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Understanding "Plural" Medicine: Alternative and Biomedical Therapy Use Among Chronic Illness Sufferers-- A Canadian Study

by

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ABSTRACT

Using the concept of the illness narrative, this thesis examines the use of alternative and biomedical therapies by individuals experiencing chronic illness. Current research indicates that individuals experiencing chronic illness represent a large group of alternative medicine users (Kelner and Wellman 1997; Sharma 1992). The main focus was to understand, using stories of illness, how individuals experiencing chronic illness were incorporating unconventional therapies into their health care strategies, and how these therapies may have promoted healing in the context of chronic illness. The illness narrative is used as both a methodological and theoretical tool in the understanding of descriptive health-seeking behaviour, illness conceptions, and healing. Drawing on illness stories from two individuals with HIV and one individual with an internal head injury, the narratives are framed between the conceptual frameworks of the care-seeking narrative and the medical dominance thesis, thus providing both a micro- and macro-understanding towards alternative health care use. The narratives reveal such themes as iatrogenesis due to biomedicine, healing promoted by alternative therapies, and the structural elements of medical dominance. While individuals remained in the care of biomedical practitioners for certain functions, the research demonstrates that biomedicine, for various reasons, was ineffective to meet individuals' entire health care needs. Furthermore, the research demonstrates that certain alternative therapies, as perceived by individuals, were effective in resolving chronic symptoms. This thesis concludes by following current research directions in complementary medicine research, which values the individual illness account as a means to validate healing promoted by alternative therapies.

ACKNOWLEDGMENTS

Many writers find this space insufficient to express their gratitude towards those they are indebted. I would, however, like to attempt my own form of gratitude here. To begin, I would like to pay tribute to those individuals who shared their brave stories of dealing with illness, without which this thesis would not exist. They are truly, as Buddhists would say, "Boddhisattvas", whose purpose and experiences serve to teach us about courage while suffering. I would like to express my extreme gratitude to my committee, Dr.s William Koolage, Joan Townsend and Joe Kaufert, who provided invaluable feedback and direction. In particular, I would like to thank Joe Kaufert for providing great inspiration and guidance in times of need. Additionally, I would like to thank the teachers I had in my course of training, Dr.s Ellen Judd, John Matthiasson, John O'Neil and Ray Wiest for giving me a solid background from which to draw upon. I would also like to thank Dr. Arthur Frank, whose writings and dialogue have recently opened my eyes to the "well" of illness meaning and experiences. The contributions of many other literary scholars, too many to list here, are also gratefully acknowledged. Vinay Bharadia was invaluable for his help with constructing diagrams, and acting as "computer guru." I would like to thank my parents for their love and support: to my father Morley, for the lively if provocative discussions, in addition to my unlimited access to free printing(!), and to my mother Joan, for always lending a welcome ear. Lastly, I am indebted to my life-partner Seema Bharadia, who in addition to providing excellent editorial skills, provided an unending well of love and support to which there can be no measure. The material and ideas put forth in this thesis, including any errors of representation, however, can only be attributed to the author.

DEDICATION

This thesis is dedicated to all who have experienced illness at some point in their lives, and to all those who show strength by living daily with illness or disease. It is through illness that health becomes recognized, and through death that the beauty and experience of living becomes valued.

Table of Contents **Page number**

LIST OF FIGURES **Page number**

Introduction

Background

In 1991, the *Canadian Medical Association Journal* reported that one in five Canadians were participating in alternative health care practices. By 1995, a Statistics Canada survey revealed that the use of alternative and complementary medicine by Canadians had grown into a billion dollar industry (Blore 1997). "Alternative medicine" is understood as any and all healing therapies which are deemed "outside" the domain of Western biomedicine, while "complementary medicine" is an attempt to combine biomedicine and alternative medicine in a cooperative nature (Crellin et al. 1997; Sharma 1992).

The use of alternative and complementary therapies by Canadians continues to grow at an exponential rate, and is beginning to parallel their use in other countries such as the United States and Europe (Berger 1993; Fulder and Munro 1985; Goldstein et al. 1988; Rankin-Box 1992; Unschuld 1980; Visser and Peters 1990). The increasing popularity of unconventional therapies in Canada is further illustrated by the growing number of alternative health care clinics, alternative and complementary medicine conferences, and new complementary medicine curriculum implemented in medical schools (LaValley and Verhoef 1995; Spencer 1995). Additionally, new research centres, such as the Tzu Chi Centre for Alternative and Complementary Medicine in Vancouver, British Columbia, represent one of the first large-scale endeavours to evaluate holistic therapies (Blore 1997).

In response to the increasing popularity of alternative and complementary therapy use by Canadians, health care researchers have already started to undertake both descriptive and

population based research. These studies have primarily involved large-scale quantitative surveys assessing Canadian physician attitudes towards the use of alternative and complementary therapies by patients (Goldszmidt et al. 1995; LaValley and Verhoef 1995; Verhoef and Sutherland 1995). There have also been several recent seminal studies using a qualitative approach to analyze alternative and complementary therapy use by individuals suffering from illness in Canada (see for example Garro 1992; Kelner and Wellman 1997a, 1997b; Pawluch et al. 1994). Much work, however, remains to be done in both quantitative and qualitative-based research. This does not negate the fact that there has been much research in this area in other countries such as in the United States and Europe (Eisenberg et al. 1993; Furnham and Smith 1988; Goldstein 1992; Sharma 1992; Vincent and Furnham 1996).

Thus, a qualitative examination of the nature of the individual search for alternative or complementary therapies by those suffering from illness in Canada is still necessary. Furthermore, how individuals conceive the illness process while using these therapies, in terms of an illness narrative, has clearly not been addressed by many studies to date. This study is an attempt to bridge this gap.

Author's Note

From an early age, I was frequently exposed to various ideas towards health care. My father is an endocrinologist, and his extended family, for better or worse, currently represent the largest number of medical degrees (22) in any single family in North America. My mother, in contrast, is a therapist in a women's health collective. Despite being exposed to different ideas towards health and healing, until recently, however, I was not aware of the depth and scope of alternative health care.

I first became actively interested in alternative health care in a graduate nursing course in the Summer of 1995 at The University of Calgary. The course was exploring the nature of mind-body healing. In the course, I was exposed to many different forms of alternative therapies, ranging from meditation, to Chinese acupuncture and Tai Chi. Despite the value of the course, I did not, however, have the opportunity to talk to people who were actively using these therapies to combat illness.

When I entered a graduate program in anthropology at The University of Manitoba a year later, I had the opportunity to take a course in the Department of Community Health Sciences. The course explored both quantitative and qualitative methods towards the research of health care. As part of the qualitative course assignment, I was required to interview someone and construct either a life-history or an illness narrative. I chose the illness narrative. I interviewed a man in his late sixties, who after suffering the complete removal of his large intestine, was maintaining his health through the use of homeopathy and acupuncture. It was at this point that my interest was sparked in the use of the illness narrative to understand alternative health care.

The Study

In this study, interviews were undertaken with three individuals suffering from chronic illness. From a descriptive angle, an attempt has been made to understand how these individuals may have been incorporating unconventional therapies such as alternative health care into their choice for health care, in addition to their use of mainstream biomedical therapies. The concept of the "illness narrative" was used as an initial point for departure. The "illness narrative", discussed in detail in the next chapter, can be defined as a story told by an individual to give coherence to

the long-term course of suffering and illness (Kleinman 1988). Chronic illness provides the basis for the illness narratives in this study. While it is discussed in more depth as an operational definition, chronic illness has been defined generally in this study as any serious, acute or long-lasting illness. It can furthermore be any illness, physical, emotional, mental or spiritual, which impedes the individual's daily ability to achieve a state of health or well being, which has not necessarily been diagnosed using biomedical criteria, and which lasts or has lasted for a significant period of time to hinder good health.

The initial focus in the study was to explore the "plural" or combined use of alternative and biomedical therapies by illness sufferers. The use of the plural model led to the expectation that individuals would be using a combination of both conventional and unconventional therapies to meet their health care needs. In the course of research, however, it became evident that while individuals continued to use biomedicine for certain health care needs, alternative therapies, for various reasons, were perceived as the most effective choice to enable healing in the context of chronic illness. Moreover, in certain contexts biomedicine became identified by individuals as causing more harm than good with regard to iatrogenesis. In the natural course of research, the focus shifted towards chronically acute and life-threatening illnesses and away from mild chronic symptoms. This added to the significance of the use of and choice for alternative forms of health care by the individuals who were interviewed. In addition, the course of research led the project to explore the more-established and "physical/material" alternative therapies such as herbal therapy and acupuncture, than "spiritual" alternative therapies such as reiki or "hands-on-healing."

In searching for a theoretical construct that would provide a relevant context for understanding the use of marginalized health services by illness sufferers, two main conceptual frameworks emerged which seemed relevant: (1) the individual care-seeking narrative as a form of illness narrative, and (2) the concept of "medical dominance." In this study, these two concepts have been used to provide both a micro and macro understanding towards the research.

The individual care-seeking narrative, also understood as a form of illness narrative, is used both as a theoretical and methodological concept. Theoretically, the narrative provides a structure for obtaining an emic or "insider's" perspective toward the use of health services by individuals experiencing chronic illness. Methodologically, the narrative provides a descriptive focus, where the individual's views and opinions can be presented in a more or less neutral and ethnographic fashion.

In addition to valuing the narrative account, the second concept, that of the structural/historical paradigm of the rise and fall of medical dominance, is also explored to understand individual experiences of illness and the individual search for therapy. "Medical dominance" may be defined as the historic process of the rise of allopathic medicine beginning in the mid-nineteenth century which attempted to co-opt or eliminate all non-allopathic or "alternative" medical systems (Baer 1989). The use of the so-called larger structural framework of medical dominance becomes useful by providing a global and theoretical understanding of the forces which form the context for medical pluralism. The care-seeking narrative becomes a reflection of the medical dominance thesis, however, when the narrative also reveals aspects of medical dominance. This present thesis examines medical dominance and argues that it is one major factor influencing the use of alternative therapies by people experiencing the impact of

chronic illness. This study, therefore, encompasses several "cuts" or "slants" across medical pluralism, each attempting to engage the other.

Concerning narrative accounts of health seeking behaviour, issues to be explored are: (1) What are the processes by which individuals suffering from chronic illness use conventional or unconventional therapies? (2) What are the combinations of therapies used by illness sufferers? (3) What is the range of illnesses suffered by individuals? (4) Have these therapies been of benefit according to the individual, and if so, how may they have enhanced the healing process of illness? (5) Which therapies, according to the individual, have had the most beneficial effects on the individual's illness? (6) How does the individual conceptualize his or her illness, and how does this influence the present and continued use of therapies?

Concerning medical dominance, issues to be explored are: (1) What are the forces which have contributed to the establishment of a "dominant" biomedicine? (2) Does biomedicine remain dominant today? (3) How has medical dominance influenced the use and choice for alternative therapies by individuals experiencing chronic illness? (4) Can aspects of medical dominance be found in individual narrative accounts of illness?

The knowledge generated by this study has many aspects. The research may be viewed as a "window" on particular uses of plural therapies by a select number of Canadian illness sufferers. The research also reveals a detailed description and analysis of the processes involved with plural therapy use by people who are experiencing illness. The particular therapies and their related illnesses are placed in a highly relevant context of individual conceptual models and healing significance, as analyzed in an illness narrative. The combination of therapies used by individuals with illness, the range of illnesses experienced by individuals, the individual's perception of the

illness and healing process associated with plural therapies, and the reasons underlying individual use of plural therapies are explored and discussed.

Valuing Illness Accounts

It is evident that biomedicine in the twentieth century, a term now used to differentiate Western medicine from other healing systems in non-Western countries, is far more complex than at any other time period. At times it has had unheralded successes never seen before in the history of humanity. Within the increasing technology and complexity of biomedicine, however, the ability to preserve and/or alter life in certain contexts has now unforseen potential, in addition to unforeseen risk. Ivan Illich (1976), an influential writer on the "culture" of biomedicine, suggests that in any medical system, "iatrogenesis", or disease caused by any facet of a medical system, increases with technological advancement, such as in the case of Western biomedicine. In the race to preserve life and to "battle" all disease in an atmosphere which promotes a certain knowledge as the ultimate "truth", one must first ask what life has been lost in this race, then which disease has been overlooked, and lastly, what knowledge has been de-valued for others.

When confronted with an illness, biomedicine immediately "reconstitutes" it as a "disease", defined as a "medical problem" to be fragmented into a series of parts that represent the scientific dichotomy of the body--namely, that of a body distinct and separate from the mind (Good et al. 1992:8). In a Western biomedicine, the body, defined as "nature", is opposed to "spirit", and the physical body becomes autonomous from human consciousness (1992:8). Body parts become "atomistic" and "independent from the whole" (1992:8). The body becomes "not only independent from culture, but prior to it" (Gordon 1988, in Good et al. 1992). The biological

nature of the body eventually becomes the basis for scientific "truth" itself (Gordon 1988). Moreover, the human actor becomes a "rational individual" whose "cognitive states reflect an image of the natural world" (Good et al. 1992:9). Biomedical disease becomes constrained to purely the physical body.

There is a strong argument (Good et al. 1992; Jackson 1994), however, which states that disease cannot be measured or quantified. Rather, disease can be replaced by the concept of "illness", which, in contrast to biomedical disease, becomes "embedded" in the "life-world" of the individual and is full of the sensory perceptions of lived experience (Klienman 1988). Illness experiences then become inseparable from personal perception and social influence (Good et al. 1992:6). Moreover, illness becomes "embodied"--"an indeterminate methodological field defined by perceptual experience and made of presence and engagement in the [natural and social] world" (Csordas 1994:12). "Embodiment" is opposed to simply part of "the body", defined as "a biological, material entity" (1994:12). Embodiment also refers to the human body not as an object, as it is for a technological biomedicine, but as the "subject of sensation, experience, and world", and, additionally, spirit (1994:8).

It is exactly biomedical values which attempt to de-value illness as represented in lived-experience. Pain for the illness sufferer is not "sensory receptors", or "affluent neuronal relays" (Good et al. 1992:9). Suffering, including healing, is not an "etiological mechanism" to be reduced to "objective" and "reductionist" terms (1992:9). Rather, lived illness experience represents concepts such as pain, suffering, healing, relationships, feelings, values, dreams, and the magnitude of sentiments which make up a complex human personality. Furthermore, illness experiences are not purely psychological in nature. Lived illness experience represents not

"mind/body", but the "body-mind"--a shared, collective meaning grounded in both physical and experiential reality.

The fact that illness can be embodied does not invalidate illness experience by any means. The recounting of personal illness experience instead challenges the central tenet of biomedical epistemology, which argues that there is objective knowledge apart from lived experience (Good et al. 1992). Moreover, the biomedical paradigm, based above all on objective "proof" derived from the Cartesian split between mind and body, cannot deny the occurrence of lived-experiences, nor can it deny their validity.

In the following study, illness narratives are presented based on interviews which represent the lived experiences of individuals who have had to deal with illness at some point in their lives, and who have faced the challenge of searching for therapy in a complex biomedicine. The narratives presented here represent a spectrum of experiences. Some individuals have managed to deal with their illnesses in such a way that illness is no longer at the forefront of their lives, dominating every life-move. Others, in contrast, continually face the challenge of unresolved symptoms including life-threatening factors. Furthermore, each narrative chronicles the personal understanding of illness experiences. Moreover, the search for relief from suffering is integral to any illness story. An illness narrative is rarely devoid of a search for therapy, despite the fact that much suffering may not be relieved. Frank states, for example, that suffering on its own can be legitimate to forming lived experience (see for example Frank 1991; 1995).

Integral to the following study, in addition to the above-mentioned issues, are several central issues which cannot be ignored. (1) Has biomedicine failed in the treatment of certain illnesses, and if so, why? (2) What other treatments may be filling the void that biomedicine has failed to address, and (3) what are the qualities, according to individual accounts, that make these

treatments successful in the prevention of illness and in the promotion and maintenance of well-being?

Chapter Outline

Chapters One and Two begin with a detailed summary of the two conceptual frameworks used to understand the use of alternative and complementary health services by individuals with chronic illness. While Chapter One discusses the concept of the illness narrative, Chapter Two provides an examination of the historical processes associated with the rise and fall of medical dominance, bringing the reader up to date on contemporary developments in Canada regarding the current state of alternative medicine. Chapter Three gives a summary of the methods used to gather data in this study. Chapter Four presents three detailed case studies of illness narratives that were selected as the focus for this research. Each narrative begins with a brief biographical essay, followed by an organized narrative. Chapter Five then provides an analysis of the apparent themes that arose from the narratives, linking the structural paradigm of medical dominance and medical pluralism to the narratives. Lastly, Chapter Six consists of a discussion of the key issues surrounding the research. Issues that are discussed in this last chapter emphasize the reasons for the use of alternative therapies by chronic illness sufferers, and explore the successes and failures of biomedicine in the treatment of chronic illness.

Definitions and Review of Relevant Literature

Alternative Medicine

"Alternative medicine" may be defined as a group of diverse therapies which have been defined for various reasons by the allopathic medical community as "outside" Western biomedicine, and as "unconventional" (Crellin et. al 1997). These labels are quickly changing, however, as alternative therapies become more accepted into wider society. Alternative therapies are based on different healing "modalities", often with origins from around the world. Healing "modalities" may be defined as the particular worldview, practices, properties and healing effects which are unique to that therapy. Modalities often overlap between alternative therapies. Examples of alternative therapies are therapies such as acupuncture, chiropractic therapy, homeopathy, herbal remedies, therapeutic touch and reiki (please see **Appendix A – "Definitions of Alternative Therapies"** below).

Many alternative therapies involve both wellness and disease models, and may promote wellness in addition to the prevention and treatment of disease as defined by the biomedical model (LaValley and Verhoef 1995:46). LaValley and Verhoef indicate that alternative therapies are "most often used by patients with chronic illnesses when standard surgical or drug interventions are poorly tolerated or have not resulted in the benefit desired by the patient" (1995:46). One might also add that alternative therapies are often used when patients are dissatisfied with both the diagnosis and prognosis of biomedical therapies. Individuals may also choose alternative therapies without having a biomedical experience. Further, alternative medicine can be the first choice of action in health seeking behaviour.

Alternative medicine is often misrepresented by the biomedical community as displacing conventional medical therapy, thereby threatening it by means of an "alternative" practice (LaValley and Verhoef 1995:46). Medical doctors maintain that alternative therapies may harm or endanger a patient and may prevent him/her from seeking proper medical care until it is too late. Alternative medicines are "feared" for disrupting orthodox medical practice or treatments, such as drug-treatment (Hook 1993). Biomedicine labels alternative therapies "quackery" for not conforming to the "scientific" paradigm, and for not providing "objective proof" regardless of these therapies having healed patients. Medicine describes its scientific perspective as the "put up or shut up" viewpoint--in other words, alternative medicine must prove itself according to orthodox "double-blind" clinical trials, while one may argue that many biomedical procedures such as surgery continue to avoid such "proving" and continue to practice unhindered by medical restraints. As will be seen in Chapter Two, however, the labelling of certain therapies today as "alternative" is a result of a complex historical process of allopathic medical dominance in Canada and the United States in the late nineteenth and early twentieth centuries, where certain therapies such as homeopathy were dominated and outlawed through an organized process of medical elitism (Coburn, Torrance and Kaufert 1983:407-432; Baer 1989).

In contrast to biomedical arguments, however, LaValley and Verhoef state "it is incorrect to conclude that the patient and the physician face competing clinical choices", with regard to alternative and biomedical therapies (1995:46). They are suggesting that alternative medicine can promote wellness alongside allopathic means, without disrupting biomedical therapy. In contrast to popular medical arguments, one might argue that it is often biomedical treatments which disrupt the healing properties of alternative medicines through toxic and iatrogenic side-effects,

rather than the opposite.

Goldstein et al. (1988:853) provide ten key characteristics of alternative medicine which, while they cannot be generalized or be deemed representative of all alternative therapies, clearly represent a contrast with Western biomedical concepts.

> (1) an emphasis on the unit of the physical body, mind and spirit; (2) a view of health as a positive state, not merely the absence of disease; (3) a concern with the individual's responsibility for his/her own health; (4) an emphasis on health education, self-care, and self-healing; (5) a relationship between the provider and the client that is relatively open, equal, and reciprocal; (6) a concern with how the individual's health reflects familial, social and cultural environments; (7) an openness towards utilizing natural, "low" technology and non-Western techniques whenever possible; (8) an emphasis on physical and/or emotional contact between the practitioner and the patient; (9) a belief that successful healing transforms the practitioner as well as the patient; and (10) an acceptance of a spiritual component in the etiology and treatment of illness.

Complementary Medicine

When alternative therapies are combined with biomedical therapies to promote healing, such as the combination of Chinese acupuncture with biomedical drug-therapy, the resulting combination has been termed "complementary medicine" (Sharma 1992). Biomedical therapies encompass the entire range of allopathic procedures and practices derived from Western biomedicine. The term "complementary" is often criticized by alternative practitioners for defining alternative therapies as secondary to the more prominent biomedicine. "Complementary medicine", however, is not to be confused with "alternative medicine." Although alternative and complementary medicine may share similar therapies, alternative medicine does not combine its approach with biomedical therapies in a formal cooperative context.

Plural Medicine

An additional term that is used today to refer to the combination of alternative and biomedical therapies is "plural medicine" or "medical pluralism." These terms refer to a group of two or more medical systems characterized by differing and unique healing modalities, which may form an opposing, competing or cooperative health care system for the society in which they occur (Baer 1989). Not only confined to Western medical systems, medical pluralism is often seen in non-Western societies as characterized by several overlapping medical systems. Medical pluralism has also become commonplace in post-colonial countries, where the dominant Western biomedicine competes with opposing medical systems. Although uncommon, plural medicine may further involve the use of two medical systems, such as biomedical and alternative, without involving a complementary or cooperative nature. In other words, plural medicine does not necessarily involve a formal cooperation between therapies, although some aspects are usually complementary in nature.

Chronic Illness

> Nothing so concentrates experience and clarifies the central conditions of living as serious illness. The study of the process by which meaning is created in illness brings us into the everyday reality of individuals like ourselves, who must deal with the exigent life circumstances created by suffering, disability, difficult loss, and the threat of death. Yes, chronic illness teaches us about death; the process of mourning for losses is as central to growing old as it is to healing (Kleinman 1988).

During the early part of the twentieth century, the prevailing forms of disease in both industrialized and "Third World" countries were primarily a result of bacteria and "acute" diseases

(Strauss et al. 1984:2). As instances of acute diseases in Western countries began to drop (the underlying reasons for this are debatable and are discussed in Chapter Six), they were slowly replaced by chronic forms of illness (1984:2). Chronic illness can be defined as:

> All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care (L. Mayo 1956 in Strauss et al. 1984:1).

The importance of the shift from acute to chronic illness can be exemplified by a dated but valuable survey administered by the United States Health Service between 1965 and 1967. The survey indicated that approximately 50% of the American population had one form of chronic illness, such that 22 million Americans experienced a degree of activity limitation, and 12 million residents were limited in a major activity (Strauss et al. 1984:2-3).

There are hundreds of varieties of chronic illnesses which vary greatly (Kleinman 1988:7;47). Heart conditions are one of the most common forms of chronic illness, followed by arthritis and rheumatism, impairments of the back or spine, mental and nervous conditions, impairments of the lower extremities and hips, visual impairments, and hypertension without heart involvement (Strauss et al. 1984:3). Other common chronic disorders are stomach and bowel complaints, and headaches. There also exist many serious and/or fatal diseases, such as Auto Immune Deficiency Syndrome (AIDS) and cancer, which have lasting chronic symptoms.

Most individuals over sixty experience at least one chronic disorder. Chronic illnesses, however, are also common in earlier life stages. For example, paralysis and the complete or partial impairment of the lower extremities and hips is most common among individuals of 17

years or younger, while arthritis, rheumatism and heart conditions are most prevalent among those 65 years and older (Strauss et al. 1984:3). Some forms of chronic illness may lead to devastating loss of functioning where the patient is totally disabled, while others may ultimately result if death. Less acute illnesses may instead disable the families' resources and require institutionalization (Kleinman 1984:7). Chronic illnesses also vary between periods from when symptoms worsen, to periods when symptoms are less disruptive (1984:7).

Kleinman further describes chronic illness as a "symbolic bridge that connects body, self, and society" to illness meanings (1988:xiii). Chronic illness is a network of interconnected physiological processes, meanings, and relationships, where the social world becomes linked to inner experience (1988:xiii). Chronic illness disrupts everyday life activities such as diet, special occasions, work, and relationships (Kleinman 1988:46). Substantial expenses are incurred, and much time is spent travelling to and from clinics, sitting and standing in doctor's offices, undergoing laboratory tests, lying in hospital beds, and waiting (1988:46). Symptoms are explained over and over again. Frustration, irritability, and exhaustion are common (1988:46). The chronic illness sufferer jumps from one therapeutic intervention to another, in the hope that relief will be found. Kleinman states:

> For the chronically ill, details are all. To cope with chronic illness means to routinely scan minute bodily processes. Attention is vigilantly focused, sometimes hour by hour, to the specifies of circumstances and events that could be potential sources of worsening. There is the daily quest for control of the known provoking agents [. . .] Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting, resentful of uncertainty, lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion, shock, anger, jealousy, despair (Kleinman 1988:45;47).

