formulate a health care construct that precluded biomedical

exclusivity, thereby affording them a broader scope of treatment options with which to achieve their desired state of wellness. The next section will discuss the two primary variables that influenced the decision to use an alternative therapy and health care conceptualizations that were constructed by respondents.

CHAPTER VII

SUMMARY AND DISCUSSION

SUMMARY

Analysis of the case histories of eight respondents who had used both an alternative and biomedical intervention to treat a physical condition revealed that the illness trajectory was a process that occurred in two phases: the acknowledgment of disorder and the response to illness. The response to illness described by individuals was a multi-action, evolving project aimed at achieving a desired goal--a particular state of wellness. Strategies intended to achieve the wellness goal were revised as disparities arose between treatment outcomes and the anticipated state of wellness. Furthermore, strategies used by individuals were not limited to a particular healing modality, but incorporated the pluralistic use of multiple health care therapies and even the attempt to use a non-medical (the legal system) intervention. Factors that facilitated the use of both a biomedical and alternative therapy were finances and social access. These factors and individuals' health care conceptualizations will be discussed next.

DISCUSSION

The underlying query throughout this project was: How and why do individuals decide to deviate from a generally accepted norm--the recognition of the biomedical physician as the exclusive medical authority, and use an alterative therapy to treat their physical condition? A basic issue confronted was the medical profession's dominance and perceived position as the true authority in health and medical care. Since the early twentieth century, gradual changes within the health care industry have moved it from free-standing hospitals and doctors practicing medicine independently to industrialized medicine practiced by physicians working for health maintenance organizations in corporate-owned hospitals, a radical transformation. The industrialization of medicine, its assimilation into a capitalist corporate culture, and powerful alliances with auxiliary industries such as the "drug companies" has resulted in the entrenchment of the biomedical profession in the economic structures of the United States. Not only does the biomedical profession have legislative and educational clout to enforce its therapeutic exclusivity, it has economic reinforcement as well. Nevertheless, Eisenberg (p. 250) found that, in 1990, persons using unconventional therapies paid approximately $11.7 billion for these services. This figure and the high percentage (34 percent) of individuals who reported utilizing the services of alternative practitioners would call into question the medical profession's claim to exclusivity. The respondents in this study confirmed that as consumers of health care

they were willing to spend out-of-pocket dollars to address their health care needs. Moreover, to them medical treatment may not automatically or entirely mean biomedical intervention.

The primary factor in a decision to use alternative medicine is access, both financial and social. Finances were a consideration for all those interviewed, some more than others. These concerns were voiced in references made about insurance coverage and/or by expressing reluctance to shoulder additional health care expenses. Although all belonged to some type of health plan, respondents accepted out-of-pocket expenses for alterative treatments. It must again be noted, however, that all respondents occupied middle-class positions in society, that is they had financial resources that allowed them to choose therapies that were not covered by their health insurance, a very crucial factor in the decision to use an alternative therapy. Even if an individual considered alternative therapies credible, lack of medical insurance reimbursement and out-of-pocket expense might make these therapies inaccessible.

All the individuals in this study had social access to alternative therapies through their social networks or lay referral systems. Most had been using some form of alternative medicine prior to the condition they presented in this study. From a broader social perspective, the availability of information and persons knowledgeable about therapies other than biomedicine may have been influenced, in part, by the holistic movements of the late 1960's and early 1970's. During this period various groups brought forward and into public

awareness holistic philosophies and ideologies, to name a couple of these groups: the women's health movement which resulted in the development of health clinics run by women for women, efforts to support "natural" home births if mothers desired it, and ultimately the pro-choice movement; and the hospice and death with dignity movement which sought to provide humane death unencumbered by aggressive medical intervention to the terminally ill. Interest in alternative therapies such as herbology and Chinese medicine was also renewed. The holistic health movement was one of several (another was the antiwar/peace effort) which comprised a larger social movement-- the counter revolution of the 60's. Most efforts and activities which fueled this movement were initiated and sustained by individuals who were young adults during that time, the "baby boomer" cohort. A theme prevalent in the counter revolution of the 60's was to "question authority" which resulted in an overall questioning of existing social norms. It is important to note respondents in this study ranged from age 35 to 52 and can be considered part of the "baby boomer" generation. Exposure during formative years to opinions and attitudes such as "question authority" and social norms legitimating alternative life styles may have influenced and affected these adult individual's willingness to deviate from a prevailing norm, in this case, the utilization of biomedical intervention for all medical conditions.