Kleinman states that individuals suffering from chronic illness face serious problems in the context of conventional medical care, because their personal illness experiences are not

legitimated and are viewed subjectively by biomedical caregivers. Chronic illness sufferers are also commonly viewed as "problem patients" for reasons such as physician difficulty in pinpointing the cause of the illness, and a perceived view of the illness sufferer as "complaining":

> Predictably, the chronically ill become problem patients in care, and they reciprocally experience their care as a problem in the health care system. Illness experience is not legitimated by the biomedical specialist, for whom it obscures the traces of morbid physiological change; yet for the care giver of the chronically ill who would be an effective healer, it is the very stuff of care [. . .] Legitimating the patient's illness experience--authorizing that experience, auditing it empathically--is a key task in the care of the chronically ill, but one that is particularly difficult to do with the regularity and consistency and sheer perseverance that chronicity necessitates (Kleinman 1988:17).

As Kleinman details, some form of *stigma* has always been associated with illness, chronic included (1988:158). During the Grecian era, stigma meant "to mark or brand", and referred to marks that publicly disgraced a person, such as signs that were cut or burnt into the body (1988:158). These signs indicated that the person was a slave, criminal, traitor, or otherwise (1988:158). Following the Grecian era, stigma became associated with a religious definition as the bodily marks of God's grace or punishment. It is here that stigma became associated with bodily disease as opposed to disgraceful bodily marks. As time progressed, the meaning of stigma shifted slightly once more to refer to "a person marked by a deformity, blemish, or ugliness" (1988:158).

Today, however, stigma has taken on a cultural identity in addition to physical, in that it refers to disgrace or difference more than a bodily mark (Kleinman 1988:159). Stigma now refers to a "spoiled identity, a feeling of being inferior, degraded, deviant, and shamefully different" (1988:59). Stigma carries religious and moral significance to the sick person, and in turn this person internalizes a sense of shame and spoiled identity (1988:160). Stigma also helps to define

the social identity of a group (1988:160). As will be discussed below, stigma plays an integral role in the life of the chronic illness sufferer, by bringing cultural notions to the formation of an illness narrative.

In sum, Strauss et al. (1984:11-16) establish a framework of seven key characteristics of chronic illness. (1) Chronic illnesses are long-term by nature. This means that treatment regimens can last up to several months, or even years. (2) Chronic illnesses are uncertain. This uncertainty can cause stress for the patient and the medical care worker by hindering the choice of an effective treatment. In addition, as previously stated, chronic illnesses are episodic in nature--that is, they are characterized by both flareups followed by the remission of symptoms. (3) Chronic illnesses require proportionately longer efforts for palliation than acute diseases. The efforts to control pain and physical discomfort, in addition to the anxiety and grief of the patient and family, must be given ample time. A flareup of chronic symptoms can lead to extensive but periodic palliative care. (4) chronic illnesses are multiple diseases. A single chronic condition can often lead to multiple chronic conditions, where the long-term breakdown of certain physiological processes can lead to the breakdown of other processes. For example, there is an interconnection between renal failure and certain cardiovascular involvement associated with diabetes. The multiplication of symptoms also affects the patient's financial resources and complicates effective treatment, thereby causing more stress. (5) Chronic illnesses are disproportionately intrusive on the lives of patients, and as indicated may radically change previous lifestyle aspects such as family, work and social structures. For example, household routines must be rearranged to accommodate physical limitations on activity, which in turn affects other household members resulting in potential inter-family stress or tension. The change of lifestyle activities also requires

organizational family arrangements, such as calling on the help of neighbours or friends to perform activities traditionally performed by the family. (6) Chronic illnesses require a wide variety of ancillary services. For example, as will be evidenced in this thesis study, chronic illness sufferers may require services from a number of medical and non-medical professionals, ranging from physicians, to social workers, occupational therapists, psychologists and alternative therapists. (7) As mentioned throughout this discussion, chronic illnesses are "expensive." The necessity for a wide variety of ancillary services necessitates ample financial resources from the patient and family. Where the patient's resources are not adequate to meet his/her health care needs, families may be forced to consume their savings, resulting in extreme financial hardship.

Lastly, it is important to note that while chronic illness can be severely debilitating, there are many people who live with chronic illness and accomplish their life goals. Elements of this will be seen in the three case studies presented in Chapter Four. There are many studies, however, which focus on the "loss of self" or "biographical disruption" as an inherent characteristic of the chronically ill (see for example Bury 1982; Charmaz 1983). While not disputing that chronic illness involves a "renegotiation" of life-aspects, Kleinman argues that studies must not only focus on individuals whose illnesses are extremely disruptive and life-threatening, but must include those instances where chronic illness is effectively and successfully resolved (1988:137). In essence, there must be a balance by focusing on suffering *and* healing as legitimate to forming lived illness experience (Frank 1991; 1995; Kleinman 1988:137).

Physician Attitudes and Perception Towards Efficacy of Alternative Medicines

As indicated, current studies examining alternative and complementary therapies in Canada have mostly remained focused on physician attitudes towards these therapies. In one study, Goldszmidt et al. (1995:29-35) administered a survey to a random sample of general practitioners in Quebec. The survey indicated that four out of five general practitioners perceived at least one of three complementary health care services as useful. This study, however, did not include any opinions from individuals or patients incorporating these therapies as a part of their healing regimen.

In an additional study, Verhoef and Sutherland (1995:511) administered a survey in Alberta and Ontario to a random sample of general practitioners. The survey indicated that in both Alberta and Ontario, acupuncture was found to be useful by 71% of physicians, chiropractic by 59% and hypnosis by 55% (1995:511). In Ontario, the survey revealed that 65% of physicians referred patients to complementary practitioners, compared with 44% in Alberta (1995:511). An additional key finding by the authors was that few physicians in Alberta and Ontario (e.g. 7%) reported significant knowledge and understanding of complementary health services (1995:511). The authors further indicated that half of the physicians in their survey were unaware of the extent to which complementary services were being used by their patients, and the extent to which these services were becoming popular. Despite this significant and valuable data, the authors data did not extend to include the individual's or patient's use of these therapies.

The first national survey of Canadian physician attitudes towards complementary medicine encompassing all provinces is currently being undertaken by Dr. Marja Verhoef, Department of Community Health Sciences, Faculty of Medicine, University of Calgary (1997: personal

communication). Again, this survey remains focused on Canadian physicians attitudes and practices towards alternative and complementary medicine, rather than the individual's use of therapies.

Patient Use of Alternative Therapies

There are, however, several recent qualitative studies examining alternative and complementary therapies by illness sufferers. Hook (1993), for example, has completed one of the few Canadian analyses of alternative medicine in the area of medical anthropology. In this study, eleven alternative healers of different specialties were interviewed, in addition to eleven family practice physicians. Fourteen individuals who frequented both alternative and allopathic practitioners were also interviewed as part of the study. The study presented an insightful theoretical framework linking postmodernism to the widespread occurrence of plural therapies, in addition to a valuable bibliography. The study for the most part, however, was clearly aimed at devaluing the individual illness/healing experience using alternative therapies. Hook devalues the effectiveness of alternative therapies by labelling them as "mystical" or "symbolic" experiences, thereby excluding the legitimacy of physical healing promoted by these therapies.

Drawing from selected examples in the literature, and using only limited informant narrative, Hook (1993) leads the reader to believe generally that alternative therapies and practitioners are no less technologically invasive or intrusive than allopathic medicine. Alternative medicines, Hook argues, assume an ideal linked to "nature", whereby alternative therapies are falsely assumed to lack danger. She states that alternative medicines are really as iatrogenic as biomedicine, and individuals using alternative therapies are for the most part similar to mid-

nineteenth century "Romanticists", exploring no more than a romantic "New Age" eclecticism with calls to order ultimately for "neoprimitivism" (Hook 1993:43). She furthermore concludes there is no difference between the amount of time a physician spends with a patient, than an alternative practitioner spends with a client.

Hook (1993) bases her statement that alternative medicine is just as invasive as biomedicine, on the comparison of alternative practitioners with family physicians. The latter of which, one might argue, represent the least invasive side of biomedicine. Moreover, Hook argues that the only reason individuals resort to using alternative therapies is to experience a "metaphysical" healing experience, rather than actual therapeutic benefits from the therapies themselves. Hook unilaterally states: "There is every indication in the literature, that people do not use alternative medicine as a *true* alternative to biomedicine, but instead use it as a complement to biomedicine" (1993:66; emphasis added). This statement clearly ignores those examples where individuals *do* choose alternative health care as a viable option to biomedicine, such as in the case narratives in the present thesis. Additionally, Hook states that the boundaries maintained between biomedical and alternative therapies, and the popularity of alternative medicine, has more to do with the "secularization" of science by alternative medicine and of the nature of our postmodern society, than with any other factor. Again, this study is more concerned with alignment with biomedical views than with the value of alternative therapies and the patient experience.

Additional studies by researchers such as Kelner and Wellman (1997a; b), and Pawluch et al. (1994), in contrast, provide insightful and valuable information on the individual use of alternative medicines in Canada. These studies are discussed in detail below.

Why are People Choosing Alternative Health Care?

It is clear that the processes involved in the individual choice for use of alternative or biomedical therapies by chronic illness sufferers are complex. There have been several popular arguments attempting to assess why it is that people choose alternative therapies in place of biomedical treatment. One argument suggests that people only choose alternative therapies when they have found little or no relief from their health problems using conventional medical services, thus becoming "refugees from conventional medicine" (British Medical Association 1986; Fulder 1988; Montbriand and Lang 1991; in Kelner and Wellman 1997). As a related point, other studies such as Furnham and Smith (1988) suggest that patients mainly incorporate alternative therapies because of negative past experience with biomedicine, rather than choosing these therapies as a result of their effectiveness (Kelner and Wellman 1997). A summary of these arguments would suggest that people are choosing alternative health care principally for purely pragmatic reasons.

Other arguments towards the individual use of alternative health care, however, suggest that the use of alternative therapies involves much more than mere pragmatism. For example, a recently published Canadian study of the use of alternative health care by individuals with HIV/AIDS concludes that the decision to seek care from alternative practitioners stemmed not from a sense of desperation, but rather from a deliberate strategy towards a belief in an "alternative therapy ideology" (Pawluch et al. 1994, in Kelner and Wellman 1997). Pawluch et al. propose that this ideology encompasses the following components: (1) definition of the illness as a chronic condition; (2) commitment to a proactive and preventative role in one's own health care; (3) a holistic understanding of health as physical, mental, emotional and spiritual well-being; (4) an openness to the full range of available therapies, and (5) an emphasis on individual and

personal responsibility for all health care decisions.

Further support for the notion of an alternative therapy ideology is provided by Goldstein (1992) in his analysis of the health movement in the United States. Discussing the recent spread of "New Age" conceptions towards health and healing, he suggests that while these ideas are diffuse and highly variable, they all emphasize the unity of body, mind and spirit including individual responsibility, anti-professionalism, self-care and personal transformation or self-realization (in Kelner and Wellman 1997). Goldstein also suggests this kind of ideology encourages people to look beyond conventional medical care, and make their own judgements about which types of therapies are best suited for their problems (1992).

Sharma (1992) however, based on a small-scale study of users of alternative therapies in a non-metropolitan area of Britain, argues that *both* ideological and pragmatic considerations influence individual decisions about what kind of treatment to seek in the face of illness (in Kelner and Wellman 1997). The patients of alternative practitioners in her study suffered from chronic illnesses for which conventional medical care had not offered much help. As a result, these individuals had turned to alternatives in the hope of finding some relief (Sharma 1992). A number of the patients, however, were also ideologically predisposed to using alternative therapies, and were highly critical of the conventional medical profession. For example, these patients had concerns about the side-effects of drugs, and were convinced that biomedicine treats symptoms rather than causes. Furthermore, these individuals felt the need to engage in an active search for information pertaining to their problems, and had considerable confidence in their ability to make independent health care decisions.

Vincent and Furnham (1996) support Sharma's conclusions, and suggest four principle reasons for people choosing alternative health care: (1) belief in the positive value of alternative care; (2) previous experience of ineffective orthodox biomedicine; (3) concern about the adverse side-effects of biomedical care, and (4) poor communication between orthodox practitioners and their patients (in Kelner and Wellman 1997).

An excellent model for understanding processes involved in the choice of health care by individuals is the socio-behavioural model proposed by Andersen et al. (Andersen and Newman 1973; Aday and Andersen 1974; Andersen 1995). This model is effectively applied by Kelner and Wellman (1997) in their analysis of 300 interviews exploring the individual's choice of biomedical and alternative health care. This model is also one that has been most frequently used to analyze health seeking behaviour (Kelner and Wellman 1997). The model delineates conditions that facilitate or impede the utilization of health services, portraying the processes of health care choices as comprised of a complex of three interrelated sets of determinants: (1) "predisposing factors" such as age and education; (2) "enabling factors" such as knowledge and accessibility of services, and (3) the need for care (Kelner and Wellman 1997). Kelner and Wellman state that while this model is traditionally used to explore the use of biomedical therapies by individuals, it is particularly suited to analyze the individual use of both biomedical *and* alternative medicine.

Kelner and Wellman's (1997) study is discussed in detail below, as it represents one of the few detailed Canadian studies relative to alternative therapy health seeking behaviour and using Andersen's model. Kelner and Wellman's study is also significant in understanding the research undertaken in the present thesis study.

In their study, 300 adults were interviewed in Toronto concerning their use of both alternative and biomedical therapies. The sample was split five ways in order to examine the motivations of patients who used five different kinds of practitioners: chiropractors, acupuncturists/traditional Chinese doctors, naturopaths, reiki practitioners, and family physicians. The study used Andersen's model to examine both predisposing and enabling factors in the search for health care, in addition to the potential role of an "alternative treatment ideology."

Predisposing factors can be defined as certain characteristics that will influence people to use certain health services (Kelner and Wellman 1997). Predisposing factors also involve particular social characteristics such as gender and level of education. Kelner and Wellman revealed the majority of users of alternative therapies in their study were women who were comparatively highly educated, such that they had some post-graduate education. Moreover, the study revealed that alternative medicine users were, for the most part, in comparatively higher level occupations such as professional or managerial positions, were employed full-time, had a high income, and despite having no religious affiliation considered themselves to be spiritual. Thus, it is clear that a large proportion of alternative medicine users as represented in Kelner and Wellman's study, tend to be women who are highly educated, and who have higher income jobs enabling them to afford the use of alternative therapies (Kelner and Wellman 1997).

Enabling factors, related to predisposing factors, refer to both community and personal resources which make it possible to use health care services (Kelner and Wellman 1997). Kelner and Wellman argue that, with regard to community resources, individuals who wish to take advantage of alternative therapies must be located in an area where such services are available on a regular basis. Enabling factors further involve "personal enabling factors", such as personal

knowledge of available services, referrals to a particular practitioner, a convenient location, and a level of income that will permit individuals to pay for alternative treatment or private health insurance.

Thus, both predisposing and enabling factors influence the individual choice of therapy, choice of practitioner, and the ability to pay for alternative health services. Kelner and Wellman state that "knowledge about what kinds of health care services are available is essential if people are to make choices about therapies" (1997:207). While there were slight variations between therapies regarding individual choice for alternative health care, Kelner and Wellman reported that 36% of their total sample chose to use an alternative therapy because it was suggested by others who had experienced positive results. Referrals came from family members, friends, acquaintances, co-workers, and other alternative practitioners, while only 3% of the total sample involved physician referrals to alternative practitioners (this would differentiate from other studies discussed earlier, such as Verhoef and Sutherland (1995), which pointed to a much higher rate of physician referrals to alternative practitioners). Furthermore, previous positive experience with alternative therapies was also a motivating factor for individuals choosing alternative health care.

Concerning the individual choice for alternative practitioners, Kelner and Wellman (1997) state that personal referrals from satisfied patients were significantly more important. Based on their findings, they state that while there were slight variations between alternative modalities, 62% of the total users of alternative practitioners were referred through either a family member, friend, acquaintance, co-worker, or another alternative practitioner (1997:207).

With regard to the individual ability to pay for alternative health care, Kelner and Wellman state that "the ability to pay for treatment is clearly a consequential factor in the utilization of

health care services" (1997:208). The authors argue that the fact that the majority of alternative medicine users have high incomes places them in a better position to afford private alternative treatments, should they so choose. As will be discussed in later sections, the relative high cost of alternative treatments can be attributed to the marginalization of these health services by a "dominant" biomedical health care structure. This would support Navarro's (1976) argument that along with medical dominance and iatrogenesis, unequal capitalist class processes are clearly influential in the use and choice for health care. Previous studies (Eisenberg et al. 1993; Fulder 1988) have also shown that income level is an important factor for people seeking alternative care. The necessity for sufficient income is important as alternative therapies are rarely supported by government insurance plans, and only partially supported by private insurance companies (Kelner and Wellman 1997).

Concerning the last factor in Andersen's model, the need for care, Kelner and Wellman indicate that out of the 240 alternative medicine users in their study, chronic illness in various forms was the most prevalent illness. Chronic illness in their study involved musculoskeletal, emotional, gynaecological, digestive, and headache-related illnesses (1997:208). Three-quarters of the patients using alternative therapies considered their health problems to be serious. The majority of these individuals, however, regarded themselves as healthy and rated their physical and emotional health as good (1997:208). Furthermore, the authors indicate that out of the total sample of alternative therapy users, the length of time endured suffering from individual illness was higher than that endured by patients of family physicians. Interestingly, while the length of treatment for alternative therapy users was shorter than for individuals using physicians, alternative therapy users went to their practitioner more frequently (1997:208). Additionally,

alternative therapy users felt that illness affected their lives more so than individuals frequenting physicians (1997:208).

In their attempt to assess the influence of an alternative therapy ideology as defined by Pawluch et al. (1994), Kelner and Wellman (1997:210) state that their study reveals a "mixed picture." Their study revealed that individual reasons for alternative therapy use involved both desperation and a strong belief in its effectiveness. Additionally, an interesting theme surfaced in this study identifying a sense of "personal responsibility" in the recognition of illness, in the choice of therapy, and in the promotion of healthy ways of living by alternative medicine users (1997:210).

Lastly, an additional and interesting idea that Kelner and Wellman draw upon is McGuire's (1988) concept of the "flexible self", meaning that an individual is able to draw upon a variety of resources in the search for better health and personal growth (1997:211). The flexible self is then free to choose from a range of options for the care of the self and the body (Kelner and Wellman 1997:211). Using this concept in the analysis of alternative medicine users, conventional medicine becomes just one option among many therapies that may be used to promote health and well-being. Kelner and Wellman conclude that the 1990s are characterized by "smart consumers" in health care, whereby well-informed individuals prefer to use their own judgement regarding health care decisions, by avoiding "institutional legitimacy" or a reliance on dominant health care structures (1997:211).

Necessity for Research on Patient use of Alternative Medicines

Turning outside of Canada, medical anthropologist Dr. Ursula Sharma, has researched the combined use of complementary and alternative medicine in Britain, and provides valuable insight towards the study of alternative medicine. In her essay, "Contextualizing Alternative Medicine: The Exotic, the Marginal and the Perfectly Mundane", Sharma states that recent developments in plural medicine worldwide have peaked the interest of anthropologists and other social scientists (1993:15). Sharma states that the abilities of an anthropologist may be implemented in the study of health seeking behaviour towards the use of plural therapies (1993:18). Anthropologists are ideal for observing the relationships between individuals' conceptual beliefs about health and illness, and their resulting action towards therapy use (Sharma 1993:18).

Sharma states: "It is by contextualizing alternative medicine in terms of the agency of the patient that anthropologists can make their most distinctive contribution to its study" (1993:18). Sharma, however, also questions the role anthropologists may have in researching this new phenomenon in light of past studies on medical pluralism in "Third World" countries (1993:15). She suggests that current studies in Western countries should not label alternative practitioners as an "other" to be studied, or as ideational "cultures" or "marginalities" (1993:15). Instead, they should rather incorporate a contemporary understanding of plural therapies which encompass an holistic system of health services (1993:15-17). Sharma also states that any study examining plural therapies must be flexible enough to include the diversity of therapies used by individuals, as boundaries are often blurred between therapies (1993:15-16). Based on her research, Sharma states that the individual's initial classification of diseases, or conceptual illness framework, is key to understanding the resulting use of plural therapies (1993:17).

Summary

The above sources reveal that there have been only a select number of detailed qualitative Canadian research projects examining the use of alternative and/or complementary therapies among individuals suffering from illness. In addition, Sharma (1992) indicates that anthropologists may be key to understanding this process by valuing the individual's use and perception of alternative therapies. While some of the larger quantitative studies reveal that Canadian physicians are referring patients to alternative/complementary health care services, it is clear that physicians know little about these therapies in terms of function, the extent of patient use, or the individual conceptualization of illness (LaValley and Verhoef 1995:47).

Thus, there is a pressing need for a qualitative examination by anthropologists and social scientists alike, of the use of alternative/complementary therapies by individuals suffering from illness in Canada. Continued studies in this area will begin to address a large gap evident in past Canadian studies. Moreover, studies examining the use of alternative therapies among individuals may be used by physicians and health care providers to gain a greater understanding of, and appreciation for, the effectiveness of alternative therapies. Additionally, health care providers and illness sufferers alike may greatly benefit from an understanding of how individuals conceptualize illness while using alternative therapies (Vincent and Furnham 1997:148-9).

Chapter One: The Illness Narrative

In this chapter, the illness narrative is defined, explored in detail and discussed, as it forms one of the main methodological and theoretical foundations for this study. As indicated earlier, the illness narrative can exist simultaneously as theory and method, depending on the context in which it is applied (Hyden 1997). The dual function of the illness narrative only reinforces the powerful concept that the narrative comprises.

Defining the Narrative: Thematic, Theoretical and Methodological Considerations

Hyden states: "The narrative is one of several cultural forms available to us for conveying, expressing or formulating our experience of illness and suffering. It is also a medium for conveying shared cultural experiences" (1997:64). Arthur Kleinman, in his book "The Illness Narratives: Suffering, Healing and the Human Condition" (1988), further defines the *illness narrative* by stating:

> Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition (1988:xiii).

Lastly, Frank states the illness narrative "falls within a loose collection of studies that emphasize the importance of story as a way of dealing with traumatic occurrence" (1998a:330).

In his valuable essay, "Illness and Narrative" (1997:48), the social scientist Lars-Christer Hyden states: "It is argued that as social scientists we can use illness narratives as a means of

studying not only the world of biomedical reality, but also the illness experience and its social and cultural underpinnings." The narrative, however, has far from long been valued for conveying social, cultural and personal meaning surrounding illness. Supporting Kleinman, Hyden states that the traditional medical view has been to regard patients' complaints about symptoms and problems with severe skepticism (1997:48). Patients' meanings pale in comparison to the medical language of organs and tissues, and to the focus on only the bodily world of the patient (1997:48) The irony, as Hyden indicates, is that doctors must depend on the patient report in order to investigate and diagnose the disease (1997:48).

Despite the medical devaluation of the patient experience, a recent shift in the medical social sciences and related fields has virtually exploded with a focus on the illness narrative. The narrative, as Hyden states, has become recognized as:

> one of our most powerful forms for expressing suffering and experiences related to suffering [. . .] patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice [. . .] the narrative's importance lies in its being one of the main forms through which we perceive, experience, and judge our actions and the course and value of our lives (1997:49).

In an increasingly fragmented and postmodern world, the illness narrative begins to replace the "grand" narratives of the past by providing multiple interpretive, context-specific, and subjective meanings (Frank 1995; Hyden 1997; Lyotard 1984).

While the early analysis of narratives focussed only on forms of representation such as identity and self, more recent analysis focusses on narrativity as a means to convey conceptual frameworks towards the knowledge and understanding of the social world (Hyden 1997:50). Hyden furthermore indicates that there has been a shift in the use of the narrative concept in the field of medicine and illness *thematically*, *theoretically* and *methodologically* (1997:51).

Thematically, interest in the narrative has shifted away from its use in the study of clinical and practical experiences, to a focus more on the patient's experience of suffering. Theoretically, while previously occupying a peripheral position in the social scientific study of illness, today the narrative plays a far more central role by capturing central aspects of illness experiences and their social contexts (Hyden 1997:51). This theoretical shift, Hyden argues, is also a reflection of the change towards greater emphasis on suffering as a focus for research (Hyden 1997:52). Methodologically, Hyden states that earlier views on illness narratives were based on the idea that identity could be conceived in terms of one individual life history. Today, however, there has been an increasing awareness that situational and contextual factors play a decisive role in the construction of narratives, and in the establishment of "collective meaning."

Theoretically, narratives can become characterized by multiple temporal events (Hyden 1997:50). In other words, narratives can "knit together the split ends of time", thereby constructing new contexts, or creating new meaning from the past (Hyden 1997:53; Garro 1992). Narratives then provide a context that encompasses both the illness event, and the surrounding life-events, recreating a state of interrelatedness from something that has previously been lost (Hyden 1997:53; Frank 1995). New meanings are created as the narrative brings together illness symptoms, biographical contexts, diagnoses and prognoses into a framework. Furthermore, the narrative offers the possibility for new interpretations, and can become a forum for presenting, discussing, and negotiating illnesses, and how one relates to illness (Hyden 1997:53).

"Illness", "Disease" and "Sickness"

To understand the illness narrative, it is important to recognize distinctions between *illness*, *disease*, and *sickness*. Kleinman defines *illness* as referring to "how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability" (1988:4). Illness, therefore, is not only constrained to purely biological processes, nor is it restricted to the illness sufferer alone. Illness, as defined by Kleinman, is the "*lived* experience of monitoring bodily processes [. . .]", and includes "categorizing and explaining, in common-sense ways accessible to all lay persons in the social group, the forms of distress caused by those pathophysiological processes" (1988:4; emphasis added). Illness experience must also include the patient's judgements about how best to cope with distress, and with the resulting practical problems in daily living (1988:4).

More specifically, illness can be defined as the "principal difficulties that symptoms and disability create in our lives" (Kleinman 1988:4). For example, one may be unable to walk up the stairs to the bedroom, or one may experience distracting low back pain while sitting at work (1988:4). Additionally, illness involves feelings such as anger due to our pain not being perceived or validated, personal demoralization and hopelessness in the thought that the disability may last forever, and family pressure to get well. "All these", Kleinman states, "are illness problems" (1988:4).

Disease, on the other hand, is "what the practitioner creates in the recasting of illness in terms of theories of *disorder*" (Kleinman 1988:5; emphasis added). The biomedical practitioner "reconfigures the patient's and family's illness problems as narrow technical issues, disease problems" (Kleinman 1988:5). Disease becomes, from the practitioner's perspective, a "problem"

or a "deviation" (Kleinman 1988:5; Frank 1997). This disease problem is then reconfigured purely as an "alteration in biological structure or functioning" (Kleinman 1988:6). For example, chest pain may be reduced to chronic coronary artery disease, while the patient's fear and the family's frustration remain unaddressed (1988:6). Kleinman states:

> In the practitioner's act of recasting illness as a disease, something essential to the experience of chronic illness is lost; it is not legitimated as a subject for clinical concern, nor does it receive an intervention [. . .] It turns the gaze of the clinician, along with the attention of patients and families, away from decoding the salient meanings of illness for them, which interferes with recognition of disturbing but potentially treatable problems in their life-world (1988:6;9).

In between illness and disease, is *sickness*--"the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces" (Kleinman 1988:6). For example, the relationship between tuberculosis, poverty and malnutrition may be termed sickness. In another example, the effects of the tobacco industry on the morbidity of lung cancer in North America is also a form of sickness (1988:6). Sickness helps to provide an important context for the understanding of illness and disease, by providing an explanatory framework to understand epidemiological patterns.

Constructing the Illness Narrative

Illness meaning is complex. It often involves multiple or multivocal meanings, with potential, actual, and concealed messages (Kleinman 1988:8). For example, chronic illness is more than the sum of its parts, it becomes inseparable from life history (1988:8). Meanings are bound within relationships, such as with the sick person's spouse, child, friend, or care giver. There are, as proposed by Kleinman, four categories of meaning which form the illness narrative.

These categories may be organized into a series of interrelated levels represented as: (1) life-world; (2) symptom as meaning; (3) cultural significance, and (4) clinical reality (**see Figure 1**).

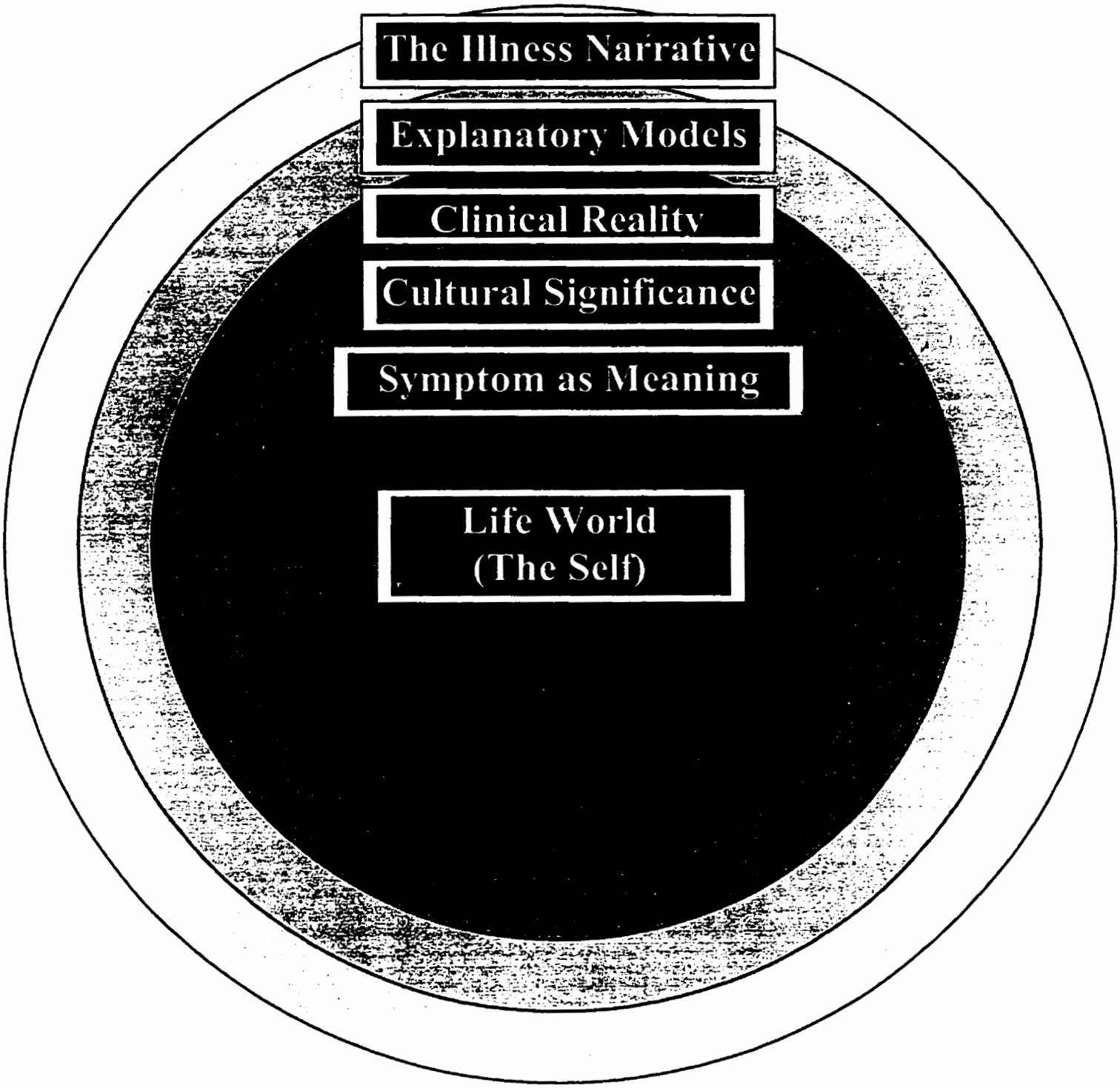
Beginning with cultural significance, Kleinman states that:

> [. . .] particular symptoms and disorders are marked with cultural salience in different epochs and societies [. . .] Each patient brings to the practitioner a story. That story enmeshes the disease in a web of meanings that make sense only in the context of a particular life. But to understand that life and the illness experience it creates, we must relate life and illness to cultural context (1988:18;96).

Examples of different culturally specific meanings towards illness are the bubonic plague or "Black Death" in the European Middle Ages, the "cult of invalidity" towards women of nineteenth century Europe and North America, Chinese "Fengbing" or mental illness, accusations of witchcraft in early Puritan New England, and the Western stigmas towards cancer, heart disease and AIDS in the late twentieth century (Kleinman 1988:18-19; Mitchinson 1991). Taking the new diseases of the Western world as a focus, cancer, for example, is viewed as a "reminder" of unpredictability, uncertainty and injustice, and indicates a lack of control over our own bodies (Frank 1991; Kleinman 1988:20). Cancer victims are also negatively stigmatized and even feared (Sontag 1988). Furthermore, heart disease is viewed as an indicator of our frenetic pace of life, while AIDS brands the victim as a stigma of "venereal sin" and "amoral promiscuity" (Kleinman 1988:22).

Related to embodied forms of social experience which shape bodily states, culturally salient illness meanings also shape suffering, with regard to distinctive moral or spiritual forms of distress (Kleinman 1988:26). Illness behaviour is directed by local cultural systems. Kleinman states: "[. . .] cultural meanings mark the sick person, stamping him or her with significance often unwanted and neither easily warded off nor coped with. The mark may be either stigma or social

Figure 1: Constructing The Illness Narrative



death" (1988:26). Furthermore, just as sickness links illness with disease, so too does cultural illness meaning mediate between sickness, as represented on a purely and alienated physiological level, and the embodiment of sickness as a human experience (1988:27). Cultural forms of illness meaning also provide justification and affirmation in the social world. Thus, the body and self is mediated by cultural symbols of a religious, moral, or spiritual kind.

Proceeding to symptom as meaning, it can be defined as the "indication of a symptom for a disability or distress" (Kleinman 1988:10). For example, back pain, palpitations or wheezing are classified as a symptom meaning. The symptom meaning is furthermore grounded in culturally standardized "truths" or common sense knowledge, which are ultimately embedded in a cultural system or knowledge base (1988:10). Because of these factors, each symptom expression takes on a unique and coloured meaning for the illness sufferer.

Contained within the level of symptom meaning are forms of knowledge about the body, the self, and their relationship to each other and to the life world (Kleinman 1988:11). For example, for many members of non-Western societies, the body is an open system linking social relations to the self, and represents a vital balance between interrelated elements in a holistic cosmos (1988:11). The body is not restricted to the private domain of the individual, but is an organic part of a mythological system linking the body to communicate with the cosmos. Additionally, social meaning is "stamped" into bodily processes and experiences (Kleinman 1988:12). Social experience becomes embodied, in the way we feel and experience our bodily states and appear to others (1988:12). "To understand how symptoms and illnesses have meaning", Kleinman suggests, "we first must understand normative conceptions of the body in relation to the self and world. These integral aspects of local social systems inform how we feel,

how we perceive mundane bodily processes, and how we interpret those feelings and processes" (1988:13). Thus, "illness idioms crystallize out of the dynamic dialectic between bodily processes and cultural categories, between experience and meaning" (Kleinman 1988:14).

At the core of illness meaning is the life world. It is in the life world that illness meaning becomes embodied, by incorporating personal and social significance as they are associated with illness. Whereas cultural meanings of illness carry significance to the sick person, it is the life world which carries meaning from the individual's life to the illness experience (Kleinman 1988:31). In the life world, sociocultural, psychological and spiritual issues become entwined, and each may influence the other. It is here that psycho-spiritual issues, for example, may directly affect an individual's illness. Kleinman states that there is now a strong body of evidence which suggests that psychological and social factors play a key role in the worsening of chronic symptoms (see Katon 1982; Kleinman 1986). It is from here that illness stems. The role of symbols and text with regards to meaning is also paramount in the life world. Kleinman states:

> Symptom [. . .] is interpreted in the context of the special meanings within which the illness is embedded. Symptom and context can be interpreted as symbol and text. The latter extends and clarifies the significance of the former; the former crystallizes the latent possibilities of the latter. The text is laden with potential meanings, but in the symptom-symbol only one or a few become effective (1988:42).

Contained within the life world is a second level, that of explanation and emotion as meaning (Kleinman 1988:43). It is in this level that the individual constructs meaningful ideas which contextualize the illness in the language of the patient.

In addition to the three levels of illness meaning which form an illness narrative, a fourth level becomes apparent which is separate but related to the previous levels, that of clinical reality. There, the interpreter of the illness narrative, whether a clinician or anthropologist, is important

for respecting the inherent meaning contained within the narrative (Kleinman 1988:52-53). As Kleinman indicates, the act of recording a case in the medical record, while at first may seem to be an "innocuous" means of description, can be anthropologically interpreted as a "ritual act of transformation through which illness is made over into disease, person becomes patient, and professional values are transferred from the practitioners to the "case"" (1988:131). The recording of the case can be seen as a secular ritual through which social reality is replicated while following the core values of the biomedical paradigm.

In the act of writing up a patient account, the practitioner may turn the sick person from a subject, to an object of professional inquiry or manipulation (Kleinman 1988:131). As in the medical case of Melissa Flowers that Kleinman details, "gone from the record is Melissa Flowers as a sick person under great social pressure, worried and demoralized by difficult family problems" (1988:135). Mrs. Flowers is permitted to speak about her disease, but not about her illness, her physical complaints are authorized, but her psychological and social issues remain unaddressed (1988:135). The diagnosis becomes a "systematic distortion" of the interview, where only facts that relate to disease and its treatment are allowed to emerge (1988:135). The chronicity of illness on a social and personal level is denied. The practitioner must be wary of these very issues.

The interpreter of the narrative must become responsible for "empathic witnessing": "[. . .] the existential commitment to be with the sick person and to facilitate his or her building of an illness narrative that will make sense of and give value to the experience" (Kleinman 1988:54).

Kleinman states:

> One of the core tasks in the effective clinical care of the chronically ill--one whose value it is all too easy to underrate--is to affirm the patient's experience of illness as constituted by lay explanatory models and to negotiate, using the specific terms of those models, an acceptable therapeutic approach. Another core clinical task is the empathetic interpretation of a life story that makes over the illness into the subject matter of a biography. Here the clinician listens to the sick individual's personal myth, a story that gives shape to an illness so as to distance an otherwise fearsome reality (1988:49).

Linked to all four levels of illness meaning is the concept of the explanatory model (see **Figure 1**). Kleinman defines "explanatory models" as "notions about an episode of sickness and its treatment that are employed by those engaged in clinical processes, whether patient or clinician" (Kleinman 1980:260, in Kaufert 1990:212). Kleinman (1988:121) further describes explanatory models as "the notions that patients, families, and practitioners have about a specific illness episode."

The explanatory model is important for several reasons. First, the explanatory model shapes individual personal illness meaning, as in the life story. In this case, the model becomes the "informal descriptions of what an illness is about", drawn from the individual's life world, which "congeal and unravel" (Kleinman 1988:122). The individual constructs personal explanatory models for the areas of disease etiology, symptomatology, pathophysiology, and natural history (Kleinman 1980; Helman 1985; in Kaufert 1990). For example, the following questions are addressed in the personal explanatory model: What is the nature of this problem? Why has it affected me? How does it affect my body? (Kleinman 1988:122).

Areas such as pathophysiology, for example, are traditionally regulated by and directed to the domain of biomedicine, but these areas may also be addressed in the explanatory model by

forming valid testimony to illness experience. Furthermore, they are important for differentiating the clinician's model from the patient's model (Helman 1985; in Kaufert 1990). Kleinman, for example, states that explanatory models are "responses to urgent life circumstances", because of this they are justifications for practical action (1988:121). Second, the explanatory model is important for how it becomes useful to the individual's family, who also contribute to illness meanings (Kleinman 1988).

Third, the explanatory model is integral for mediating between client and practitioner interaction (Kaufert 1990). For example, assuming there is a valid and equal interpretation of the patient's model by the physician and/or interpreter, the personal explanatory model guides proposals for treatment by the practitioner (Kaufert 1990). The individual's explanatory model also becomes useful by helping the practitioner to value the individual's illness experience (Kleinman 1988:122). The practitioner may further help the individual and family to understand personal illness conceptions (1988:122).

In sum, life-world, symptom meaning, cultural significance and clinical reality are integral to forming the personal illness narrative. They are connected by and incorporate explanatory models from both social and cultural contexts, practitioner, family and illness sufferer. Drawing from the social and cultural world within which the illness sufferer exists, illness experience is shaped by socio-cultural definitions of disease and illness behaviour. At the core of the illness experience, however, is the individual's life world, where socio-cultural definitions of illness and suffering become enmeshed with personal meaning. It is here that personal illness meaning is created, apart from socio-cultural norms. Finally, the interpreter of the narrative plays a key role in ensuring that individual meaning is properly recorded and communicated, by empathically

validating personal illness experience. Kleinman concludes:

> Thus, patients order their experience of illness--what it means to them and to significant others--as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. Over the long course of chronic disorder, these model texts shape and even create experience. The personal illness narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering. To fully appreciate the sick person's and the family's experience, the clinician must first piece together the illness narrative as it emerges from the patient's and the family's complaints and explanatory models; then he or she must interpret it in light of the different modes of illness meanings--symptom symbols, culturally salient illnesses, personal and social contexts [. . .] Illness narrative, again like the ritual use of myth, gives shape and finality to a loss [. . .] Telling this tale is of great significance (1988:49;50).

Types of Illness Narratives

While the illness narrative may stand on its own, thereby representing illness meaning, there has been much literary debate as to types of illness narratives. As Hyden (1997) suggests, illness narratives are concerned in a broad sense with issues such as illnesses, illness episodes and illness experiences, but may also be broken down into specific classificatory frameworks. Frank cautions that by classifying illness narratives, there is always the risk of creating yet another "general unifying view" of the illness experience (1995:76). Ultimately, he suggests, classificatory frameworks act as a form of "listening device" to encourage closer attention to the stories of sick persons, by "sorting out the threads" of narratives of illness (Frank 1995:76). Furthermore, it is recognized that the inherent nature of narratives often encompass many different genres, thereby blurring boundaries between classifications (Frank 1995:76). Thus, classifying illness narratives can only be a general tool for understanding illness meaning.

The "Restitution" Narrative

Arthur Frank, author of The Wounded Storyteller: Body, Illness, and Ethics (1995), classifies the illness narrative according to three main genres: "restitution", "chaos" and "quest." The restitution narrative can be defined generally as the denial of illness, achieved by the individual focussing exclusively on the restoration of good health, realistic or unrealistic as that may be: "Restitution stories attempt to outdistance mortality by rendering illness transitory" (Frank 1995:77;115). Individuals constructing restitution narratives often outrightly deny that they are sick. For example, a cancer patient undergoing surgery may deny or make light of the fact that s/he is facing a potentially fatal illness (Frank 1995:78). In another example, cancer support groups may only concentrate on discussion with those members who are in remission, rather than those who are in the midst of the disease (1995:78).

Frank states that the restitution narrative does not only reflect a "'natural' desire to get well and stay well", but also follows institutional models for how illness is to be told (1995:78). For example, in one popular American hospital brochure, cancer patients are portrayed as unilaterally overcoming the disease, while the treatment process through which this was achieved, including less successful case-studies, are completely overlooked (Frank 1995:79). Thus the brochure, by focussing on particular illness stories, encourages the restitution narrative by defining "models of the stories patients *ought* to tell about their own illnesses" in an institutional framework which only values the "culturally preferred" narrative (Frank 1995:79,83; emphasis added).

Furthermore, the restitution narrative is inextricably tied to the "Parsonsian sick role" ultimately ingrained in biomedicine, and which defines getting well as the only option after an illness episode. Frank states:

> Precisely because getting well is the only outcome Parsons considers as acceptable, his theory of the sick role both reflects the assumptions of modernist medicine and inscribes the validity of these assumptions in a broader narrative of what society requires to function successfully (Frank 1995:82-83).

Additionally, the restitution narrative fosters a self which ultimately becomes "dissociated" or cut-off from the body (Frank 1995:85). Supported by the modernist deconstruction of mortality in which the body is compartmentalized into a series of parts, the restitution narrative claims only a *body* which needs to be "fixed" (Frank 1995:85-86). Frank states: "In the restitution story, the implicit genesis of illness is an unlucky breakdown in a body that is conceived on mechanistic lines [. . .] In modernist thought people are well *or* sick. Sickness and wellness shift definitively as to which is foreground and which is background at any given moment" (Frank 1995:88;9; original emphasis). Lastly, the cure for a restitution body can only be commodified, supported by the commercial-medical notion which proclaims, "for every ailment there is a remedy" (1995:88). The drawbacks of the restitution narrative are clear--it has the capacity to rob meaning from the families of dying patients, and, for those patients living with illness, leaves nothing to fall back upon (Frank 1995:94).

The "Chaos" Narrative

Opposite of the restitution narrative, the chaos narrative imagines life never getting better (Frank 1995:97). Whereas restitution stories reassure the listener that a happy ending is possible, chaos stories are devoid of any hope for establishing good health. Chaos narratives are furthermore characterized by the absence of narrative order, without sequence or discernable causality (1995:97).

The pure essence of a chaos story in fact cannot be told, as it does not contain words, nor can it be directly communicated through language. It is only through retrospective reflection and meditation by the storyteller, that enough distance is achieved for the telling of a story (Frank 1995:98). Thus, in pure form, the chaos narrative is not a narrative at all, but an "anti-narrative", representing "time without sequence, telling without meditation, and speaking about oneself without being fully able to reflect on oneself" (Frank 1995:98).

Key elements that may identify a chaos narrative are stories which suggest that what is being told is only the "tip of the iceberg" for all that is wrong (Frank 1995:99). Other direct features, as mentioned, are a lack of narrative order, conveyed through the narrative phrases of "and then and then and then", which ultimately interrupt the teller's own narrative flow (1995:99). Additionally, lack of control, such as a cancer patient may feel towards his or her body, is a key factor of the chaos narrative.

The chaos narrative is one of the most difficult to hear, as it represents one of the most embodied forms of a story (Frank 1995:101). Chaos stories are both on the edges of a wound, and on the edges of speech (1995:101). The chaos story, Frank suggests, is told in the silences that speech cannot penetrate or illuminate (1995:101). Furthermore, because the chaos story is always beyond speech, it is always lacking in speech, as "chaos is what can never be told; it is the hole in the telling" (1995:102).

A good example of the chaos narrative are the stories told by Holocaust witnesses and survivors. In Holocaust stories, there exists a "hole" in the narrative which cannot be filled in (Frank 1995:95). Frank writes, "The story traces the edges of a wound that can only be told around. Words suggest its rawness, but that wound is so much of the body, of its insults, agonies,

and losses, that words necessarily fail" (1995:98). Holocaust chaos stories furthermore directly invert modernist presuppositions of liberation as the end result for Holocaust survivors. Witnesses, on the other hand, do not think of liberation as any great dividing line that orders their experience. "The Holocaust witness who resists this narrative imposition inverts the narrative order by showing the interviewer the inapplicability of finding any ending in liberation" (1995:105).

Frank states that there is a great need to honour and respect the nature of chaos stories, and to incorporate them both into moral and clinical contexts (1995:109). Chaos stories must be valued on their own for what they represent, in order to avoid the denial of lived illness experience. Frank states:

> Until the chaos narrative can be honoured, the world in all its possibilities is being denied. To deny a chaos story is to deny the person telling this story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care. Clinicians cannot entertain chaos because chaos is an implicit critique of the modernist assumptions of clinical work (1995:109;111).

The "Quest" Narrative

The quest narrative, differing from both restitution and chaos narratives, meets suffering head on by accepting illness and seeking to use it (Frank 1995:115). Illness forms the basis for a journey, which ultimately becomes a "quest" (1995:115). The goal of the quest may not always be clear, but present is every belief that there is something to be gained from the illness experience (1995:115). Where restitution stories claim identity only through the possible remedy for the illness, and chaos stories represent suffering which is too great to be told, the quest narrative begins from the individual's perspective (1995:115). Quest narratives furthermore tell of

searching for alternative ways of being ill (Frank 1995:117). The idea of illness as a journey emerges as the individual realizes a sense of purpose.

Drawing from Joseph Campbell, Frank suggests that the quest narrative comprises a three stage process: (1) *departure*; (2) *initiation*, and (3) *return* (1995:117). *Departure* begins with a "call", such as the symptom of an illness. The call of departure as a symptom in an illness story indicates that the body is not healthy. The call may initially be refused or denied by the ill person. Eventually, unmistakable symptoms emerge and diagnoses are made, and a "first threshold" is crossed (1995:117). The threshold may be events such as hospitalization or surgery. The crossing of this threshold begins the second stage, that of *initiation* (Frank 1995:118). Initiation is viewed both implicity and explicitly, as it is often only through the initiation process that an awareness of initiation occurs (1995:118). The initiation stage further involves a form of self-conscious transformation.

The final stage is the *return*, characterized by an individual who is marked by illness, and who has travelled through and beyond other worldly experiences (1995:118). The goal of the entire journey is likened to a Bodhisattva, the compassionate being who vows to return to earth to share enlightenment with others (Frank 1995:119). The individual in a quest narrative conveys experiences about overcoming the agony of illness.

Within the three-stage process of a quest narrative, further typologies can be drawn. Quest narratives can also be classified according to three facets: (1) the *memoir*; (2) the *manifesto*, and (3) the *automythology* (Frank 1995:119). The *memoir* combines the telling of an illness story with the telling of other events in that person's life (1995:119). The memoir is similar to an autobiography which has been interrupted by an illness episode. Furthermore, events in the

memoir are not told chronologically, nor are they rehearsed in detail. Rather, the present circumstances become occasions for the recollection of certain past events, continually interrupted by illness (Frank 1995:120).

In contrast to the memoir, the *manifesto* carries a prophetic truth which has been learned from the illness experience, and which carries demands for social action (1995:120). An example of a manifesto quest narrative is the breast cancer survivor who will not conform to medical norms by refusing to wear a breast prosthesis after her mastectomy (Frank 1995:121). "The *manifesto* asserts that illness is a social issue, not simply a personal affliction. It witnesses how society has added to the physical problems that disease entails, and it calls for change, based on solidarity of the afflicted" (Frank 1995:122).

Lastly, the *automythology* draws from the metaphor of the Phoenix "reinventing itself from the ashes of its own body" (Frank 1995:122). Individual change, rather than social reform, is emphasized, as the individual becomes one who not only has survived, but who has been "reborn" (Frank 1995:123). The automythology quest narrative contains words such as *momentous*, *decisively*, *universe*, and *destiny* (Frank 1995:124). The only drawback for quest narratives emerges when, similar to the restitution narrative, a quest goal cannot be found by the individual.