Since the 60's and the early 70's, holistic health care has enjoyed a slow steady growth in credibility as evidenced by the partial legitimation of chiropractic medicine through insurance

reimbursements, state licensing boards for naturopathic physicians, acupuncturists and massage therapists, as well as public interest in the wide spectrum of "New Age" healing arts (e.g., crystal healing, color therapy and aromatherapy). The plethora of unconventional therapies (some belonging to long standing healing paradigms, others which seem questionable, e.g., healing through soul retrieval) which is available and accessible to the public encourages, in individuals who are willing to consider and explore the viability and credibility of these therapies, familiarity with alternative healing modalities.

Respondents considered alternative therapies viable and their health care construct reflected this belief by encompassing a range of treatment options that included but were not limited to biomedicine. None of the respondents verbalized perceptions of dissonance between healing paradigms. Issues or concerns about scientific medicine versus non-scientific medicine or personal conflicts about one therapy's dominance over another did not arise in the interviews. Individuals had reconciled therapeutic differences by conceptualizing an inclusive health care scheme. This was done in two ways: therapies were categorized as effective for particular conditions or therapies occupied a place on a health-care continuum. Those who categorized therapies described a system of appropriateness. One respondent describes his categorization of therapies as follows:

> You go to the doctor [biomedical] for something specific.
> I have a broken finger, a hurt shoulder, something in my
> eye . . . like an emergency, you go to them when you are
> cut or something. . . . Whereas the other [the
> alternative practitioner] is more the total being.

The respondent had categorized biomedicine as being effective for acute interventions. Another respondent made this same determination but included pathological conditions. "If your appendix are (sic) going to kill you, I think you should have it out. If you have a raging infection, then an antibiotic is a good thing."

In this conceptualization, the alternative therapy, by default (". . . the other is more the total being"), is for non-acute conditions. Expanding this point, the first respondent explains that the therapy the alternative practitioner administers is 'preventative but also recuperative." With this statement, the individual is flanking biomedicine and acute interventions with the "preventative" alternative therapy on one side and the "recuperative" alternative therapy on the other (in this case the same therapy--Chinese medicine), essentially categorizing both biomedicine and alternative treatments according to perceived effectiveness.

Persons whose health care constructs resembled continuums described a kind of progression or transition from one therapy to the other, although biomedical intervention was still perceived as most effective in acute, pathological conditions.

> Like if you start out with a cold and you try the herbs, massage, acupuncture and if you get no results from that and it goes into an infection, then I can see doing an antibiotic. . . . If for some reason Eastern [medicine] doesn't work then I would go to Western . . . I think they have a place together.

People who had conceptualized types of health care as a continuum were more likely to use multiple therapies simultaneously.

People who categorized therapies according to perceived effectiveness were more likely to have a sequential pattern of utilization.

When asked if they perceived different expectations for behavior from their biomedical physician and alternative practitioner, most respondents said they did.

> It seems the regular doctor . . . is more regimented. You go in . . . very scientific . . . Whereas the other one is homey, the office and the equipment. You can let the curtain down.

> Let me think. Is there a difference between Hawaii and Antarctica . . . Western will listen to symptoms and say this is what is wrong with you. That's it. The Eastern will listen to what you have to say, as a whole, they listen . . . with ears and their intuitive self. And they get a picture of the whole person. Not looking at an x-ray, putting on a cast and sending you on your way.

All respondents verbalized perceiving biomedical intervention as limited in varying degrees, primarily because biomedicine is predicated on the premise that all physical disorder has an identifiable, specific, physiological etiology. Sometimes the biomedical profession is not able to find etiology, as is the case with cancer, Alzheimer's disease or migraine headaches, therefore treatment seems futile and mainly aimed at symptom management.

> I don't fit what it says in the book. . . . I should be healed, so if I'm not then it must be something else. . . . They are all throwing their hands up, not knowing what to do with me.

Most often it was the perception of biomedical limitation that motivated individuals to seek out therapies based on ideologies not restricted to science, etiology, and technology but that also addressed the whole person and moved into the subtler realms of prevention and non-acute (medically stable injuries that are still

disrupting the individual's ability to function) and/or subacute

disorders (stress). This seems ironic since as Brown (p. 77) states,

"Medical science rescued the medical profession." It was on the

foundation of scientific medicine that the profession claimed to be

"more effective" and "the only true valid medicine" (Brown, p. 78).

IMPLICATIONS

Before elaborating on the implications of this study it is

important to acknowledge its most obvious weakness. Although all

groups of the theoretical sample are represented, the total sample

size is small and represents a limited segment of American population

as a whole. The respondents were primarily (the exception being one

Eurasian male) comprised of educated, middle-class Caucasian men and

women. Furthermore, half of the respondents were health care

professionals. This clearly skews the findings. However, as was

discussed earlier, the intent of the study was not to have conclusive

findings, rather it was to begin an exploration of a phenomenon--the

use of alternative therapies. The findings of this study have

satisfied the purpose of generating grounded theory as Glaser and

Strauss have set forth, that is "to develop a theory that accounts for

much of the relevant behavior" (p. 30). The process described by the

respondents explains how they arrived at the decision to use an

alternative theory. In addition, analysis of the case histories

indicated that key variables influenced that decision. Therefore,

although the sample population is limited, the implications are, nevertheless, important. They are as follows.

First, respondents described a response to illness process in which they were active participants, evaluating the efficacy of their therapy course and making choices based on those evaluations. This seems to contradict the notion of the passive patient who defers personal judgment and opinion to the authority and direction of the physician (Suchman's Dependent-Patient Role--Stage IV). In addition, response to illness was not a single decision to seek treatment, rather it was an evolving, dynamic process utilizing a pluralistic therapy approach.

Second, individuals indicated that medical interventions limited to biomedicine did not meet their total health care needs. Those interviewed perceived that biomedical therapies were most valuable and had a critical role in the treatment of acute conditions. Health care conceptualizations described by respondents were not constructed around the exclusive use of biomedical therapy. Instead, individuals perceived and utilized a pluralistic treatment approach. According to those interviewed, alternative therapies filled a need, successfully treating stable, non-acute medical conditions and sub-acute disorder, as well as contributing positively to treatment plans in which they augmented biomedical interventions. This would suggest that alternative therapies may be able to provide valuable treatment options to health care consumers.

Third, current insurance reimbursement policies are heavily biased toward biomedicine and essentially assure the profession's exclusivity. If alternative therapies can successfully augment biomedical intervention, as well as effectively treat various disorders, as indicated by those interviewed, then current health care funding policies do not support or provide financial accessibility to therapies that could provide health care clearly seen as beneficial by consumers.

What are the implications for further research given the findings of this study? More study would be needed to confirm the process described by those interviewed. Is it a generic process, that is, do people evaluate their treatment outcomes regardless of the healing modality they are using? And, do individuals make therapy choices based on these evaluations? Furthermore, research would be needed to confirm the health care constructs described by the respondents. How prevalent are the people who perceive alternative therapies as credible contributors to a system of health care? Are the health care constructs similar or different than the ones described by the respondents? In addition, the effectiveness of alternative therapies would need to be confirmed. Should further study indicate that large segments of the population perceive alternative therapies as credible and research supports their soundness and efficacy, those findings would contribute another variable to the already tumultuous health care environment.

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APPENDICES

APPENDIX A

INFORMED CONSENT FORM

I, _____, agree to take part in this research project on the integrated use of biomedical therapy and unconventional therapy as a treatment for a physical condition.

I understand that the study involves an interview in which I will be asked to answer questions about my treatment decisions.

I understand that answering these questions can be a risk in that it may involve discussing issues that may be uncomfortable. Further, I understand that I do not have to answer any question I do not want to and can stop the interview at any time.

I may not receive any direct benefit from taking part in this study. But the study may help increase knowledge that may help others in the future.

Nina van Es has offered to answer any questions I have about the study and what I am expected to do.

She promised that all information I give will be kept confidential and the names of the people in the study will also be kept confidential.

I understand that participation or the refusal to participate will in no way affect my relationship with my health care professional.

I have read and understand the above information and agree to take part in the study.

_____   _____
Date   Signature

If you have concerns or questions about this study, please contact the Chair of the Human Subjects Research Review Committee, Office of Grants and Contracts, 105 Neuberger Hall, Portland State University, (503) 725-3417.

APPENDIX B

RESEARCH APPROVAL

OFFICE OF RESEARCH AND SPONSORED PROJECTS

DATE: August 5, 1993

TO: Nina van Es

FROM: Laurie Skokan, Acting Chair, HSRRC 1993-94

RE: HSRRC Approval of Your Application titled "The Patient's
            View: Illness and the Treatment Response"

In accordance with your request, the Human Subjects Research Review
Committee has reviewed your proposal referenced above for compliance
with DHHS policies and regulations covering the protection of human
subjects. The committee is satisfied that your provisions for
protecting the rights and welfare of all subjects participating in the
research are adequate, and your project is approved.

The Committee would like to suggest to you to drop "to the extent
permitted by law" in your informed consent form. It is not an issue
in your proposed project and it may arouse undo [sic] concern. Also,
please note that in Section II of your July 27, 1993 [sic]
application, on page 2, you would still need to change "anonymous" to
"confidential."

Any changes in the proposed study, or any unanticipated problems
involving risk to subjects, should be reported to the Human Subjects
Research Review Committee. An annual report of the status of the
project is required.

c.   Office of Graduate Studies

approval.mem