The Care-seeking Narrative

A fourth genre of illness narrative, as proposed by this present thesis research, is the *care-seeking narrative*. As Frank stated earlier (1995:76), an illness narrative can contain aspects of many different genres, despite being classified as one or another. The care-seeking narrative, therefore, is not only concerned with the search for care, and in addition to many other genres, may incorporate aspects from restitution, chaos, and quest.

The care-seeking narrative, as the name implies, encompasses the search for care by the individual. The search for care may be defined as all activities by the individual which are associated with obtaining therapeutic relief from an illness, disease or sickness. The care-seeking narrative should not imply, however, that effective therapeutic relief has been found. For example, the quest narrative does not necessarily imply that all narratives contain aspects of "the quest" (Frank 1995). Rather, the care-seeking narrative is concerned with the *processes* surrounding the search for care.

While the search for care is the focus for the care-seeking narrative, the narrative is also surrounded by additional themes. For example, the narrative encompasses aspects of the individual's illness and conceptual model towards the illness. Aspects of the illness are described, such as when it began (illness genesis), how it may have been caused (illness causation), how the individual thinks about the illness (explanatory model), and how the illness has affected the individual's life (life-disruption). The narrative is also concerned with how these factors influence the search for care.

As the search for care becomes the focus, additional factors also come into play. For example, as Garro indicates (1992), the search for *diagnosis* is paramount in any illness narrative

for how it affects the search for care. Furthermore, as the narratives in this study attest, the search for effective care can also directly affect the illness, induce other iatrogenic forms of disease, and alter the individual's explanatory models. Lastly, the health and healing of the individual is an important focus in the care-seeking narrative, for evaluating how certain therapies may have altered the illness course and contributed to the overall health of the individual. Thus, the care-seeking narrative is entwined with many other interrelated factors.

Illness *as* Narrative, Narrative *about* Illness and Narrative *as* Illness

Differing from Frank's presentation of three main genres in understanding the illness narrative, Hyden proposes a typology based on the formal aspects of illness narratives, that of the relationship between narrator, narrative and illness (1997:54). Hyden proposes three ways in which narrator, illness, and narrative may be interrelated: (1) illness *as* narrative; (2) narrative *about* illness, and (3) narrative *as* illness (1997:54).

Beginning with illness *as* narrative, Hyden states that narrator, illness and narrative are combined in one and the same person (1997:54). The illness is expressed and articulated both in and through the narrative form (1997:54). In addition, the narrative plays a central role in the illness genesis, and in influencing how the illness shapes the life of the individual. In effect, the illness *becomes* the narrative, by depicting personal illness experiences. As in many instances, the illness narrative integrates illness experience into a "new whole", which in turn becomes part of a new social reality (1997:54).

In narratives *about* illness, the narrative conveys knowledge and ideas about the illness (Hyden 1997:54). An example is when doctors or professional caregivers talk about the patient's

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illness. In this instance, the narrative is used in a clinical context to formulate and convey clinical knowledge, whereby the caregiver may gain a more detailed knowledge of the patient (1997:54). As Kleinman has suggested, narratives about illness may be used by the caregiver to satisfy *empathic* witnessing and/or care (1988).

Lastly, narratives *as* illness applies to situations where the narrative generates the illness (Hyden 1997:55). This is similar to Frank's chaos narrative, where the patient lacks sufficient narrational means for expressing or articulating past or present experiences and events (1997:55).

Roles of the Illness Narrative--Why do we Need Illness Narratives?

Traditionally, narrative research has focussed on the written, literary and formalized story. Hyden expands this focus, by asking what can the narrative accomplish with respect to the individual's interaction with others, and the construction of social realities (1997:55). Hyden proposes five interrelated roles that the illness narrative may satisfy: (1) to transform illness events and construct a world of illness; (2) to reconstruct one's life history in the event of a chronic illness; (3) to explain and understand the illness; (4) to assert or project one's identity as a form of strategic interaction, and (5) to transform illness from an individual into a collective phenomenon (1997:55).

In Hyden's first role, "the narrative construction of an illness world", aspects of illness take on unique meanings for each individual (1997:56). In relation to Kleinman's "life-world" discussed earlier, illness is translated into meaningful events which make sense to the life-course of the individual (Hyden 1997:56; Kleinman 1988). In the narrative construction of the illness world, the experience of illness is articulated, while a unified context is constructed (Hyden

1997:56). The illness narrative, as many authors have suggested (Frank 1995; Garro 1992; Kleinman 1988), creates something new, where suffering is given new form, while illness is positioned in time and space within a personal biography (Hyden 1997:56). As Hyden relays, "The narrative transforms symptoms and events into a meaningful whole, thereby creating the world of illness" (Hyden 1997:56). Or, as Arthur Frank states, "Serious illness is a loss of the 'destination map' that had previously guided the ill person's life: ill people have to learn to think differently" (1995:1).

In Hyden's second role, the narrative reconstruction of life history, the reconstruction of identity and personal life is paramount (Hyden 1997:56). As previously noted, chronic illness powerfully affects life-factors such as individuality, identity and life-projects (Kleinman 1988). As a result, illness reshapes personal identities and life histories (Hyden 1997). "By uncovering a means of interpreting the illness, we become better able to re-establish the relationship between the self, the world and our bodies" (Hyden 1997:57). The reconstructing narrative is concerned with giving meaning to illness by placing it in the context of one's life, and with reconstructing the narrative of the self (1997:57). Furthermore, Frank states that stories help to repair the damage that illness has done to the individual's sense of where s/he is in life, and where s/he may be going: "stories are a way of redrawing maps and finding new destinations [. . .] the self is being *formed* in what is being told" (1995:53;55; original emphasis).

In Hyden's third role, the narrative explanation and understanding of illness attempts to address serious questions posed by the individual, such as: Why me? Why was I the one afflicted? How will the illness affect the functioning of my body? (Hyden 1997:57). In the narrative explanation, individuals seek to understand the causes of the illness and to relate the

illness to personal lives (1997:57). This is similar to the explanatory models as defined by Kleinman (1988:121), which encompass not only personal models, but extend to family and caregivers. The narrative explanation may also be used as an avenue to discuss explanations for the illness, or to provide ways to relate to the illness (1997:57). Relating *to* the illness is an integral and important development for transforming illness into part of one's own life (Hyden 1997:58). It is also here that illness may share particular cultural ideas and conceptions towards illness.

In Hyden's fourth role, narratives may also be used as a strategic device by affecting social interaction (Hyden 1997:59). Narratives may be used to assert moral values, and to convey social action such as in Frank's *manifesto* quest narrative (Hyden 1997:59; Frank 1995). As previously mentioned, narratives *about* illness may also be used to aid clinical situations (see for example Clark and Mishler 1992). Frank further states: "[illness] stories can teach professionals what illness feels like as an experience of suffering and what professional behaviour looks like to those being treated" (1998a).

In Hyden's fifth and final role, narratives may be valued by transforming individual experience into collective experience (1997:59). There are many ways in which narratives can transcend individual experience, such as in the case of chronic pain (Garro 1992) and AIDS (Carricaburu and Pierret 1995).

Social Context of the Illness Narrative

It is important to note that while there are many different types of illness narratives and roles at play, they occur in different social contexts. Distinguishing between different narrative contexts is important, due to particular contexts influencing the narrative's form, presentation and interpretation (Hyden 1997:62). For example, Kleinman (1988) focuses on the clinical context for illness narratives, and how they may aid or hinder clinical encounters. Clinical contexts may also be termed "institutional contexts", such as in a medical care environment (Hyden 1997:62). Illness narratives also occur in "everyday contexts", such as when individuals simply relay their illness stories (1997:62). Lastly, illness narratives can occur in "elicited contexts", such as the contexts forming the interviews in this study.

Illness narratives may also be presented in different forms. For example, they may be presented orally or as written textual narratives (Hyden 1997:64). Narratives may also be presented in various social forums ranging from communal narratives focussing on collective experiences, to individualized narrative situations (1997:64). Both narrative context and form are linked to social and cultural contexts, and are tied to historical and temporal changes.

The Narrative in Biomedicine

Kleinman states that the interpretation of illness narratives is a core task of the work of doctoring, but argues that as a whole, this skill has "atrophied" in biomedical training (1988:xiii-xiv). He states that an unintended outcome of the modern transformation of the biomedical care system is it drives "the practitioner's attention away from the experience of illness" (1988:xiv). Consequently, Kleinman argues, the biomedical system contributes to the alienation of the

chronically ill from their professional caregivers (1988:xiv). In part, this is a result of "clinical reality", a result of the clinician's "definition of the problem at hand and the awareness of the others' expectations about how to act therapeutically" (Kleinman 1988:52-53).

Biomedical physicians furthermore "sleuth" for "pathognomonic", or observable pathological signs that pinpoint a specific disease (Kleinman 1988:16). "This interpretive bias to clinical diagnosis", Kleinman argues, "means that the patient-physician interaction is organized as an interrogation" (1988:16). "The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not" (Frank 1995:5). Kleinman argues that while an interrogative style may be necessary to quickly diagnose an acute disease and provide effective treatment as quickly as possible, this method is clinically inappropriate to use with the chronically ill (1988:129). Kleinman further states:

> Practitioners, however, are not trained to be self-reflective interpreters of distinctive systems of meaning [. . .] They are rarely taught that biological processes are known only through socially constructed categories that constrain experience as much as does disordered physiology; this is a way of thinking that fits better with the secure wisdom of physical science than with the nervous skepticism of the medical profession. The upshot is that practitioners, trained to think of "real" disease entities, with natural histories and precise outcomes, find chronic illness messy and threatening. They have been taught to regard with suspicion patients' illness narratives and causal beliefs. The form of those narratives and explanations may indicate a morbid process; the content may lead them astray. The way of the specialist diagnostician, which is not to credit the patient's subjective account until it can be quantified and therefore rendered more "objective", can make a shambles of the care of the chronically ill (1988:17).

Thus the illness narrative, while it may be effectively used in clinical contexts, has yet to be widely applied and valued by biomedicine in the understanding of illness and disease.

Summary

It is clear that the illness narrative is a complex yet useful tool for understanding illness experience. Frank states: "The *personal* issue of telling stories about illness is to give voice to the body, so that the changed body can become once again familiar in these stories" (Frank 1995:2; emphasis included). The illness narrative can convey illness meaning on both personal, cultural, social and clinical levels. The narrative is furthermore constructed on many levels encompassing unique explanatory models, beginning with the "self", and proceeding to cultural and clinical levels. The illness narrative can be interpreted using many different typologies, such as restitution, chaos, quest, care-seeking, illness as narrative, and narrative as illness (Frank 1995; Hyden 1997). Lastly, the illness narrative may play many different roles, and exist in different socio-cultural contexts. For example, illness stories may convey meaning to friends and family in a social context, or aid clinical analysis in a medical context.

In the next chapter, medical dominance is discussed as it provides a context for understanding the use of multiple medical systems by individuals coping with illness. As will be discussed, in addition to valuing narrative accounts, the medical dominance thesis can provide a further understanding of illness experiences by providing cultural and historical significance.

Chapter Two:

An Historical Framework towards the Understanding of Plural Medicine

As stated, this study is exploring medical pluralism by examining individual accounts of illness, by valuing both the individual account and how it may fit into larger structural or "macro" frameworks. While the individual narrative of care-seeking behaviour can be valued on its own for what it represents, a focus on larger structural elements, namely that of "medical dominance", can be valued for providing an additional explanatory framework for understanding medical pluralism. It is recognized here that the narratives presented in later sections may not be able to fully engage the nature of the structural elements. Narratives cannot always provide direct reference to historical developments which have occurred many years earlier, or indicate an "awareness" of shaping structural factors. Nevertheless, the concept of medical dominance provides a useful framework for understanding the historical development of medical pluralism, which in turn can be applied to individual narrative experiences. Moreover, as will be detailed in Chapter Five, there are several themes derived from individual narratives which can be seen to engage the structural elements of medical dominance.

Medical Dominance, Medical Pluralism, and Alternative Medicine: The Power Over Health

The role and influence of medicine in the Western world has long been a topic for discussion and analysis in the social sciences. In particular, the notion of "medical dominance" has been given much attention. Beginning with Freidson's (1970) discussion of medicine and professionalism, "medical dominance" has been defined as "consisting of the control over the content of care, over clients, over other health occupations, and over the context of care" (in Coburn 1988:92-116). Indeed, it is clear that the dominance of medicine is very real. For example, the power and position of doctors have played a principle role in determining the shape of the health care system, and in the evolution of modern medicine as a whole (Larkin 1988:117-33). The medical profession is further viewed as the clearest example of "professionalism", whereby medicine has gained autonomous control of its knowledge base, clinical practices, and competing health occupations (Larkin 1988).

While the historical development of medical dominance is not questioned, the extent to which medicine dominates the reality of health care today has fuelled much debate. Freidson argues medicine has retained its elitism through "restratification", maintained through the control of the medical system by a select number of physician elites (Freidson 1994). Others such as Coburn, however, contend that recent changes have led to a decline in the power and prestige of medicine, also known as "proletarianism" (Coburn et al. 1997:1-22). While medicine may be retaining its autonomy, scholars argue it is certainly losing its dominance as a result of the transfer of medical power to government legislation (Coburn et al. 1997). Furthermore, competing health care occupations in the context of medical dominance, also known as "alternative medicines", are

rapidly filling in the void where medical dominance has declined. The question remains as to whether a decline in medical dominance over health care has also led to a decline in the power of the biomedical paradigm to maintain and define health.

Thus the purpose of this chapter is to explore these issues, by discussing the history of medical dominance in Canada and the United States in relation to medical pluralism and alternative medicine. "Medical pluralism", as previously discussed, may be defined as a group of two or more medical systems which are characterized by differing and unique healing modalities, which may form a cooperative or competing health care system for the society in which they occur (Baer 1989). "Alternative medicine" may be defined as a group of a diverse number of healing modalities which have been defined for various reasons by the allopathic medical community as "outside" Western biomedicine (Crellin et al. 1997).

Beginning with the mid-nineteenth century, this chapter will discuss the rise of medical dominance in the context of medical pluralism. In particular, the claim to dominance by medicine over competing or alternative health occupations such as homeopathy will be emphasized, with particular reference to the processes in which these competing occupations were eliminated or co-opted into the medical profession in Canada and the United States. The "fall of medical dominance" thesis as proposed by Coburn (1993:129-38; 1988; et al. 1983:407-32) will then be discussed in detail in the Canadian context, with particular reference to the role of alternative medicines. It will be concluded that the fall of medical dominance has led to an increase in autonomy for competing alternative health occupations, while the dominance of the biomedical paradigm to maintain biomedical notions of health has weakened, illustrated by the rise of alternative notions of health and what it means to be healthy.

Medical Pluralism in the Nineteenth Century: The Rise of Medical Dominance

Baer (1989:1103) states that: "the relationship between biomedicine and alternative medical systems has been characterized by processes of annihilation, restriction, absorption, and even collaboration." Other authors frequently contend that alternative practices can either be (a) absorbed or co-opted into conventional medicine, (b) disappear or become an accepted specialty (Crellin et al. 1997:55). In order to fully understand the process of medical dominance over alternative health occupations, a discussion of the nature of health occupations in the nineteenth century is first necessary.

Medical dominance in Canada and the United States began in the mid-nineteenth century, when medicine mostly lacked power and status, and firmly established itself by World War I, at which time it largely controlled the growing means of health production (Coburn 1988; Coburn et al. 1983). It is in this period that medicine was transformed both internally and externally "to give it a uniquely powerful and monopolistic position in the healing division of labor" (Coburn et al. 1983).

Early Plural Medical Systems

In early nineteenth-century society, two health systems coexisted: a "domestic mode" in which medical care was performed within the family, and a "petty commodity mode" in which medical care assumed a monetary exchange value (Baer 1989). The former consisted of a variety of folk-medical systems, such as Euro-American ethnomedicine, African-American medicine, and American-Indian medicine (Baer 1989). These were often labelled "heterodox" medical systems (Hamowy 1984). The latter consisted mainly of allopathic or "orthodox" medicine, which was

performed by trained physicians who charged a fee for their services. Competing and non-allopathic health occupations such as homeopathy, while also performed by trained physicians for a fee, remained a heterodox medicine. As will be seen, this form of medicine did not maintain its commodity value over time (Baer 1989).

Homeopathy vs. Allopathic Medicine

The were clear differences between allopathic and homeopathic medicine. Allopathic medicine relied extensively on "heroic" treatment consisting of massive blood-letting, blistering, and the administration of purgatives and emetics (Hamowy 1984:23). Between 1780 and 1850, this form of treatment was favourably used by the University of Edinborough medical school (Joan Townsend, personal communication 1998). The most common forms of heroic treatment were the mineral poisons of calomel (mercurous chloride) and tartar emetic (tartrate antimony) given to "cleanse the stomach and bowels" (Baer 1989). At times patients did not survive this regimen, as the level of endurance demanded by this form of treatment was often worse than the illness itself (Hamowy 1984:23).

Homeopathy, on the other hand, was characterized by non-toxic, low-dose remedies with little or no side-effects. Homeopathic medicine was developed in early nineteenth-century Germany by the German physician Samuel Hahnemann (1755-1843). Hahnemann had obtained a formal rigorous allopathic medical education, but soon became distrustful of allopathic treatments (Hamowy 1984:25). Hahnemann's research led him to the conclusion that the most efficacious remedy for any illness consisted of a substance that, when given to a healthy person, mirrored similar symptoms of the particular illness at hand. Further, when administered to a person

exhibiting these symptoms, the remedy resolved the illness. This theoretical construct, *similia similibus curantur*, "like treats like" or the "law of similars", became the foundation for homeopathic therapeutics (1984:25).

Contrary to strong allopathic drugs, homeopathic remedies consisted of particular flora and fauna suspended in extremely dilute solutions through a process known as "succession" or violently shaking the solution. The more dilute solution had the stronger the effect. Low dose solutions, for example, would consist of one drop of the compound from a "mother tincture", and 99 drops of pure alcohol or water. This would give a ratio of 1/100, 0.01 or 1CH (Panos and Heimlich 1980). Dilutions in Hahnemann's time went up to 200 CH and more. Homeopathy further supported the recuperative powers of the organism itself, and advocated fresh air, proper diet, sunshine, bed rest and personal hygiene, none of which were supported by nineteenth century allopathic medicine (Hamowy 1984:26).

Hahnemann published his first book on homeopathy in Germany in 1810. He became well-known for treating a Cholera epidemic, when allopathic medicine had failed. Homeopathy was brought to North America by a German physician in 1828, who settled in New York City (Hamowy 1984:26) (see **Figure 2**). Homeopathy was then imported to Canada in Ontario by Joseph J. Lancaster, who quickly developed a popular following (1984:26). As Ontario was the most accessible province for American travellers and settlers, it became a major destination for irregular practitioners such as homeopaths (Connor 1991:59). Additionally, Canadian practitioners residing in Ontario often attended American schools in the neighbouring states of Ohio, Pennsylvania, New York and Michigan (1991:59).

The Hahnemann Medical College was established in 1836 in Philadelphia, and the American Institute for Homeopathy was established in 1844. Homeopathy soon found a niche in the competitive medical market-place, and before it became popular with the wealthy was first popular with the working classes. The main reason for homeopathy's popularity was that it was often the only form of care in physician-starved areas (Baer 1989). Also, where elite physicians were available, they were far more expensive than homeopathic physicians (Baer 1989). For example, in the mid-nineteenth century, the allopathic physician ratio in Canada was at times one physician for every 2,400 residents (Hamowy 1984:15;21).

FIGURE 2: CHRONOLOGY OF THE ESTABLISHMENT OF ALTERNATIVE THERAPIES IN 19TH CENTURY NORTH AMERICA

1813	"Thomsonianism" developed by Samuel Thomson
1820	Eclecticism founded by Wooster Beach
1828	Homeopathy first introduced in New York
1844	Establishment of the American Institute for Homeopathy (AIH)
1859	Canadian Bill recognizing legal rights of homeopaths in Ontario
1861	Canadian Bill recognizing legal rights of eclectics in Ontario
1865	Homeopaths achieve legal recognition in Canada East; Creation of the Montreal Homeopathic Association and the Canadian Institute for Homeopathy
1866	Development of "Christian Science" by Mary Baker Eddy
1869	Ontario Medical Act incorporates homeopathic and eclectic representation on the Canada Medical Council; Homeopathy and eclectic medicine are gradually absorbed into the College
1870	The American Medical Association (AMA) includes homeopaths and eclectics on medical examining boards
1892	Development of osteopathy by Andrew Taylor Still
1895	Development of chiropractic therapy by Daniel David Palmer
1900	Eclectic medicine completely disappears in Canada

Thomsonianism, Eclectic Medicine and Christian Science

"Thomsonianism" was also a popular alternative to orthodox medicine, and was formed by lay healers, herbal practitioners, artisans, farmers and working people (Coburn et al. 1983). Developed in 1813 by a New Hampshire farmer named Samuel Thomson, thomsonian therapy completely rejected allopathic treatments, attacking mineral poisons as "instruments of death" (Hamowy 1984:24). Thomsonian therapy supported botanical (herbal) remedies, and recommended steam baths and bed rest. As a result, Thomson soon came to be recognized as a medical botany pioneer of both nineteenth and twentieth century times (Crellin et al. 1997). Thomsonianism became quite popular, with the 1822 publication of Thomson's book, "New Guide to Health" (Hamowy 1984:24). The thomsonians continued to fight to remove legislation that provided for the elite status of physicians (Coburn et al. 1983).

A related "irregular" form of medicine that emerged in the latter half of the nineteenth century was called "eclecticism" or eclectic medicine. Formed by previous advocates of thomsonianism, eclectic medicine also incorporated some of the more positive aspects of allopathic medicine into its practice, such as surgery (Connor 1991). It is argued that naturopathy today is simply a revived form of eclecticism, not including forms of allopathic surgery (Connor 1991).

The origins of eclecticism date to the 1820s, when Wooster Beach, a New York physician, founded the first series of eclectic colleges (Connor 1991). Eclectics differed from thomsonians in their inclusion of allopathic practices, and their exclusive treatment of the "enlightened" classes, in direct opposition to thomsonian mentality (Connor 1991). By 1890, more than thirty eclectic colleges had been founded. By the turn of the century, however, eclecticism was in steep decline

partially due to eclectic practitioners' decisions to join ranks with the allopaths, in addition to competition from orthodox physicians.

In addition to homeopathy, the thomsonian movement and eclecticism, there were additional "heterodox" healing systems which challenged orthodox medicine. One of these alternative movements was that of christian science, founded in 1866 by Mary Baker Eddy (Baer 1989). Christian science viewed material reality, including disease and illness, as illusory, and completely eliminated the use of drugs (Baer 1989). One of the main purposes of the christian science movement, clearly related to the goals of the thomsonians, was to protest the restrictive lifestyle that physicians imposed on upper and middle-class women, manifesting in what has been called the "cult of invalidity[1]" (Baer 1989). Because christian science did not administer drugs, however, it was for the most part ignored by allopathic physicians until the early twentieth century.

Osteopathy and Chiropractic Therapy

In addition to christian science, two other non-allopathic medical systems emerged in the latter half of the nineteenth century, osteopathy and chiropractic. Founded by Andrew Taylor Still, an allopathic physician disenchanted with the false claims of allopathic medicine, osteopathy was founded in 1892 on the principle that disease was due to the faulty articulations or "lesions"

[1]For a detailed discussion of the nineteenth-century medical treatment of women in Canada see Mitchinson, 1991

in various parts of the musculoskeletal system (Baer 1989). A particular characteristic of osteopathy was that it extended to those unable to secure an allopathic education or treatment, and welcomed patients from the uneducated classes (Baer 1989). By the 1890s, osteopaths had attained limited practice rights.

Chiropractic was founded in 1895 by Daniel David Palmer, and the Palmer Infirmary and Chiropractic Institute was established in Iowa in 1898 (Baer 1989). Nineteenth-century chiropractic was based on the principle that subtle adjustments of the spinal column could lead to optimum health by resolving energy imbalances. Similar to osteopathy, chiropractic welcomed thousands of students unable to access either allopathic medicine or medical schools (Baer 1989).

The Decline of Pluralism

The nineteenth century was thus characterized by a "pluralistic" health care system with a number of different and competing practicing healing modalities. By 1900, there were estimates of 110,000 allopathic physicians, 10,000 homeopaths, 5,000 eclectics, and over 5,000 other practitioners in the United States (Baer 1989; Coburn et al. 1983). Further, there were 126 allopathic schools, 22 homeopathic Colleges, and 9 thomsonian schools in the United States, while osteopathy was in the process of institutionalization and professionalization (Baer 1989). Medical pluralism was at its height. Key developments in Canadian and American medicine, however, would soon change this diversity.

Nineteenth-century allopathic/orthodox medicine arose in a climate of competing health care, facing two main problems: (a) that of restricting or eliminating competition from opposing alternative health occupations, also called "irregulars"; and (b) attempting to license and unify all

allopathic practitioners, who called themselves "regulars" (Coburn 1988; Coburn et al. 1983).

"Irregular" forms of health care, such as homeopathy and thomsonianism, were considered by many as serious alternatives to orthodox allopathic treatment. As their acceptance became more widespread, however, they were subject to virulent attacks and criticism by the allopathic medical community as "quacks" (Hamowy 1984:26). The term "quackery" arose from the 16th century Dutch word *quackalver*, meaning "one who quacks like a duck boasting about the virtues of his medicinal salves and ointments" (Gevitz 1988). The first publication of the Canada Medical Journal printed an extensive review of a monograph denouncing homeopathy as "derogatory" and "quackery" (1988:63,66). Ironically, allopaths went as far as to accuse homeopaths of manslaughter, when allopaths had often administered fatal remedies. The vicious attacks were widespread throughout medical journals, and were aimed at any form of non-allopathic therapy. As evidenced in this 1832 statement by an anonymous Canadian physician:

> No greater imposition exists in Upper Canada than Quackery--its every-day use makes it appear tolerated by the laws of the land; it is an existing evil under which this Province has long groaned, but to which public attention should be directed. The regular practitioners meets it in every day's travel, is perplexed with its impudence, and with horror views its ravages and its influence (Hamowy 1984:22).

In another example of scathing criticism towards non-allopathic occupations, an October 12, 1838 petition in the Toronto *Patriot* states:

> Quacks are an intolerable nuisance in any and every country, but especially in this, where empiricism and radicalism go hand in hand. It is a monstrous grievance that our government should allow the Province to swarm, as it does, with these pestilent vagabonds... (Hamowy 1984:29).

Antagonism from allopathic medicine towards other health occupations was not universal, however. To the dismay of the allopaths, an 1859 provincial bill passed in Canada West (Upper

Canada) recognized the existence of homeopathic physicians and provided them with their own board of examiners (Hamowy 1984:66). These sentiments were supported by large sections of the Canadian public, who clearly opposed a medical monopoly formed by regular practitioners (Hamowy 1984:61).

Homeopathy, therefore, became the first irregular health profession to be legalized (Coburn et al. 1983). The law provided that an applicant passing the examination set by the homeopathic board, and having satisfied the authorities of his merit, was entitled to practice homeopathic medicine in Canada West (Hamowy 1984:66). Candidates were also required to have spent at least four years in the study of allopathic medicine (1984:66). At the time, homeopathy received further considerable economic and political support from its wealthy clients and patrons (Coburn et al. 1983). In 1861, a second act was passed granting eclectics similar rights. Thus, the medical climate was characterized by a general lack of regulation of all health professions.

Eclectics did not escape criticism, however. In response to the legal recognition of eclecticism in 1861, the Montreal-based *British American Journal* likened eclectics to "vilest imposters who act in the name of medicine" (Connor 1991). Another issue criticizing eclectics stated: "Such are men in general utterly uneducated, many scarcely able to write their own names [. . .]" (Connor 1991).

In addition to government and strong public support, another significant factor in the success of homeopaths and eclectics was the failure of the creation of the College of Physicians and Surgeons of Canada West in 1840, and the subsequent inability of the medical community of Canada West to reinstate this College by 1859 (Hamowy 1984:35;66) (see **Figure 2A**). Canada

East (Lower Canada), on the other hand, had been able to establish their own College of Physicians and Surgeons of Lower Canada in 1847, thus providing stronger resistance to irregulars based on stricter medical licensing laws (1984:49;66). Nevertheless, homeopaths were able to secure legal recognition in Canada East in 1865, creating the Montreal Homeopathic Association, and establishing a homeopathic dispensary, hospital and medical school (1984:67). By this time, the Canadian Institute for Homeopathy was also created (Connor 1991).

At the same time in Canada West, the orthodox medical community achieved some concessions with the enactment of the Medical Act of 1865, which created a medical board empowered to set the educational requirements necessary for medical licensure in the area, and to determine the curriculum to be followed by medical schools in Western Canada (Hamowy 1984:68). Moreover, registration was the sole means through which a practitioner could be licensed, and only registered physicians were entitled to employ any name or title indicating they were licensed practitioners (e.g. physician, doctor of medicine) (1984:68). More significantly, contrary to previous medical acts, the Act contained no severe punishment of unregistered physicians, aside from a $50 fine (1984:75). Therefore, unregistered regular and irregular physicians flourished. Irregulars such as homeopaths gained more autonomy than orthodox medicine had predicted. At this time in mid-nineteenth century Canada, one orthodox physician in the *Upper Canada Journal* described the state of affairs in medicine as equivalent to the "fall of Rome, lest nothing be done to save it" (1984:79).

FIGURE 2A: THE DECLINE OF PLURALISM: CHRONOLOGY OF THE RISE OF MEDICAL DOMINANCE IN CANADA AND THE UNITED STATES

1839	Creation of the College of Physicians and Surgeons of Upper Canada
1840	College of Physicians and Surgeons of Upper Canada disbands
1847	Establishment of the American Medical Association (AMA) in direct response to homeopaths and eclectics
1865	Medical Act establishes medical licensure and educational standards in Western Canada
1867	Establishment of the Canadian Medical Association (CMA)
1869	College of Physicians and Surgeons of Ontario reinstated eclectic and homeopathic representation in the College eliminated
1872	Eclecticism begins to disappear in Canada
1874	Upper Canada Act establishes strict regulation against unlicensed or "irregular" medical practitioners
1900	Homeopathy and eclecticism disappear in Canada
1904	AMA establishes a national annual report to rank medical schools, to be conducted by Abraham Flexner
1906	AMA grants medical licensure exclusively to students enrolled in schools approved by the American Council of Medical Education
1910	Publishing of the Flexner Report
1912	Passage of the Canada Medical Act unifying medical education across Canada
1916-1920	Closure of many allopathic schools in the United States; complete closure of non-allopathic schools in the United States; Complete closure of homeopathic schools in the United States; homeopathy disappears in North America
1920	CMA eliminates self-care by controlling hospitals, health occupations and prescription medicines; Opposition to CMA from populist movements in Canada
1930	Depression drastically curtails CMA power
1940	Canadian Government directly integrates policy planning with CMA; Establishment of Canada's medical elite "Group of Seven"

Allopathic Regulation in Canada

The prayers of the Canadian orthodox medical community to eliminate "irregular" practitioners began to be answered, however. By 1867, the first national federal Canadian Medical Association (CMA) was established, in the words of later Prime Minister Dr. Tupper: "to protect the health and lives of the people of this Dominion from the unskilled treatment of incompetent men, and to provide in the most effectual manner for the due qualification of the members of a profession so important as our own" (Hamowy 1984:97). The CMA's ultimate goal was to eliminate all heterodox "sects" entirely, and had strict rules against "consorting" with irregular practitioners (1984:98). The CMA also strived to establish a uniform system of medical education and code of medical ethics, and regulate the granting of licenses (1984:97). Despite organized discrimination against irregular practitioners, membership in the CMA was poor due to a purely voluntary form of recruitment, with few professional advantages (Connor 1991). Therefore, despite having an organized association, during the early years the CMA posed no real threat or professional disadvantage to irregular practitioners (Connor 1991).

The goals of the CMA began to be established, however, with the passage of the provincial Ontario Medical Act of 1869, also reinstating the Ontario College of Physicians and Surgeons (Connor 1991). The Act incorporated both homeopathic and eclectic representation on the Medical Council, causing much internal friction and controversy among allopathic practitioners (Hamowy 1984:102;105). Opposition to the inclusion of irregular practitioners in the Act, however, quickly turned to support upon the realization that through this inclusion the number of irregular practitioners would ultimately diminish, and irregulars would be co-opted into the orthodox medical profession. Regular physicians anticipated that irregular medicine would be

made extinct by "hugging" it to death (Connor 1991).

The Act of 1869 stated that before obtaining license to practice, all homeopaths and eclectics had first to obtain four years of orthodox medical education and be registered on a list of licensed practitioners, in order to guarantee their "competency" (Hamowy 1984:101;103). In doing so, homeopathic and eclectic boards became abolished, and the number of licensed irregular practitioners ultimately became reduced. Developments after the Act were such that students attempting to study homeopathy had to pay double the tuition compared to an orthodox medical education, drastically reducing the number of eligible homeopathic students (1984:115).

By 1872, eclecticism had virtually disappeared in Canada, leaving homeopathy alone in the competition. Homeopaths, while still on the Ontario Medical Council, cooperated with the wishes of the Council for more rigorous requirements for licensure, and a reduction in the number of entrants into the profession (Hamowy 1984:115). Later that year however, the homeopathic representation on the Council resigned, protesting the failure of their key representative Dr. Campbell to be re-elected, and the unfair nature of examinations for homeopathic students (1984:116). Upon resigning, the homeopathic representatives introduced a new bill into the provincial legislature seeking the incorporation of a homeopathic College of Physicians and Surgeons of Ontario, exhibiting similar powers as those of the Ontario College (1984:117). This homeopathic college never came to be realized.

In 1874 a new Act was introduced in Upper Canada, further regulating unlicensed practitioners. The Act made unlawful any unregistered person professing to practice medicine or administering medical advice, under penalty of a $100 fine and/or thirty day imprisonment (Hamowy 1984:121). A public prosecutor in each province was appointed to regulate this

legislation. The Act caused considerable paranoia in medical circles, as each member was under the scrutiny of their fellow colleagues. Robert Hahn terms this process "collegial vigilance", whereby each member guards against "incompetence and moral impropriety among colleagues" (1995:144). Prosecutions against "illegal" practitioners, while at first few in number, gradually increased.

By 1900, due to the power of the Medical Acts, homeopathy was effectively eliminated from posing any competitive threat to the Canadian medical community. Similar to the elimination of eclecticism which left homeopathy by itself, the elimination of homeopathy left the new "drugless" forms of medicine, that of christian science, osteopathy and chiropractic therapy also standing alone (Hamowy 1984:185-194). Initially, these therapies gained some autonomy by the fact that the Medical Council of Ontario, by nature of their past legislation, did not take into account the practice of medicine without drugs. Therefore, the Council could not prosecute drugless practitioners (1984:194). The Council could only resort to strongly advising the public to "avoid" these practitioners. While christian science and chiropractic therapy were slightly less vigorous in their attempts to gain legitimacy for drugless practitioners, osteopaths attempted to gain entry into the Ontario College of Physicians and Surgeons, ultimately failing after several attempts. It would not be until 1925, with the passage of the Drugless Practitioners Act in Ontario, that a board was created to license all drugless practitioners. Ironically, this legislation led to the elimination of drugless practitioners in the province, in similar fashion to the 1869 Medical Act which eliminated homeopaths through regulation of their licensure. In other provinces such as Saskatchewan and Manitoba, drugless practitioners would have to wait until the mid-1940s before being legally recognized by their respective provincial medical Colleges (1984:228;232).

The final decline of alternative competing health professions in Canada came with the passage of the 1912 Canada Medical Act, preceded by the American Flexner Report of 1910 discussed below. Propelled by physician-turned-politician Dr. Thomas Roddick, the Act standardized medical licensing procedures in all provinces across Canada (Coburn et al. 1983). The ultimate goal of the Act, in the words of Roddick, was to "promote and effect the assimilation and unification of the various standards of qualification established by the several Provinces of Canada as conditions of admission to the study and practice of Medicine" (Hamowy 1984:241). "Assimilation" also meant the effective elimination of any and all competing health occupations.

American Regulation

Developments in the United States occurred somewhat later than in Canada, but mirrored Canadian legislation. The success of homeopathy and thomsonianism prompted allopathic physicians to establish in 1847 the American Medical Association (AMA) , with the goal of "elevating" standards for medical education, and to control the occupation in its own "elite" image (Baer 1989; Schudson 1974; Coburn 1993). The establishment of the AMA was a direct response to the encroachment on medical territory by non-allopathic therapies. The AMA barred homeopaths from regular medical societies, hospitals, college faculties, and consultations with regular physicians (Baer 1989). Despite this antagonism towards irregular practitioners, in 1870 the AMA, similar to Canadian legislation, was forced to include and legally recognize the presence of homeopaths and eclectics on medical examining boards (Baer 1989). Furthermore, homeopaths established their own hospitals and medical schools, such as the American Institute

for Homeopathy (AIH) established in 1844 (Coburn et al. 1983).

One of the key features of mid nineteenth-century allopathic medicine in the United States was the ability for individuals to easily and quickly obtain a medical education with as little as one year of training, due to the rapidly growing number of medical schools (Baer 1989; Coburn 1988). Tuition to attend medical schools was inexpensive, and entry into the medical profession virtually unrestricted (Hamowy 1984:27). This was far different from Canada, which at this time had strictly limited its medical schools and regulated its medical education, and was severely critical of their American neighbours to the south regarding the low quality of American medical education (Hamowy 1984:74). As a result of the state of medical education in the United States, however, there was an abundance of allopathic physicians with many different levels of training and claims to practice (Baer 1989). The ease with which one could obtain an allopathic medical education fostered considerable competition between "country" and "urban elite" allopathic physicians, creating much internal fragmentation within the discipline (Coburn 1993). Newspapers often reported attacks by one doctor on another, while educated laypersons displayed their contempt for the standard treatments of the time of bleeding, blistering and purging, ultimately encouraging less invasive treatments such as homeopathy (Coburn 1988). Nineteenth-century medicine was ". . . technically ineffective in preventing or curing illness, and divided into several warring sects", while "physicians as a group were merely scattered members of the lower professional stratum, earning from several hundred to several thousand dollars a year and having no special status in the population" (Coburn et al. 1983).

The Commodification of Health

Through the rise of nineteenth-century industrial capitalism, however, allopathic medicine was transformed from a petty to a capitalist commodity (Baer 1989). During this process of "commodification", physicians attempted to legitimize themselves by claiming to be "scientific", and allopathic medicine began to hold itself utmostly above sectarianism. This new ideology became extremely compatible with the emerging capitalist world view justifying the increasing power of an elite corporate class (Coburn et al. 1983). This new capitalist class preached the progressive ideal of "efficiency", which glorified "science" as the legitimating principle of the new system of stratification, as it offered great "promise" of producing a more efficient labor force (Coburn et al. 1983). In order for change to be legitimate, it had to be viewed as progress (Larson 1977:32). Furthermore, allopathic medicine fostered a new world view based on a shift to a biomechanical conception of the body and an environmental focus for disease causation, beginning to focus on pathogens as the cause of disease--the "germ" theory (Baer 1989; Coburn et al. 1983). This view diverted attention away from the social origins for illness, appealing even more to the "elite" class (Baer 1989; Coburn et al. 1983). The germ theory gained additional support through new revolutions in surgery, aided by anaesthetics and disinfectants (Coburn 1988). Through the use of disinfectants, medical science saw its first victories in reducing morbidity and mortality (Coburn 1988).

As a consequence of the new scientific ideology, the AMA, which consisted of elite practitioners and medical researchers affiliated with prestigious universities, along with the industrial capitalist class, was permitted to establish political, economic and ideological dominance over rival medical systems, such as homeopathy (Baer 1989). In effect, allopathic medicine, or

the new "biomedicine" focusing on pathophysiology, became a vehicle through which the bourgeoisie came to exert indirect control over medical reality (Baer 1989). Science became inseparable from a perception of progress because it was the exclusive product of specialized communities of scientists (Larson 1977:32).

By 1906, the AMA decided to grant licensure only to graduates of schools that were deemed "acceptable" by the Council of Medical Education (Baer 1989). This development marked the beginning of the fall of the pluralistic medical system in the United States, as it effectively put a cap on who could practice "acceptable" medicine (Baer 1989). The second major development in the fall of pluralistic medicine in America was the publishing of the Flexner Report in 1910, by Abraham Flexner.

The Flexner Report

In 1904, the AMA set up an annual report to rank medical schools on a national basis (Schudson 1974). Under the direction of the Carnegie Foundation for the Advancement of Teaching, Abraham Flexner, along with Nathan Colwell, was asked to perform such a study. The Report emerged in a time called the "Progressive Era" (1890-1914), in which certain social and personal conditions were identified and defined as "problems", along with suggested societal remedies to these problems (Kunitz 1974). Problems referred to such conditions as heavy drinking and juvenile "delinquency", which were attributed to the disintegration of the previous forms of social control of traditional family and community life, viewed as a result of recent urbanization of industrialization (Kunitz 1974). The new industrial cities in turn were viewed as the antithesis of the idealized "rural" environment of the past (Coburn 1988). This "progressive

ideal" focusing on industrialization as the root cause for moral disorder, ignored underlying causes for inequality--that of capitalist processes which involved the elite control of the social means of production (Navarro 1976).

Societal solutions to progressive problems, however, equalled new forms of social control rather than analyzing class differences. These new forms of social control were characterized by the emergence of the new occupations of "consulting" or "helping" professions which involved "controlling" some aspect of the public's belief (Kunitz 1974). The new helping professions also claimed the license for autonomous "professional" status, referring to an occupation that, because of its expertise, moral standing and societal importance, claimed legitimization as a form of self-government (Hahn 1995:148). Medicine, not surprisingly, was one of these new "professions." The Report encouraged the professionalism and elitism of medicine by claiming for its "professional" status over its previous classification as a "business."

The Flexner Report drastically altered the socio-economic composition of the allopathic medical profession (Baer 1989). The Report recommended that more than half of the medical schools across the United States and Canada be closed (Chapman 1974; Schudson 1974). The Report suggested a universal four year medical education, with entrance requirements of two years of medical science, and suggested that medical schools be strongly tied to the university environment, providing further legitimization and validation (Chapman 1974; Larson 1977:34). Flexner supported a universalistic medical education characterized by restricted entry to a select few, whereby students were free from "dogma", and learned scientific facts free from "theoretical divisions" (Schudson 1974; Coburn et al. 1983).

Flexner's definition of medicine was "science", and that the medical practitioner must be a "scientist" (Chapman 1974; Coburn et al. 1983). In 1910, Flexner's recommendations were readily endorsed by the American allopathic medical community, and while medical schools were already in steep decline due to previous legislation from the AMA, his report furthered the process (Schudson 1974). As a result of the Report, the number of medical schools in the United States declined from 95 in 1916, to 79 in 1924 (Baer 1989). The number of medical graduates declined annually from 5,000 in 1900, to 3,000 by 1920 (Coburn et al. 1983). The Report contributed to the closure of eight schools which educated African Americans, and the closure of medical schools for women (Baer 1989). The number of homeopathic schools in the United States declined from 12 in 1910, to 5 in 1920. Throughout this period most homeopathic physicians were ultimately "assimilated" into biomedicine (Baer 1989). Large sums of monetary support from figures such as Rockefeller and others supported the few allopathic medical schools that stayed open, and enabled universities to build laboratories, buy equipment and hire full-time instructors (Schudson 1974; Coburn et al. 1983).

The number of allopathic medical schools in Canada, however, were not nearly as affected by the Report as in the United States. In fact, in 1867, nearly 45 years earlier, both Upper and Lower Canada had enacted regulated medical curriculum in a limited number of schools, and required four years of study including clinical experience in a hospital (Hamowy 1984:74). The Flexner Report did, however, contribute to more conservative Canadian medical ideals, including contributing to the ultimate demise of non-allopathic occupations which originated from the United States (with the exception of drugless practitioners) (Coburn 1988; Coburn et al. 1983).

The medical educational reforms instigated by Flexner led the biomedical profession to become a largely "white upper and upper-middle class male preserve" (Baer 1989). Furthermore, the Report led to a reform in medical training and education "so as to produce a uniform body of knowledge and to ensure that all recruits were socialized into it" (Coburn et al. 1983). The overall effect of the Report was to decrease the production of new physicians, ultimately easing the competition within the profession and raising doctors' incomes.

With the advent of the Flexner Report, medicine restricted entry into the profession and claimed superiority over all other competing medical systems. The purpose, so medicine claimed, was to protect the public from the potential harm posed by competing or "quack" medical occupations. It is Hamowy's (1984) main thesis, however, that medicine's claims for restriction were based on a false claim for superiority, underneath which lay a real claim for medical and economic monopoly over health and health care. The medical ideal of "safeguarding" the public from "incompetent" practitioners, insuring the quality of medical care provided through "licensing", was falsely used to obtain public support for medical power. Upon analysis, licensing only provided evidence that a practitioner met certain standards upon entering the profession, but provided no information about the practitioner's current competence (1984:2). Moreover, licensed practitioners do not necessarily provide a higher quality of care (1984:3). Such medical policies as increasing the cost of entry, limiting the number of new entrants, restricting advertising, discouraging price competition, and restricting the availability of substitute services only served to increase the economic gain of medicine (1984:1). Moreover, medicine was characterized by the following distinct capitalist market forces which marked the rise of medicine as unique: (1) the potential for unlimited expansion; (2) extreme competitiveness aimed ultimately

at limiting competition, and (3) the readiness of the state to act as sponsor for the most dominant or "trustworthy" profession (Larson 1977:19-25).

In the introductory preface in Hamowy's book (1984:xi), Walter Block states that according to orthodox theory, the necessity for licensing arises from the "complexity of the physician's calling, the innocence of the general public in matters medical, and the threat to health posed by unskilled practitioners." He further states that medicine claims that "without strict licensing legislation, quacks would overrun the health care industry, imposing worthless and even harmful remedies on an innocent citizenry", while "legitimate doctors would be powerless to stem the tide" (1984:xi). What Block is referring to is the widespread belief by practitioners and the general public that the only way to avoid this "horror" is to give the men and women of medicine the power to police their own country, where acting to promote the public welfare (1984:xi). Drawing from the work of George J. Stigler, Nobel Laureate and Fraser Institute editorial advisor, Block states that "...the main effect of most regulations and licensing requirements is to erect barriers against entry into the regulated industry or profession and thereby create a cartel, with all its attendant gains in income, power, and prestige" (Hamowy 1984:xii). Thus, this theory suggests that instead of an enhanced quality of health, the maximization of wealth is the goal of the medical profession.

Hamowy states that beginning with the nineteenth century, every policy and statutory enactment for which the medical community lobbied, had the objective of the maximization of incomes, status and prestige of the profession (1984:2). The monopolization of medical knowledge was achieved through the limitation of access to university training and the mystification of the public about this knowledge (1984:5). Hamowy states:

> Orthodox physicians are invariably portrayed as singlehandedly protecting medical science and the quality of medical care against the incursions of countless quacks and charlatans, while the profession's unrelenting demands for strict licensing legislation are presented as the product of a humanistic concern that the public be protected from incompetents. Homeopathy and eclecticism--the two major heterodox therapies of nineteenth-century medicine--if they are mentioned at all, are dismissed as unscientific nonsense, their practitioners amateur bunglers who preyed on the credulity of ignorant men and women (1984:6).

Thus, the allopathic profession's attempt to suppress alternative health occupations came not from a selfless interest to improve the quality of medical care offered to the public, but from a desire to lessen outside competition, ultimately resulting in an increase in incomes through the control of capitalist class relations as supported by the state (1984:125; Navarro 1976).

The American and Canadian medical systems thus underwent a transformation from a relatively pluralistic form in the late nineteenth century, to a dominant one in the early twentieth century (Baer 1989). Scientific training became dominant even for the other competing health occupations, and as organized biomedicine achieved hegemony over its rivals it co-opted most of the homeopaths and eclectics by admitting them into state medical societies (Baer 1989). Private foundations such as Rockefeller refused to fund alternative competing medical schools, leading to the departure of many homeopathic and eclectic physicians from their professional associations (Baer 1989). Homeopathic and eclectic schools either closed or "converted" into biomedical schools (Baer 1989). By 1936, the New York Homeopathic College, the last homeopathic school, renamed itself the "New York Medical College" (Baer:1989). Medical pluralism was effectively eliminated.

The Consolidation of Medical Dominance in Canada from 1920-1940

Turning now to later developments in Canada, by the end of World War I medicine had obtained control over the health means of production both in the hospital, and over other health occupations and clients (Coburn 1988:92-116). Medical control over patent and prescription medicines effectively eliminated self-care (Coburn 1988). Medicine, however, was far from controlling the context of care completely. Internal fragmentation persisted, and the post World War I years were characterized by much instability. Medicine was still opposed by working-class organizations and politicians (Coburn 1988). For example, one of the main forms of opposition to medical dominance in Canada in the 1920s came from the agrarian parties, who through populist movements prevented medicine from attaining a complete monopoly of care (Coburn 1988). These kinds of political resistance from the working classes against upper-class elite physicians support Navarro's (1976) thesis that medical dominance ultimately stemmed from capitalist processes, rather than a battle between strictly medical associations and the general populace. At this time the Canadian Medical Association (CMA) was also in a perilous state, and was on the brink of disbanding (Coburn 1988; Coburn et al. 1983). By the 1930s, the Depression led to doctors suffering a drastic loss of income, and despite protests from doctors the seed of medical insurance was planted in some Canadian provinces.

Wartime 1940s saw continuing pressure for reforms for health care in Canada. Despite this opposition, for the first time the Canadian government integrated much of its policy and planning with the medical profession (Coburn 1988). National health decisions directly reflected the CMA's "Group of Seven", formed by an elite group of physicians (Coburn 1988). Medical and government decision-making power was consolidated, whereby military manpower planning was

largely left to the medical profession (Coburn 1988). Medicine at this time further controlled health workers through the direct control over education and the labour process (Coburn 1993). The nature of the state's involvement was indirect in that it controlled educational institutions and hospitals in conformity with the wishes of the medical community (Coburn 1993). The medical community was at the height of its power.

The "Fall" of Medical Dominance

Up to the 1960s, doctors, known as "medical men", ruled their own occupation and had the power to exclude, limit or subordinate other competitive health occupations such as chiropractic therapy, midwifery and nursing (Coburn 1993). Health care "bureaucracies" were staffed from the "top down" (Coburn 1993). In Canada, for example, the Ministers of Health and their Deputies were doctors, and these medical leaders influenced and directly wrote state-policy (Coburn 1993). Medicine, in effect, had become a "private government."

The early 1960s, however, mark the beginning of a period of decline in medical control over health and health care, which has led to a shift in the state of health services in Canada. The 1962 Saskatchewan doctor's strike opposing a Canada-wide state/provincial health insurance marked the beginning of the fall of Canadian medical dominance (see **Figure 2B**).

FIGURE 2B: CHRONOLOGY OF THE "FALL" OF MEDICAL DOMINANCE IN CANADA

1962	Saskatchewan doctor's strike opposing national health insurance fails
1966	National health insurance implemented
1967-1971	Castonguay-Nepveu Commission criticizes the power of medicine to control health care
1971	National health insurance encompasses all provinces
1972	Hastings Report criticizes the power of medicine to control health care
1982	Commencement of the Ontario Health Legislation Review
1985	Bill 94 of the Canada Health Act bans extra billing by doctors
1986	Ontario doctor's strike opposing Bill 94 fails
1990	Ontario Health Legislation Review professionalizes the alternative therapies of midwifery, chiropractic and massage therapy, among other health professions
1996-1997	Establishment of the Canadian Complementary Medicine Association (CCMA) to protect the rights of doctors practicing alternative therapies

Government sponsored health insurance in Saskatchewan occurred in the midst of fierce opposition and confrontation from doctors, culminating in a twenty-day strike (Coburn 1988:92-116). Doctors did not give up easily. Throughout the early 1960s doctors combatted the idea of national health insurance, first by pushing doctor-sponsored medical plans, and second by influencing other provincial governments to support only doctor-sponsored programs (Coburn 1988). By 1964, however, based on the recommendations of the Royal Commission on Health Services set up by a minority Liberal government, the process of national health insurance was implemented. By 1971 health insurance encompassed all provinces, largely due to the 50% funding from the federal government (Coburn 1988).

The initial effect of national Canadian health insurance prompted many studies attempting to assess the health problems of Canadians, such as the Castonguay-Nepveu Commission (1967-1971) and the Hastings Report (1972) (Coburn 1988). These reports aimed at combatting the "distortion" of health care due to medical dominance, through the reorganization and "rationalization" of health care services by following ideals of "effectiveness" and "efficiency" (Coburn 1988; 1993). Both implicit and explicit in these reports was the intention to reduce the power of medicine to control health and health care (Coburn 1988).

With the implementation of health insurance, doctors immediately lost their control over the terms and provision of health insurance (Coburn 1988). The use of computers and central payment permitted the complete documentation and monitoring of the work and income patterns of Canadian doctors, and medical review committees in each province were empowered to investigate any monetary discrepancies (Coburn 1988; Coburn et al 1983). In opposition to this monitoring, doctors in the 1970s began to threaten to withhold services and to strike. These

strikes, however, ultimately failed, and some provincial governments retaliated by publishing the incomes of all doctors.

The hospital was one of the first "battlegrounds" for medical power between government and medicine. Hospital budgets came under extreme government scrutiny and control (Coburn 1988). The use of new technology such as computer diagnosis, and the "rationalization" of care to avoid duplications, restricted the work of hospital physicians (Coburn et al. 1983). Additionally, an increase in the number of chief hospital administrators were university-trained managers rather than physicians, resulting in the loss of physician rapport with hospital administration (Coburn et al. 1983). Physicians fought back by manipulating the utilization of procedures to obtain certain income levels (Coburn 1988).

A second development in the decline of medical power was the decline of medical graduates by 50%, due a reduction in government funding of post-graduate medical training (Coburn 1988). The external funding of universities and hospitals gave the government complete control over medical manpower (Coburn 1988). Yet a third development was the increase in health care bureaucracies. Physicians in politics were soon "swamped" by health bureaucrats, lay planners, managers and accountants, ultimately resulting in the loss of the previous medically-tied political power (Coburn 1993; Coburn et al. 1983). For example, in Ontario all health ministers prior to 1968 were physicians, while after that year they were for the most part ministers without a medical education (Coburn 1993).

By the 1980s, the battle was not yet over. Doctors retaliated once more with the use of "extra-billing and user fees", over and above what government insurance would pay, such as recommending further treatments, ordering extra tests, and prescribing additional medicines

(Coburn 1988; Hamowy 1984:xviii). The Canadian government, in turn, reacted by reinstating another Hall Commission which recommended that extra-billing be banned (Coburn 1988). In 1985, with the introduction of Bill 94, the Canada Health Act effectively banned all extra-billing. As a result, doctors displayed the most vicious public reaction since the Saskatchewan doctors' strike nearly twenty-five years earlier (Coburn 1988). In the summer of 1986, Ontario doctors led another twenty-day strike that stormed legislative buildings, criticised the government as "Nazis", and withdrew all essential health care services (Coburn 1988). The strike, however, was only supported by 60% of doctors. The fact that many doctors and the public were against the strike ultimately resulted in failure. Extra-billing was at an end, and medicine's image was in "tatters." Medicine had become characterized by the regulation of the state through professional organizations (Coburn 1993).

Coburn (1993) states that in analysing the fall of medical dominance, one is examining not just an occupation or profession in relationship to the state (government), but a whole series of interacting occupations and professions in which medicine was at the apex. He argues that state-health occupation relationships are mediated and shaped by the relationship of medicine within the state, and that a decline in the power of organized medicine has brought with it more direct state-health occupation interaction. Furthermore, drawing on Johnson's (1982) idea, Coburn (1993) states that professions and the state are not external to one another, but intermingle and interpenetrate, in that their boundaries are permeable.

Moreover, the "state", Coburn argues, has never been "neutral" regarding the health professions (Coburn 1993). This has been clearly demonstrated by state-medicine interactions. As previously discussed, the state first accorded medicine a monopoly on the market in the

nineteenth century, and then reinforced that monopoly in the early twentieth century by restricting the activities of other health occupations and the public (Coburn 1993). Second, during World War II medicine was intimately involved in federal policy. Third, the decline of medical dominance has been characterized by an infiltration of state power into professional organizations, whereby state rationalization led to the reduction of medical control over health care division of labour, and the restructuring of state-profession and interprofessional relationships. Medical dominance can thus be described as an initial external authority beginning in the late nineteenth and early twentieth centuries, followed by the penetration of medicine into the state, and finally the infusion of the state into medicine (Coburn 1993).

The state, however, was not universally responsible for initially granting medicine professional autonomous or monopolistic market control (Larson 1977:24-5). The state could eliminate competitors such as in the case of competing health occupations, but it could not force consumers to agree to use medicine or consent to a monopoly. It is what Larson terms the "negotiation of cognitive exclusiveness" that was key to medicine securing a medical monopoly (1977:24-5). This concept refers to a process whereby medicine unified itself around a demonstrably superior definition of the medical "commodity", and guaranteed a reliable production of producers (1977:24-5). In other words, medicine achieved monopoly when it convinced the public, rather than physically demonstrated its overall effectiveness and superiority, over all competing non-allopathic health professions. Once this had been achieved, the state contributed willingly to a medical monopoly by means of registration and licensing (1977:23). Furthermore, under the pretense of ensuring public health, medicine had secured a privileged conduit to governmental backing for its monopolistic claims (1977:23). These arguments would

support Navarro's (1976) conclusion that as inequalities are forcefully established, capitalist processes underlie medical dominance.

The Rise of Alternative Medicine

It is at this time in the early-to-mid-1980s that competing or "alternative" health occupations began to establish themselves, filling in the void where medical power left off. For example, Nursing, which was previously subordinate to medicine, began to practice independently (Coburn 1988). Midwives began to gain recognition in the form of traditional and non-invasive birthing practices, and other drugless healers such as chiropractors began to gain legitimacy. One may argue that this period of resurgence in "alternative" competing health occupations marks the beginning of the questioning of biomedicine, and its right to determine how medical care is delivered (Coburn 1988). Whether this is directly reflective of a postmodern or "fragmented" society is debatable (Hook 1993). This period also marks the shift from curative to preventive medicine, and the "birth" of patient-centered medicine.

Presently (1998), there are literally hundreds of alternative forms of medicine across North America and Europe, ranging from re-established therapies such as homeopathy, osteopathy and naturopathy, to ancient healing systems such as traditional Chinese medicine, to more esoteric or spiritual therapies such as reiki and sound therapy. Moreover, alternative therapies, as they become more widespread, are fast becoming "conventional" therapies, replacing their "alternative" label.

The rise of competing alternative health occupations has been further aided by internal fragmentation within the medical community, led by physicians who favour the decentralization of

technology and expertise (Coburn et al. 1983). This biomedical shift has also been aided by what has been called the "interdisciplinary model for the multicausality of disease" or the "biopsychosocial model", which in addition to a biological etiology for disease recognizes the importance of social and cultural etiologies in the definition and treatment of illness (Kleinman 1988; Turner 1990). An example of this internal fragmentation is illustrated by the development of what are called "complementary physicians"--physicians who, alongside their medical practice, also practice and support one or more alternative therapies such as acupuncture. Furthermore, the Canadian Complementary Medicine Association (CCMA), distinct and independent from the CMA, was recently established (1996-1997) to support complementary physicians, and to protect them from harassment from the medical colleges (Dr. Roger Rogers, complementary physician and core founder of the CCMA; personal communication, 1997) (see **Figure 2B**). These changes do not, however, negate the existing power of the biomedical community to dominate notions of health, as discussed below. For example, there is a definite reason why the new CCMA is not contained within or supported by the CMA.

An earlier key development in the expansion of the autonomy of competing or alternative health occupations in Canada was the 1982 enactment of the Health Professions Legislation Review (Coburn 1993) (see **Figure 2B**). The Review was initially due to public pressure arising from complaints criticising what were viewed as "overlapping" health services, such as the dual nature of midwifery and hospital attended births. Over eight years the Review consulted with hundreds of professional interest groups, and finally reported its recommendations in 1990. Rather than being detrimental to competing health occupations, the 24 out of 75 professions that were selected included such alternative therapies as midwifery, chiropractic and massage therapy,

in addition to allopathic occupations (Coburn 1993). The legislation loosened the boundaries between health professions and required that each profession, in addition to their professional associations, have their own governing bodies or colleges. The establishment of regulatory colleges provided competing health occupations with increased autonomy from direct medical control. "Autonomy" refers to two notions of autonomy, both "collective" and "individual" (Hahn 1995:148). "Collective autonomy" refers to the control of the organization by its own members, while "individual autonomy" refers to the self-control of each member in his or her own work (Hahn 1995:148).

Increased autonomy for alternative health occupations, however, was not without consequences. Mandated by the Health Disciplines Act, each college was required to have 40% of the governing council of the colleges as lay members (Coburn 1993:129-38). The colleges were designed to be part of a system of organizations with lay input, and to be responsive to quasi-state influence even direct state control. As a consequence, the colleges' power had narrowed in that they were directly answerable to state authority and public opinion (Coburn 1993). Thus, the gaining of power by competing health occupations also ironically led to greater state control through regulatory bodies, and autonomy became "relative" to state control.

It should be noted, however, that not all alternative or competing health occupations have been professionalized and/or included in this legislation, and while they may not be protected from medical scrutiny, they have maintained autonomy where professionalized alternative occupations have lost. For example, therapies such as homeopathy and naturopathy, which were not included in the legislation, maintain their autonomy, and in the case of naturopathy has its own independent provincial and national regulatory boards.

Medical Dominance and the Biomedical Paradigm

As previously indicated, medicine over the last century has followed a pattern beginning with a rise to dominance and followed by a slow decline in power over health care, whereby decision-making authority was transferred to, or appropriated by, the state level. It is misleading to think, however, that medicine, while having lost its dominance, is still not the main form of health care, nor are capitalist processes of inequality not in play (Navarro 1976). Indeed, medicine as an occupation is still the dominant form of health care in the North American health care system (Coburn 1988).

The question remains, however, as to whether the biomedical paradigm upon which medicine is predicated has also declined with the fall of medical dominance, and if inequality still exists based on notions established by the dominant class (Navarro 1976). In other words, in light of a decline in medical dominance, does the biomedical paradigm still dominate "health" and the ideological framework to maintain this health?

Biomedicine, critical medical anthropologists argue, is a cultural system, contained within a distinct paradigm or worldview. A "paradigm" refers to a learned and shared set of tacit understandings, accessible through a long process of socialization (what is often given the broadly definable term "culture") (Larson 1977:32). Aspects of a worldview relate how the world is divided, interconnected and known, and specify what is valued and what is not, what is good, beautiful, right, wrong or indifferent (Hahn 1995:131). A worldview further provides rules of conduct whereby the society's members know how to behave and how to judge the behaviour of others (1995:131). Thus, a cultural system has four distinct components: (1) a domain of knowledge or belief, or a definition of the cultural system; (2) a system of values and ideals of

behaviour; (3) an organized means for teaching this domain and cultural values to recruits and other participants, and (4) setting norms of behaviour and practice in which these beliefs, values and teachings are enacted (1995:132). Biomedicine can no longer be viewed as an impartial body of knowledge, as it is clearly rooted in cultural presuppositions and values associated with rules of conduct, and embedded in a larger societal and historical context.

One may argue that in biomedicine, the paradigmatic model or worldview is based on the bio-chemical/mechanical framework for disease causation. Illness is restricted to purely the physical level of the body, isolated to distinct body parts. Medicine prevents and cures, studies and treats not persons or their bodies, but the diseases of bodies (Hahn 1995:133). Disease becomes an "entity", an "independent thing", such that death is viewed as "failure", "defeat" (1995:134;139). In biomedicine, shared definitions of reality are based on relatively uniform and standardized practices. Biomedicine searches for universal causal laws, claims to enact "value-free" and empirical observation and analysis, and emphasizes the assumptions of objectivity, rationality, replicability, comparability and generalizability (Clarke 1983:72; Larson 1977:32; Hahn 1995:149). Kaptchuk states:

> Western medicine is concerned mainly with isolable disease categories or agents of disease, which it zeroes in on, isolates, and tries to change, control, or destroy. The Western physician starts with a symptom, then searches for the underlying mechanism--a precise *cause* for a specific *disease*. The disease may affect various parts of the body, but it is a relatively well-defined, self-contained phenomenon. Precise diagnosis frames an exact, quantifiable description of a narrow area. The physician's knowledge is analytic--cutting through the accumulation of bodily phenomena like a surgeon's scalpel to isolate one single entity or cause (1983:4; emphasis included).

The scientific paradigm, as a consequence, facilitates the formulation of new theories and the testing of predictions that fit only within this scientific model (Patel 1987). Because scientists

are the only producers of scientific knowledge, the lay public has no choice but to accept, without shared understanding, the scientific definitions of practice and progress (Larson 1977:32).

The result of the above factors concerning the biomedical paradigm, as advocates of alternative paradigms would argue, is that the scientific model leads to a diminished ability to interpret and perceive phenomena that lie outside the boundaries of the biomedical paradigm, and to incorporate differing worldviews. For example, a non-specific pain which manifests over the entire physical body, with seemingly no cause, may be simply classified by the biomedical model as a product of the patient's "imagination" or "anxiety" (something that will pass with no serious repercussions), rather than as a serious illness to be explored on levels beyond the physical body. Furthermore, the elite nature of medical training ensures that the average layperson does not strictly follow biomedical conceptions of disease and the body.

Thus, biomedical notions of health are not universal. Biomedical knowledge notwithstanding, alternative forms of medicine follow a different model of health, basing notions of health on a paradigm that includes concepts such as "energy", "holism" and "harmony", and treating illness as unique to the individual rather than to the mass public, while recognizing and valuing personal or "subjective" models of illness causation (Patel 1987:669-78). In an alternative model, health involves not only physiological health and the absence of disease, but in addition to psychological and spiritual well-being. Optimum health is viewed as tied to many levels, where illness is first seen to manifest on the "energetic" level before it proceeds to the physical. In contrast to the biomedical physician, Kaptchuk states, for example:

> The Chinese physician, in contrast, directs his or her attention to the complete physiological and psychological individual. All relevant information, including the symptom as well as the patient's other general characteristics, is gathered and woven together until it forms what Chinese medicine calls a "pattern of disharmony" (1983:4).

Getting back to the root issue, one argument is that, following the logic of the transfer of medical power, if dominance over health care is now maintained within the state level, then the potential for the biomedical paradigm to dominate individual and societal notions of health is more powerful than ever before. State controlled health care would maintain a hegemony over the means of health and the definition of both health and health care (see **Figure 3**). A contrary argument suggests, however, that the decline of medical dominance has led to the decline of the biomedical paradigm--a consequence of medicine losing to the state its power over health care, and the resurgence of alternative health occupations or what may be called "counter-hegemonic" health movements (see **Figure 3A**).

Figure 3: Individual Dependence on Biomedicine

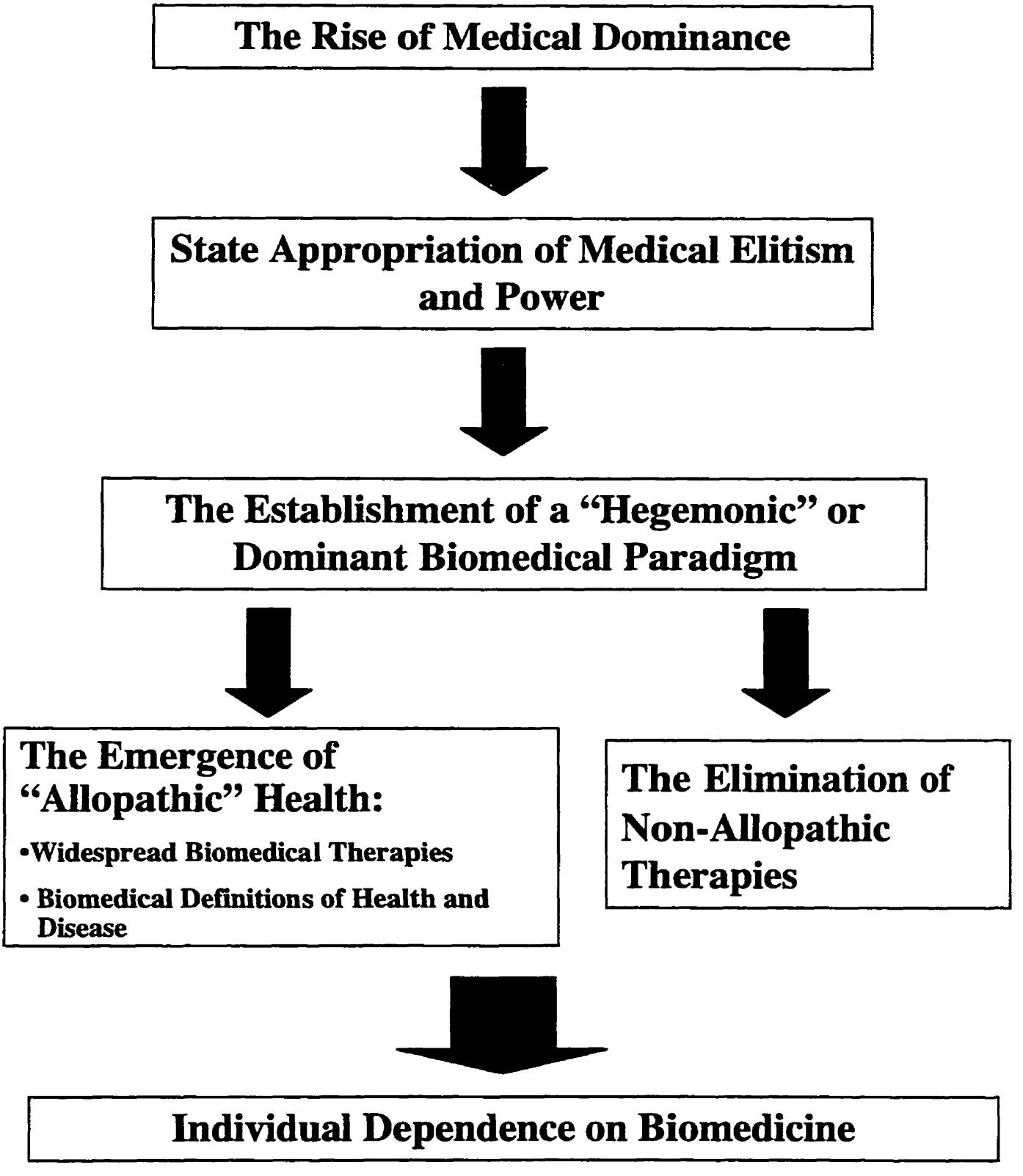
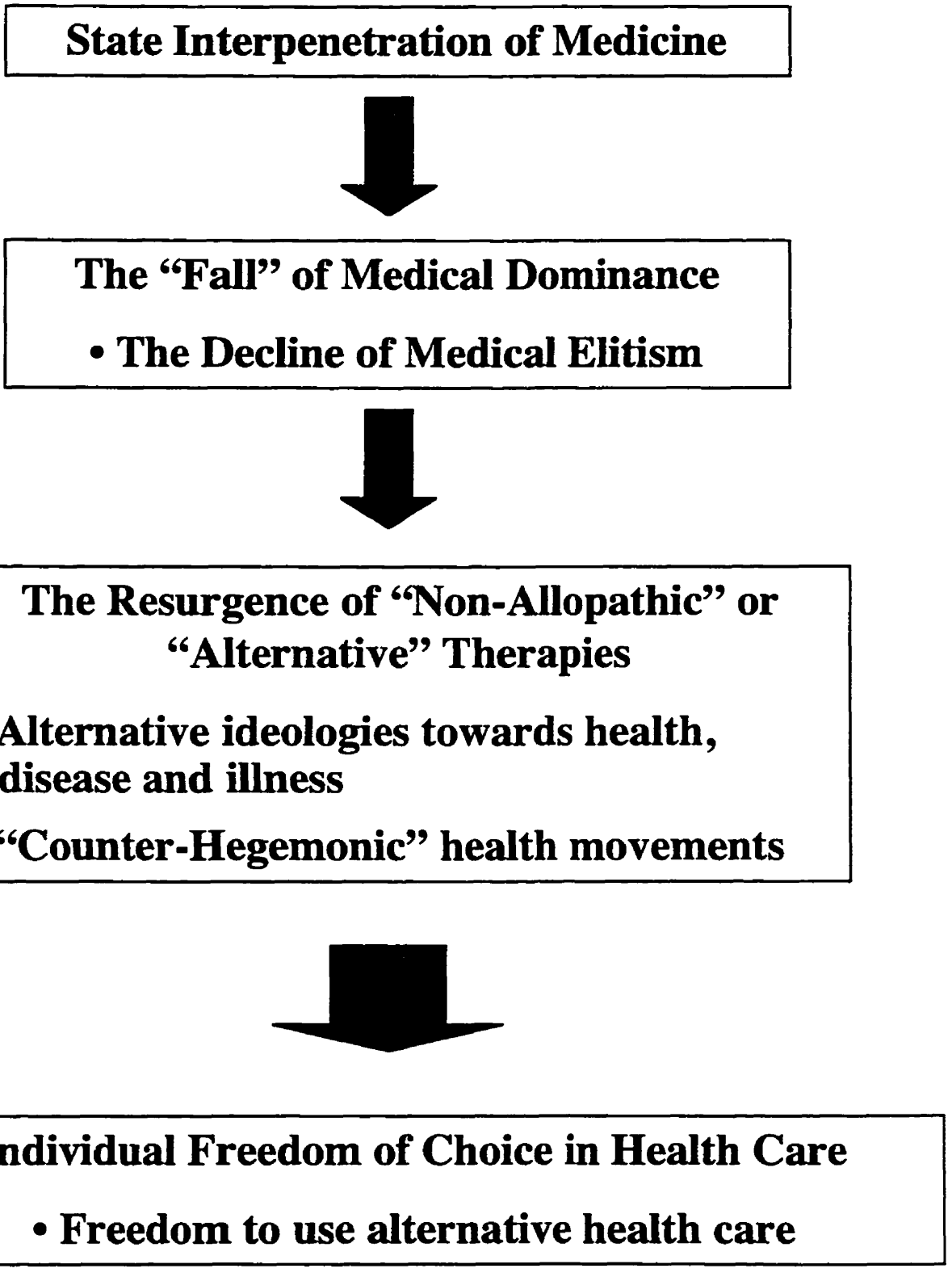


Figure 3A: Individual Freedom of Choice in Health Care



In order to fully understand these issues, one must first examine several distinct yet interrelated concepts: (1) the role of the state, doctor and individual in maintaining health; (2) the nature of hegemony; (3) the role of alternative health occupations, and (4) the role of "medicalization."

As previously discussed, the role of the state in maintaining health has been through the appropriation of medical power, and through the infiltration of state power into professional organizations. State rationalization therefore led to the reduction of medical control over the health care division of labour, and the restructuring of state-profession and interprofessional relationships (Coburn 1993:129-38). The state, however, did not change the paradigm through which this health was achieved--namely that of the biomedical model, nor did it change its capitalist structure based on the unequal control of the social relations of production. The role of the doctor in maintaining health, then, has diminished, in that doctors have lost their dominance to the state. Doctors, however, have maintained their autonomy to promote their own notions of biomedical health. The role of the individual in health maintenance, one might argue, depends partly on individual worldview concerning illness causation, partly on the financial means available to the individual (which remain unequal in a capitalist system), and partly on the health services or infrastructure available to resolve illness and maintain individual health (Navarro 1976). The means to maintain health, in turn, depends on the nature and form of the health care system, which in the Western world is characterized by a biomedical and capitalist hegemonic system (Navarro 1976).

"Medicalization", a characteristic of a dominant biomedicine, refers to the "process and product of defining and treating human experiences as medical problems", or "a process by which

non-medical problems become defined and treated as medical problems, usually in terms of *illnesses* or *disorders*" (Broom and Woodward 1996; Stoppard 1990; emphasis added). Medicalization is a widespread process in the practice of allopathic medicine, accomplished through specific processes such as using medical language to describe a problem, or through adopting a medical framework or intervention to treat or understand a problem (Broom and Woodward 1996).

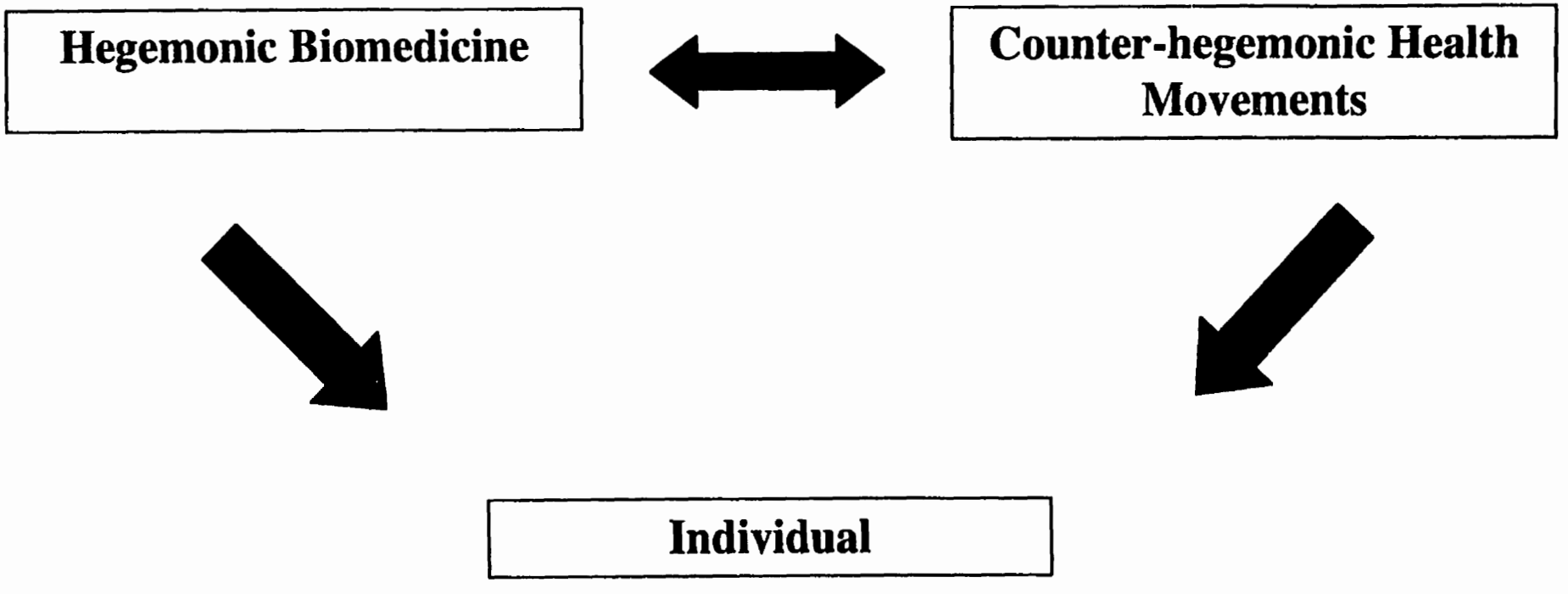
Therefore, the answers to the above questions are many-fold. In any hegemony there are always counter-hegemonic movements such as alternative views and ideology (Findlay and Miller 1994). As previously discussed, such is the nature of the current North American health care system, illustrated by the resurgence of alternative or competing health occupations. One may argue that the biomedical paradigm has indeed maintained power through the transfer of medical power to the state, and through the maintenance of existing capitalist class relations. The biomedical paradigm, however, is far from omnipotent. Where the biomedical paradigm is maintained within the state level to control health and health care, there are also competing health occupations which provide alternatives to the biomedical paradigm for disease causation, including the practical means to achieve health along alternative ideology. Furthermore, the fall of medical dominance has encouraged a resurgence in counter-hegemonic health occupations, thereby diminishing biomedical dominance. Doctors, while they may have lost their medical-professional dominance, still have the autonomy to promote biomedicine, but individuals now have the choice between dominant or alternative forms of health care (see **Figure 3B**). While medicalization may continue to be perpetuated in the search for health care, it is not a reflection of medical dominance, as individuals now have the option to choose alternative models of illness

causation. The relative decline in the power of professional medicine and in the biomedical model does not, however, diminish the fact that the biomedical paradigm still dominates health care, or that it still has considerable power to marginalize alternative health occupations as it continues to do today. Moreover, capitalist inequalities remain, as they are ingrained in any capitalist system (Navarro 1976). These structural issues as they apply directly to individual experiences with illness and health care strategies will be discussed further in Chapter Five.

Bakx summarizes the context of the fall of medical dominance and of the modernist enterprise:

> [. . .] just as the promises of the captains of industry, the scientists, the planners, and other architects of the New Jerusalem were never realized, so too the biomedical 'fraternity' has failed to cure the 'modern' illnesses of the western disease profile as dramatically and effectively as it did, say, 'consumption' earlier this century. Furthermore, the modernist project is perceived as having actually contributed to that poor health profile by creating amongst other things, the industrial city, nuclear pollution, irradiated food, and antibiotic resistant bacteria. In short modernism, biomedicine included, has become politically and culturally out of 'synch' with a growing section of the population [. . .] biomedicine is in danger of losing both its actual and ideological hegemony because: firstly, it has culturally distanced itself from the consumers of its service; secondly, it has failed to match its propaganda promises with real breakthroughs in combatting the diseases created by modernism itself; thirdly, patients have become further alienated by negative physical and psychological experiences at the hands of biomedical practitioners themselves (1991:24-25; 33; emphasis in original).

Figure 3B: Hegemonic and Counter-hegemonic Health Movements



Summary

It is clear that medicine has been marked by a process of an historic rise to elitism and dominance, followed by a slow but steady decline in medical power whereby medical control was transferred to the state level. Just as medicine gained its dominance through various forms of antagonism and regulation aimed at destroying all competing health occupations and maintaining an economic monopoly, medicine neglected the fact that the vehicle through which it appropriated this power, that of the state, could easily be used to dissolve it in similar fashion.

Medicine as a form of health care in North America, however, has by no means completely lost its power, and remains the dominant form of health care in North America by maintaining its hegemony over health services, and by promoting capitalist inequalities. As will be seen in later chapters, medical dominance can have very real damaging effects in the lives of everyday individuals. One may argue, however, that rather than continuing to maintain medical elitism, the shift in medical power to the state has resulted in counter-hegemonic movements marking the decline in the dominance of the biomedical paradigm towards defining notions of health. This decline in the dominance of the biomedical paradigm has resulted in a resurgence of competing alternative health occupations, whereby those occupations have gained autonomy alongside orthodox practitioners. Furthermore, new concepts of health and what it means to be healthy have arisen and are providing strong options to the biomedical disease framework.

In Chapter Four, narratives are presented which detail the search for, and use of, alternative and/or plural health care services by individuals dealing with various forms of chronic illness. As previously indicated, there exist two conceptual frameworks for understanding this search: (a) individual narrative meaning, and (b) medical dominance, the latter of which has been

discussed in detail. The question remains as to how medical dominance underlies the experiences of individual people, who today are far removed from the historical processes which inherently shaped the health care system in which we are now emersed.

While at first glance medical dominance may seem unrelated to individual care-seeking behaviour, there are elements which point to the conclusion that the underlying effects of medical dominance remain powerful. This will be explored in further detail in Chapter Five. Furthermore, the question remains as to what kind of health care system the chronic illness sufferer must deal with at present, and what kinds of medical dominance s/he must face. The answer, as will be seen, is complex and many-faceted. Certain aspects of medical dominance remain, while others have disappeared only to be replaced by different forms. Most importantly, for those who are receiving no help from dominant health care services, there are now new forms of health care from which to choose.

Chapter Three: Methods

In this chapter, methods are presented detailing how information was gathered in the present research study. As an introductory note, and as detailed in Chapter One, the key method used to collect information was the illness narrative, based on tape-recorded interviews with individuals dealing with serious or chronic illness. The main goals were: (1) to use the descriptive narrative to identify health seeking behaviour with regard to the use of conventional or unconventional health services by individuals experiencing chronic illness, and (2) to reveal details as to how the nature of chronic illness affected the use of these services. The two theoretical frameworks of the care-seeking narrative and the medical dominance thesis were then applied to the narratives.

Theoretical Context of Narrative Method

The use of illness narratives in this research is a key methodological tool for understanding individual perceptions of chronic illness, and for tracing the history of illness associated with the use of plural health care services. Personal illness narratives are the ideal tool for understanding chronic illness, as its debilitating and long-lasting nature leads to detailed personal documentation of illness history (Kleinman 1988:48). Kleinman states that the value of the illness narrative lies in its ability to help resolve suffering and to provide effective care for illness sufferers:

> There is evidence to indicate that through examining the particular significances of a person's illness it is possible to break the vicious cycles that amplify distress. The interpretation of illness meanings can also contribute to the provision of more effective care. Through those interpretations the frustrating consequences of disability can be reduced (1988:9).

Using an analysis of illness narrative, the illness sufferer's social context may first be revealed. For example, the individual's family social context, occupation history, education and residence history may be documented. The use of the illness narrative locates the individual's illness in a particular conceptual context, revealing an important perception of individual illness as it is associated with plural therapy use. Both the individual's illness history, and the themes of causation, treatment, healing, acceptance and worldview are highlighted. Furthermore, use of illness narrative enables the dynamic between the use of plural therapies to be revealed. When, where, how and why an individual began using plural therapies, and the individual's opinion towards these therapies, is documented. The researcher, using the illness narrative, becomes an interpreter through which the individual's explanatory model is mediated (Kaufert 1990:214).

This research draws upon illness narratives of individuals suffering or having suffered from chronic illness, in an interview context. Interviews were semistructured, based on semistructured questions, and were conducted in 45 minute sessions, including follow-up interviews to track developments of key informants when applicable.

Interview questions defined the topic and issues to be explored, with the possibility of the interviewer or respondent pursuing additional related issues and topics. Questions were structured loosely around six main categories, as defined by Britten (1995:252): (1) behaviour or experience; (2) opinion or belief; (3) feelings; (4) knowledge; (5) sensory experience, and (6) background or demographic details. The main goal of the interview and related questions was to discover the individual's own framework of meanings concerning illness and the use of plural therapies.

While the interview remained open-ended, the following interview questions and issues were raised: (1) "Please give a brief description of your education (formal and informal), work and family history" (2) "Has your illness been medically diagnosed, and at what period in your life did the illness appear?" (3) "What were the symptoms leading up to your illness?" (4) "How did you perceive your own health leading up to, and during the time you first perceived your illness?" (5) "What kinds of plural therapies have you been using to cope with your illness?" (6) "How have these therapies helped to relieve your illness?" (7) "Which therapy or therapies if any, in your opinion, was/were/is/are the most effective?" (8) "What, in your opinion, were the major factors contributing to your illness?" (9) "How do you perceive your own health after using these therapies?" (10) When you first began feeling the effects of your illness, what therapy or therapies did you first choose, and why?

Target Group

Information was gathered from May to December 1997. Interviews were initially undertaken with ten adults (five men, five women) of middle age, who were suffering or who had suffered from chronic illness, as defined above. The main target group was defined as individuals suffering from chronic illness, who had used or were currently using plural therapies, and were associated with either alternative therapy clinics or alternative therapy practices in Winnipeg, Manitoba. From the total number of ten individual interviews, three key interviews were selected and transcribed. While the gender distribution of these key narratives turned out to be all male, no direct gender-limiting factor was applied by the researcher. Key narratives were selected based upon amount of detail, relevant illness story, use of therapies, individual interest, and the potential

for follow-up interviews.

At the beginning of the study, interviews were additionally undertaken with alternative and complementary practitioners. Five interviews were undertaken with alternative and complementary practitioners from diverse backgrounds, as they were associated with alternative health clinics and alternative therapy practices in Winnipeg. The main purpose of interviewing practitioners was to obtain access to possible patient informants, due to the fact that practitioners performed a very real "gatekeeper" role (Hammersley and Atkinson 1983). Accordingly, the data obtained from the practitioner interviews has been used as cursory to that obtained from individuals. The use of additional interviews with practitioners has been used to supplement the data obtained with chronic illness sufferers, and in some cases provides a national Canadian context for the research. Due to the scope of the study, however, the main focus of the research remained largely on illness sufferers.

Use of "snowball" sampling, a qualitative approach used to identify informants by informants nominating others, was used to obtain initial contact with individuals (Creswell 1994; Joe Kaufert, personal communication 1998). The subsequent communication between researcher and individuals was further employed towards establishing a larger group of informants. "Purposive" sampling, which involves the directed selection of informants by the researcher, was used to resolve any access problems that arose in the attempt to establish a balanced informant group (Creswell 1994). Individuals, clinics, private practices and contact numbers/addresses were also identified through continual monitoring of a Winnipeg alternative medicine and "New Age" newsletter, "The Aquarian." "The Aquarian" provides detailed and updated information concerning listings of alternative therapies, local centres and practitioners. Additionally,

individuals were identified by informing alternative practitioners of the intended research and practitioner referral to patients. The informant group was focused on obtaining validity of narratives rather than attempting to satisfy complete representation, and was not limited to a set number of informants or a strict control group.

Selection for informants was not restricted based on the demographic factors of gender (despite a gender-balanced initial target group), age, education, "class", social or ethnic background, occupation, or use of a specific therapy or duration of therapy. These are, however, excellent indicators and have been employed in other studies (Kelner and Wellman 1997a; b). Demographic variation, while valuable, was not used as a focus for this research.

The above-specified target group was justified for several reasons. It is clear that the individual use of plural therapies involves the use of not only multiple healing modalities, but the use of multiple therapies within modalities. For example, an individual suffering from chronic back pain may have used alternative therapies such as acupuncture, reiki, and massage therapy, in addition to biomedical therapies such as pain relief drugs and physiotherapy. Thus, a group of chronic illness sufferers limited strictly to acupuncture and biomedical pain relief drugs, for example, would clearly not be representative or valid concerning the actual varied individual use of plural therapies. The broad membership criteria towards use of therapies as defined in this study, is a purposeful attempt at establishing a descriptive and emic perspective towards individual care-seeking behaviour and perception of the efficacy of plural therapies. This is a methodology clearly supported by Sharma (1995:15-18). This study, therefore, is a preliminary descriptive analysis of narratives which cannot sample for or systematically control for demographic variation.

This study has chosen to focus on the use of plural therapies by chronic illness sufferers, rather than to focus on one particular illness group. The underlying reason for this focus is that chronic illness encompasses a broad range of largely untreatable and undiagnosable illnesses by biomedical standards, thus resulting in a large proportion of chronic illness sufferers using plural therapies (Kelner and Wellman 1997; Sharma 1992). As indicated, however, as the study progressed, it became increasingly focussed on chronically acute and/or life-threatening symptoms than on mild chronic illnesses. This may have led to a sample bias, however, this study does not claim to make overarching generalizations based on the sample. Finally, this study has limited the sample to a small number of illness narratives due to the time-consuming nature of qualitative information gathering and data analysis, and the recognized scope of the study.

Ethics

For the intended research, confidentiality was maintained based on the guidelines specified in the consent form illustrated in **Appendix B** (please see **Appendix B--"Consent Form"** below). Prior to the interview, a detailed consent form was signed and/or read through by both the interviewer and individual to be interviewed, and consent was negotiated based on the following terms: (1) participation by individuals was voluntary, and was not solicited through any other means; (2) the interviewee, participant or individual was free to withdraw from the research at any time, without consequence; (3) every effort was made to maintain complete confidentiality, based on the clear and prior specifications of the participant, as was negotiated in the consent form--no personal information, including proper or place names, was released without expressed consent from the participant; (4) quotations were not attributed to named individuals without their

expressed consent and review of the quotation; (5) upon individual request, transcripts of only those participants' transcribed or taped materials were freely given to participants, and (6) the participant had the right to modify the consent form at any time in the consent negotiation.

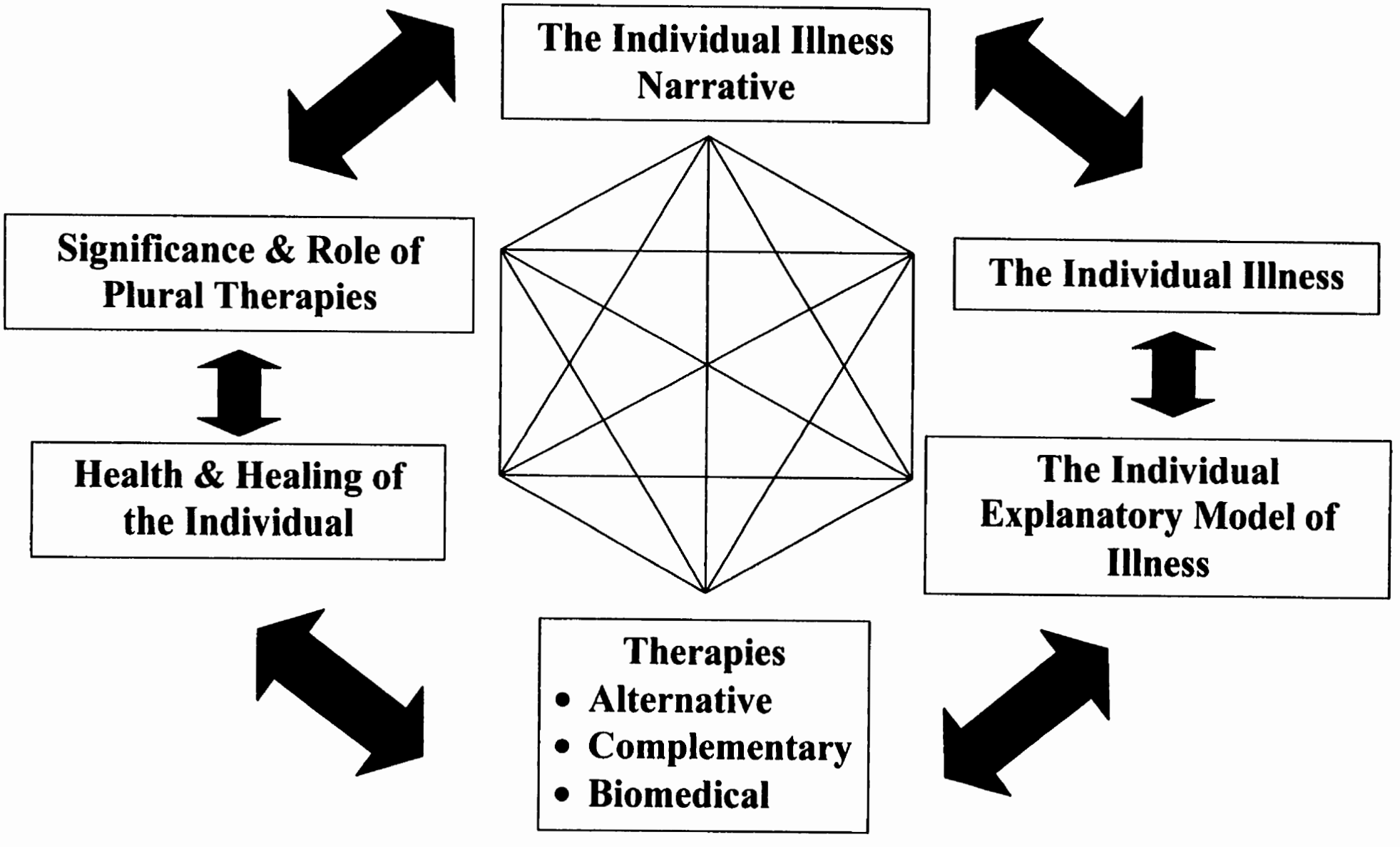
Conceptual Model

Due to the qualitative design of the intended study, variables have not been identified as "independent" or "dependent." Rather, variables are seen as "interconnected" and "interrelated." Further, variables in this study were not "measured" quantitatively, but were "recorded" qualitatively.

The variables in this study may be discussed as relationships between categories or themes, and as discussed earlier in the care-seeking narrative. Prior to research, six potential thematic constructs were identified: (1) the individual illness narrative; (2) the individual illness; (3) the individual explanatory model of illness; (4) therapies (alternative, complementary, biomedical); (5) the health and healing of the individual, and (6) the significance and role of plural therapies.

The potential relationships between themes were understood not as direct causal relationships, but as a "web" of interconnected relationships between themes, with the potential of any number of possibilities (see **Figure 4**). One may begin at any particular theme, and then proceed to analyze the relative themes that are connected to it. One may also move back and forth between themes. Thus, one theme may precede the other, based on the particular nature of the individual's illness narrative.

Figure 4: Conceptual Model: Relationship Between Themes



Research Context

Interviews were done exclusively by the principle investigator in the City of Winnipeg, Manitoba, Canada. There were no co-investigators involved in the study, or the use of additional trained interviewers aside from the researcher. The research further involved the duration of one week travel outside Winnipeg to Vancouver, British Columbia. Vancouver hosts a variety of alternative therapies, and is a leading city in alternative health care. The main purpose in visiting Vancouver was to obtain interviews with alternative/complementary practitioners to gain a national Canadian perspective, and for the observation of the new Tzu Chi Research Centre for Alternative and Complementary Medicine. The core of the research, however, was focused in Winnipeg, and remained directed a individuals experiencing illness.

Individuals were identified either by referral from practitioners, or through the individual's association with either alternative therapy clinics or private practices. Upon obtaining individual consent through a written consent form, interviews lasted approximately 45 minutes. Follow-up interviews were then undertaken with individuals where additional information was necessary. Where individuals were contacted through practitioner referral, every effort was made to ensure confidentiality of the individual, by the practitioner first contacting the individual and requesting consent on behalf of the researcher.

Thematic Analysis

The research has drawn upon several analytical techniques. Due to the nature of this qualitative design, analysis in this study was undertaken simultaneously with data collection, interpretation and narrative writing, and was continued at the end of the study. Rather than attempting to satisfy broad generalizations such as in a quantitative study, analysis focused on the internal validity of informant narrative.

Data was analyzed using content analysis and specific coding procedures (Berg 1989:105-127; Strauss and Corbin 1990:61-143). Content analysis is most often used for analyzing recorded verbal communications, such as in illness narratives. Content analysis has been broadly defined as "any technique for making inferences by systematic and objective identifying [of] special characteristics of messages" (Berg 1989:106). Content analysis in this study involved both manifest and latent content. The former refers to the physically transcribed and directly observable jargon and/or words or phrases also known as "in vivo codes" (1989:106). The latter involves an interpretive reading or sociological analysis of the symbolism underlying the physically presented data (1989:107). Manifest and latent analysis allows for a balanced interpretation, while the validity of latent content has been substantiated with follow-up interviews. Units of analysis in transcribed narratives involved the identification of: (1) key sentences, paragraphs or phrases; (2) groupings of words around main conceptual clusters or ideas, and (3) the whole unit of the sender's message (Berg 1989:113).

Concepts, categories, relationships between categories and theory were developed in the course of coding as used in Grounded Theory (Strauss and Corbin 1990). Coding is defined as the process of analyzing data (Strauss and Corbin 1990:61). Open coding is defined as the

process of breaking down, examining, comparing, conceptualizing and categorizing data (1990:61). Open coding was used to identify concepts in transcribed interviews, by naming phenomena, followed by concept identification, then concept grouping and categorization. After the categorization stage, dimensions within categories, such as the properties of categories along a continuum, were established (Strauss and Corbin 1990:69-72) (Please see **Appendix C--"Example of Code Notes"** below).

Additionally, field notes and diary entries were regularly reviewed, and analysis involved "member checking", or the verification and validification of the researcher's interpretations by informants (Creswell 1994:167).

Significance of Research

As discussed above, the majority of Canadian studies (with the exception of those previously detailed) examining plural medicine have remained focused on large quantitative surveys of Canadian physician attitudes and practices towards complementary and alternative medicine, while consistently avoiding the systematic analysis of alternative/complementary therapy use by the Canadian individual or patient (Goldszmidt et al. 1995; Hook 1993; LaValley and Verhoef 1995; Verhoef and Sutherland 1995).

The knowledge generated by this study has many aspects. As previously stated, the research may be viewed as a "window" on the particular use of plural therapies by a select number of Canadian illness sufferers. The research also reveals a detailed description and analysis of the processes involving plural therapy use by illness sufferers. Additionally, the particular therapies used by individuals and related illnesses are placed in a highly relevant context of conceptual

models, significance and healing, as analyzed in an illness narrative. The combination of therapies used by illness sufferers, the range of illnesses suffered by individuals, the individual's perception of the illness and healing process associated with plural therapies, and the reasons underlying individual use of plural therapies are explored and discussed.

This research will be invaluable for health care provision, health care service delivery, and in the education of health care providers. As previously stated, the research may be used by physicians and other health care providers to gain a greater understanding of and appreciation for plural therapies. Additionally, health care providers and consumer groups of illness sufferers alike may greatly benefit from an understanding of how individuals conceptualize their illness while using plural therapies. This research also begins to fill a large gap in health care provider awareness of plural therapies, as identified by LaValley and Verhoef and discussed above (1995:45-49). Furthermore, this research may be useful for public policy makers, by providing a detailed description of how individuals are actually using plural therapies, in light of health policy such as health insurance and health care delivery (Vincent and Furnham 1997).

Chapter Four: Case Narratives

...when everything else fails and even the doctors kind of give up on you...you know what choice have I got?...You know I get thrown out of a hospital...all of a sudden you've had a problem you get thrown out on the street...and you have to try to deal with things

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I find that with alternative healers...if you're interested they will just give you a wealth of knowledge...they don't hold back...whereas doctors like to keep things: "I am the doctor and I'll tell you what you need to know--don't ask me anymore"

I have seen most people who go on drugs suffer from iatrogenic disease: disease caused by the treatments that the doctors give you...and I believe because of the toxicity of some of the drugs, that it probably leads people to an early grave

Introduction

The above statements were made by three individuals whose illness narratives are the focus for this chapter. The three narratives come out of a series of interviews held with chronic illness sufferers, who were searching for effective therapeutic relief. They represent, in basic form, the *care-seeking narrative*, previously discussed in Chapter One. The narratives were chosen based on their representative details and relevant stories about coping with chronic illness and search for therapies. There was broad variation in the narratives with regard to type of illness suffered, in that the selected narratives consist of two individuals dealing with HIV, and one coping with an internal head injury.

As discussed earlier, chronic illness is varied in scope in terms of illness type, etiology and symptom picture. Accordingly, chronic forms of illness necessitate many kinds of treatment. Moreover, chronic illnesses are often mis-diagnosed, and at times no underlying physiological cause can be found for the illness using conventional biomedical techniques (Kleinman 1988). As a result of all of these factors, as will be illustrated by the three case narratives, individuals experiencing chronic illness often go beyond conventional biomedical care in their search for

effective therapies to treat their chronic conditions. Therefore, the use of "alternative" forms of health care is common among chronic patients (Garro 1992:100-37).

In the interviews, individuals were asked to talk about their experiences with chronic illness and their search for therapy. The narratives began with the individual telling the story of his illness--how and when it began, how it may have disrupted his life, and the search for diagnosis and effective treatment. Similar to Garro's (1992) research documenting chronic illness and the construction of narratives, the narratives in this chapter reconstruct past events. In addition, the present is explained with reference to this reconstructed past. As a result, both past and present are used to generate expectations about the future (Garro 1992:101). Thus, temporal events are used to recreate new meaning (Hyden 1997).

These narratives represent a spectrum of individual experiences. The narratives presented here represent the "lived" or "embodied" illness experiences of individuals who have had to deal with illness at some point in their lives, and who have faced the challenge of searching for therapy in a complex biomedicine. The reader will discover that some of these individuals have managed to cope with their illnesses in such a way that illness is no longer at the forefront of their lives, while others continually face the challenge of unresolved symptoms including life-threatening factors. As will be discussed in the next chapter, the narratives also refer to structural elements which reflect the social, historical and political influences of the medical dominance thesis. Furthermore, each narrative chronicles a personal quest for therapy. More than the mere recounting of an illness event, it becomes clear that the narratives represent a life altered by illness (Frank 1995; Garro 1992).

Both similarities and differences can be drawn in the way the three individuals present their illness stories. One of the main similarities between the narratives is the difficulties each individual faced in seeking effective care for a chronic condition. Search for therapy often involved ineffective treatment, and dealing with an impersonal biomedical health care system. One of the clear differences was the variation in illness among the three individuals; indeed, HIV is very different from an internal head injury. Nevertheless, the fact that they are two types of chronic illness reveal significant commonalities between the narratives. Furthermore, as many authors have argued in the past, the three narratives also may stand on their own, thereby defying comparison, by offering unique accounts of lives profoundly changed by chronic illness (Frank 1995; Garro 1992; Kleinman 1988).

In this chapter, the interview material is organized and presented in a way that summarizes the life-events and illness history of the individual. This allows for comparisons across the three narratives, and helps to identify similar themes (Garro 1992:101). An analysis of the pertinent themes, using added narrative examples, is then provided in Chapter Five.

Using a classificatory model effectively applied by Garro (1992:102) in her study of chronic pain, individuals may be seen to reconstruct their illness histories following a specific pattern of stages. First, the narratives begin by indicating what may be called the "illness genesis." The illness genesis can be derived from the individual's own explanatory model or worldview, and communicated through how the individual talks about how the illness began. The illness genesis, as exemplified in this study, may also combine both exterior (alternative and biomedical), and personal models for the construction of the illness genesis. This becomes apparent in the narratives of HIV, where an early biomedical diagnosis is often made, and in other illnesses where

the awareness of exterior information surrounding the illness event enmeshes with personal models. The illness genesis also usually indicates certain precipitating factors for the cause of the illness, in addition to other contextual and surrounding details.

Second, the narratives continue by indicating a period of time up to the individual's realization of the disruptive nature of their chronic symptoms (Garro 1992:102). This period can be as short as a number of days, to as long as weeks, months, and even years. Particular characteristics that are indicative of this second stage are the disruption of daily life activities, such as work and family life. This stage is also characterized by a transition to the individual's realization that therapy is needed.

Following from this second period, a third stage emerges as the individual searches for a clear diagnosis for their illness (Garro 1992:102). The diagnosis often involves a search for an exterior, usually biomedical description, rather than the individual's model alone. A biomedical diagnosis, however, as in the narratives cases, did not necessarily end the individual's chronic symptoms, as curative biomedical treatment for chronic symptoms is rare (Kleinman 1988). As a result, individuals in this study often pursued other forms of unconventional treatment such as alternative therapies, despite having a biomedical diagnosis. The search for diagnosis, as in the second stage, may be very short, or may last years (Garro 1992:102).

A fourth stage, although not necessarily last, is the search for effective therapeutic treatment. Due to the varied nature of chronic illness, individuals in this study often faced a lengthy search for effective therapies which could treat their chronic conditions. As mentioned earlier, conventional biomedical therapies can have no potential for resolving or helping chronic symptoms. As a result, the individuals in this study pursued alternative health care. Many of

these alternative therapies provided relief, although these therapies still had to contend with the complexity of chronic illness.

Lastly, the narratives represented here are not intended to be "quantified." The pain, suffering and healing of each individual is not to be "rationalized" or "objectified", or re-classified into a "medical problem" or disease in order to be understood or deemed "valid" (Good et al. 1992). The experiences represented here cannot be "measured", but should be understood for what they represent: they are "lived" experiences, personal stories shared by individuals who want to express the experience of dealing with an illness. Personal illness stories are not only limited to the individual dealing with the illness, extend to the people around them--their family, friends and caregivers (Frank 1991). Most important, these stories can extend to the people who simply want to learn about what it is like to deal with an illness.

To maintain the confidentiality and anonymity of the individuals described below, place and proper names have been changed wherever possible, as indicated in the Ethics section in Chapter Three. For a more detailed explanation of the therapies presented below, please see **Appendix A--"Definitions of Alternative Therapies."**

I – Doug's Story

I first met Doug in the summer of 1997, when I was conducting fieldwork interviews for this thesis. My first impression was that there was nothing seriously wrong with him. There was no indication that he had suffered from a serious internal head injury fourteen years earlier from a car accident. We met at a local coffee shop, and drove to his small house located in a quiet community. Prior to the interview, the only indication that there might have been something amiss with Doug was the decor of Doug's house, which was filled with odds and ends located in curious piles. As was later revealed, this decor was necessary for living with an internal head injury, as the performance of daily activities required that Doug literally *see* everything in front of him. The atmosphere, similar to one of Kleinman's interviews, bordered on claustrophobic (1988). Overall, Doug was serious and eager to begin the interview to tell me his story.

Doug's story distinctly represents the care-seeking illness narrative, characterized by a focus on the search for relief of suffering and the understanding of his illness. The narrative constructed by Doug focuses on his understanding of his illness and the medical care he received, and the effects that both have had on his life. As in any narrative form, there are, however, other aspects from different narrative genres apparent throughout Doug's story. For example, adding aspects from both *chaos* and *quest* narratives, Doug views much of his past problems as due to an improper diagnosis of his internal head injury at the time of his accident, and due to the ineffective and poor medical care he received after this time. Doug clearly indicates this accident as the beginning of his problems. It was his discovery of alternative health care, however, which helped to significantly improve both his chronic symptoms and his overall life.

Doug currently receives alternative health care from a herbalist and chiropractor. He uses herbs to help improve his memory, bowel elimination, circulation, and general energy levels which help him to perform daily activities. Chiropractic therapy helps to keep his spine aligned so that he may walk without pain.

Background

Doug, 59 years of age, was born in 1939 on a farm in rural Manitoba. His mother was a home-maker, his father a carpenter. The oldest of three brothers, Doug's education was scattered as his family moved locations several times. Eventually Doug settled on mechanics as a trade, and trained at a technical college. Throughout his career, Doug worked in many mechanic-related positions such as heavy mechanics, which involved automotive, diesel and diesel-electric. This expertise brought him to several northern communities, where he worked as a diesel-electric station attendant monitoring the electricity for a small station.

Before his car accident, Doug was working as an airport inspector, which involved the inspection of equipment, the supervision of aircraft fueling, and the maintenance of the runway and electrical/emergency power units. At the time of the interview, Doug had been away from his job for twelve years. He is currently divorced from his wife, and lives with his only son. Previously, he had been an energetic man, traveling to the many places that his work required, and able to perform the tasks of a demanding job. He now views himself, however, as a victim of the medical "establishment."

Illness Genesis

In 1983, Doug was involved in a serious car accident on his way home from his work at the airport. Doug was hit on the driver's side of his car by a gravel truck which ran a red light. He was immediately rushed to the hospital by ambulance, but as he explains, he did not receive the most appropriate attention. When admitted to hospital, he was immediately strapped to a board. The attending staff, however, failed to give him a thorough examination. It was not until the next morning that the hospital staff noticed that Doug still had glass from the accident embedded in his back, and promptly removed it.

Talking about his experience directly after the accident and at the hospital, Doug notes:

> They hauled me to the hospital in an ambulance...[2]I spent the night strapped to a board of some sort [laughter]...and I don't really remember what time they--well I think it was early in the morning that they untied me from the board--and they found out that all night I had been strapped to this board, no one had ever thought to take the glass out that was still under me...and so I was strapped to this board in the panic--I guess when they were going to change shifts in the morning--the nursing staff or doctors I don't know what they were--then suddenly someone realized that I still had all this glass under me...and so I guess there was a panic to pick the glass out of me [laughter]...they untied me and turned me over and picked all this glass out...and then the next morning I guess the doctors come in and they did a bunch of tests and they x-rayed me, and then they give me a set of crutches and said "go home!"

As Doug explains, he was discharged the very next day from the hospital, his internal head injury completely unnoticed by hospital medical staff. Suffering from internal bleeding and acute pain all over his body, he was referred to a specialist who prescribed a powerful anti-inflammatory

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[2]Three periods indicate a break in the verbal pattern.

drug, "Naproxin." Although providing some initial relief, the drug ultimately caused him more acute symptoms, resulting in a bleeding ulcer for which he was prescribed additional medication. This would be the first of many experiences in which his condition actually worsened by the prescriptions he was given by biomedical physicians and/or specialists.

Prior to the accident, Doug was in good health, and able to keep up a demanding job and attend to family life. The accident which precipitated his head injury, and ineffective and damaging biomedical treatment, however, slowly changed his previous lifestyle and activities.

From Illness Genesis to Life Disruption

Miraculously, Doug eventually made it back to work after his accident. Over the next six months, while maintaining his work activities, he began to experience symptoms of chronic fatigue and memory loss. These symptoms began to prevent him from being able to perform his normal work duties, and he was soon forced to take an additional sick-leave. Doug was initially referred to a work counselor who recognized that there was a problem, but was unable to pinpoint the cause. In the meantime, Doug was referred to a psychiatrist, who gave him additional medication.

There was a specific period when Doug realized that something was seriously wrong. Doug understands this time as a period of confusion, frustration and uncertainty. Talking about his experience at work, he explains:

> ...and I remember trying to get to work, and I would collapse several times in the walk from my parking spot to my work-place, and later on, when I got to work, I really didn't know what I was doing there...my in-basket was piling up, and I just, you know, everything was foreign to me...I didn't know what it was all about...

It was at this time that Doug realized that he would have to seek serious medical care to try to understand the chronic symptoms he was experiencing, and which were ultimately making his previous lifestyle impossible.

The Search for Diagnosis

Over the next year and a half, Doug would embark on a very long search for diagnosis. This period was marked by Doug's uncertainty as to why he was experiencing his symptoms, and despair at finding no relief or justification for his condition. Doug continued to experience memory loss, general confusion and disorientation, including muscle pain.

Doug consulted many biomedical physicians and specialists. None, however, could find any underlying cause for his persistent symptoms. Prescribed drug after drug, Doug soon developed serious side-effects, which added other conditions to his already long list of unexplainable symptoms. Thus Doug's life was not only disrupted by his illness, but from damaging drug-induced side-effects.

He first experienced the cessation of bowel elimination and colon movement. In addition to developing bowel problems, Doug further developed Type II diabetes, which, while perhaps not attributed to a drug side-effect, he was again prescribed an additional medication with potential side-effects. It is this additional diabetic medication, which Doug believes caused a heart attack several years later in 1990. Thus, Doug was not only suffering from symptoms produced by his body, but from the powerful and often toxic effects of biomedical drugs. Describing his experiences with drug-induced side-effects, Doug notes:

> ...my elimination stopped...and my belly swole up so bad...I guess that was another thing that...after the accident that...my elimination slowed down, and then, when I was on this medication...that just plugged me up solid...and I swole up...oh I don't know, I could put a cup of coffee on my belly, like that, but...it was terrible...

Throughout this process, Doug also had to deal with many other factors related to his search for biomedical diagnosis, one of which was the "regimen", rigid schedules and authoritative attitude of biomedical doctors. For example, he often had to attend early morning doctor's appointments, which ultimately exhausted him. Furthermore, Doug would often be prescribed medication with no thorough explanation provided by the doctor as to the potential side-effects and toxicity. In addition, Doug's illness caused repercussions which extended both to his family and social life, and which ultimately led to his divorce. Describing his feelings at this difficult time in his life, Doug notes:

> ...like I just...I still felt so terrible...I guess by that time, I had been away from my job...wife left me...I had moved to this house...and...you know everything was, you know, everything was going wrong, and, everything that could go wrong did go wrong...

Throughout Doug's experience from illness genesis to search for effective therapy, his experiences with conventional biomedicine proved only to be destructive to his overall health. His problems began by a careless biomedical misdiagnosis of a life-altering condition. His condition was further complicated as physicians and specialists alike could find no cause for any of his symptoms, until it was too late. Doug's search for diagnosis only proved to hinder his health further.

Looking back and reinterpreting his hospital experience immediately after his accident, Doug is able to give two reasons why the doctors missed his head injury. The first reason, in Doug's words, is that "they minimized everything...and they went on the basis of 'well [laughter]

you're right side up and your blood's flowing and uh, you got a blood count and, so away you go!'" The second reason, in Doug's opinion, was that the hospital did not give ample time for a thorough medical examination. As Doug states: "I just got the feeling that 'hey' everything was filled up, and 'hey, we haven't got room for more people here.'"

Two years after his accident, with no diagnosis or effective therapy for his chronic symptoms, Doug was on the verge of complete mental and physical exhaustion. Attending yet another specialist, he was finally given some answers which made sense. The specialist correctly diagnosed that Doug had been experiencing symptoms caused by an internal head injury, and that he was definitely not "going crazy." This injury had been mis-diagnosed by hospital medical staff two years earlier. Moreover, because of this late diagnosis, Doug had missed the opportunity for significant rehabilitation.

The Search for Effective Treatment

Up to the point that Doug suffered a heart attack in 1990, and despite the correct biomedical diagnosis of an internal head injury which provided a context for such symptoms as chronic fatigue and memory loss, Doug's symptoms remained constant over the seven years since he had experienced the accident. His frequent visits to various biomedical practitioners and specialists provided no effective therapeutic relief. Thus, he had not found any significant relief by using biomedical therapies.

One of the last major health problems that Doug endured prior to seeking effective care was his heart attack. He spent three weeks in the hospital, followed by rehabilitation at a refit centre. Incredibly, he was not taken off the diabetic medication until sometime later, which

according to Doug was a likely precipitator of the attack. In the aftermath of his heart attack, and similar to his past experiences with doctors, Doug still attained no detailed explanation of his condition. Additionally, Doug was also put on heart medication at this time. Despite the possible positive effects that the new heart medication may have had, Doug again experienced serious side-effects from drug-treatment, such as fatigue. Rather than physicians validating his complaints, he was coerced into taking the medication under threat of additional heart complications. Talking about his experiences, Doug explains:

> I've been complaining ever since I started taking this stuff...that it creates...a feeling of tiredness...you know your full energy isn't there...but they say "Well, you way one against the other and, you know, would you sooner be tired?", and then they scare you with the threat of...heart pains or something like that...

In desperation after suffering all that he had suffered with no significant biomedical therapy or relief in sight, Doug began to explore additional therapies, in the form of alternative medicine and related therapies. Attending a holistic conference, Doug overheard a herbalist describing her practice, and asked her if she could help with his condition. This would mark the end of Doug's quest for effective therapy, and the beginning of a significant healing process.

One of the first things that Doug and the herbalist worked to heal was his poor bowel elimination, which gradually improved. Doug's other persistent and chronic symptoms, such as his memory loss, disorientation, fatigue and pain also began to improve significantly. In addition to herbal therapy, Doug also found relief with chiropractic therapy, which, by aligning his spine, helped with his walking and balance. In addition, the use of herbs eventually enabled Doug to manage his diabetes on his own. As a result, he stopped taking the diabetic medication, but still remained on heart medication. Stopping the diabetic medication, as it turned out, significantly

improved his energy levels. Commenting on his decision to use alternative therapies, Doug notes:

> Well nothing else was working...it's something I hadn't never tried before...so, you know as far as I was concerned I had nothing to lose...well, ever since the accident things just seem to get worse and worse...to the point I had the heart attack...you know at that point I thought I'd been following all the doctor's wishes and...spending half my life in the doctor's office...which I was getting pretty depressed about...so at this point...I thought I had nothing to lose...

When asked how he thought the use of alternative therapies such as herbs helped his condition, Doug responded:

> Oh! there was no...I just felt so much...better...not as good as I did previous to the accident...but...at least I could function...go through a day without...massive pains...and fatigue--well I still have the fatigue but not nearly as bad--so there was a vast improvement over what it had been before

Despite the success Doug experienced in using alternative forms of health care, he had to explore the use of these therapies on his own accord. He felt that no physician was particularly interested in his case, and that biomedicine basically "gave up" on treating him. He was informed that there was nothing the present biomedical system could do to help his condition, and that if he wanted to explore unconventional therapies he would have no support, financially or otherwise. Talking about how he felt regarding these matters, Doug explains:

> ...the way I understood it was...there was nothing they [the doctors] could do for me...if I wanted to do it on my own fine, go ahead but...there was nothing that they would be able to do for me...out of the present system...

Doug feels that in a long-term process of healing, alternative therapies gradually helped to resolve many of his chronic symptoms. He notes that in using alternative therapies, he would gradually lose awareness of his symptoms, such as stammering, until they disappeared altogether. In contrast to biomedical drug-treatment, Doug believes that when properly administered,

alternative therapies such as herbs have little if no side-effects. In the case of drug-therapy, he believes that the beneficial effects are often untrustworthy, in comparison to the potential harmful effects drugs may have. Doug further states that he has experienced virtually no positive or beneficial effects from conventional biomedical treatment.

Doug feels that while doctors may have potential diagnostic abilities, they are overall, a "necessary evil." He believes that there are other, more effective ways to maintain health than relying on traditional biomedical procedures. He is very thankful for the accessibility to alternative practitioners, when all biomedical avenues had failed him. When asked if he thought biomedicine had helped him at all, Doug replied:

> My feeling is no...it's practically the opposite...but...you know, in my experience it was the Naproxin that created my stomach ulcers...it was the Chlorpropamide that created the heart attack...and...you know what other stuff I've taken...I guess there's other stuff as well that...I've taken in the past and you know, had bad effects from...

When asked about his view towards the future, Doug still hinted to the fact that, despite his success using alternative therapies, biomedical drugs still had the potential to dominate his life:

> Well, I'm waiting for...hoping that some doctor is gonna say--gradually, or whatever--stop taking these things...maybe it's something that's totally harmless...but...you know, just the same, if I get the feeling that my energy is being robbed from this...then...maybe it isn't right...because I don't really know why I'm taking these things [drugs].

Overall, Doug believes he has resolved many of his chronic symptoms with the use of alternative therapies. While he may never achieve the level of health he enjoyed previous to his accident, Doug is content in his current level of health and functioning. Although he still has his bad days, Doug is now completely self-sufficient. He spends his time collecting information about various alternative therapies, and volunteers at a local head injury association.

II – Ben's Story

This narrative represents a different response to chronic illness, although it is clearly related to Doug's quest for proper care and diagnosis. I was introduced to Ben through a Sound Therapist, who was treating Ben for chronic symptoms attributed to the early stages of the fatal HIV virus. I was interested to meet Ben, as I knew there were many people dealing with HIV who were exploring alternative forms of health care. As with Doug, upon the first impression there was no clear indication that Ben was suffering from a life-threatening disease. His physical appearance was of a man of middle age, with a strong, robust and healthy-looking physique.

We conducted the interview in Ben's small but tidy apartment, one of about a dozen suites specifically built and funded for people living with HIV. In comparison to Doug's house, Ben's apartment was virtually spotless. Similar to Doug's head injury which necessitated keeping objects in plain view, Ben's level of cleanliness was also a reflection of living with HIV. By maintaining a sterile environment, the risk of contracting a viral or bacterial infection is lowered. Indeed, for an HIV sufferer, infection cannot be taken lightly, as even the mildest of infection could prove to be deadly. We began the interview with Ben eager to tell me his story.

Ben's narrative focuses on his understanding of the HIV virus, and of the therapies he uses to combat the virus. His story furthermore encompasses a life affected by the loss of his partner also due to HIV, and a spiritual worldview which helps him cope, both physiologically and psychologically, with the difficulties of living with HIV. Differing from Doug, Ben combines both alternative and biomedical therapies together, in the hope that this will keep the virus at bay. While he recognizes the limitations of biomedicine, he continues to use biomedical drug therapy,

and feels that each form of medicine has its place in maintaining overall health. Ben's story, while maintaining the core nature of a care seeking narrative, also contains strong elements from the quest narrative. Ben understands his illness as a journey which encompasses both better health and the future possibility of death and transformation.

Background

Ben is 49 years old, and was born in Ontario. His father was in the military, and his family moved each time his father was posted to a new location. Eventually Ben went to a technical school in Ontario. After completing his education, he then worked in the Navy for three years. Following this, Ben pursued various other jobs such as a farmhand, and in construction, splitting field-stone for fireplaces. Later on he secured a position with a G.S.I. oil exploration company, which payed for his additional education in geophysical research. He then changed occupations once more and worked for a provincial government investigating fraud until his retirement 17 years later. Ben's illness would be a key factor in his leaving this job, and would change his lifestyle significantly.

Similar to Doug, before contracting HIV Ben was working in a demanding job which required a high level of energy. As a result of contracting HIV, however, Ben decided to take early retirement. At the time of the interview, Ben was living by himself, supported by a settlement package from his previous company.

Illness Genesis/Search for Diagnosis

In 1994 Ben was medically diagnosed with the HIV virus. At the time of the interview, he had not yet progressed to full-blown AIDS. His illness genesis was combined with diagnosis, in that both were relatively short. One underlying reason for this was that despite being a disease which causes chronic symptoms, biomedical tests can now identify HIV infection quickly. The other reason for the short time of genesis and diagnosis, is that Ben knew immediately how he had contracted the virus. He had been living for some time with his partner who was also HIV+, and although they were taking precautions, Ben still managed to contract the virus.

From Illness Genesis to Life Disruption

As mentioned earlier, one of the major effects that HIV had on Ben's life was taking early retirement. The main reason for this, was that Ben's level of fatigue could not stand up to a full work week. There are other important elements of life disruption that Ben experienced, however.

Recently, Ben's partner died from an infection due the advanced stage of the HIV virus. Ben considered his partner to be his "soul-mate", and was devastated when he lost him. Furthermore, life disruption, as in the case of HIV, does not necessarily precede the search for effective therapy, as HIV is most often a terminal disease. In other words, life disruption continues throughout Ben's life, since the loss of his partner, and as the chronicity of his symptoms gradually increase. Moreover, Ben experienced other aspects of life disruption, such as drug-induced side-effects, which were a part of his search for effective therapy.

Search for Effective Therapy

Ben began exploring both biomedical and alternative therapies from the very beginning of his contracting the HIV virus. In contrast to Doug, Ben's search did not involve a long quest for effective therapy. This was partly a result of his previous knowledge of alternative therapies used to treat his late partner, and partly a result of his knowledge of the body. Ben's mother was a pharmacologist, and because of this he learned many aspects of the body and the medicinal use of herbs while growing up. In the course of his varied formal education, Ben also took additional courses on biology and chemistry, thereby boosting his already detailed knowledge. Through these courses, Ben obtained a good understanding of human anatomy and pathophysiology which he uses in conjunction with his use of alternative therapies. Ben began exploring in earnest "plural" therapies, or the combination of both alternative and biomedical therapies to promote healing. Talking about this period of education, he explains:

> I basically did what I did on my own...but I knew I had done research and I had been taking molecular biology at university...I knew how the body worked...I knew how the body absorbed...and when it came to plants I knew that they do have medicinal properties...and having been brought up with herbs my mother, when she was in England, she studied pharmacology but in those days it was mainly herbal pharmacology they studied, so we were raised on herbs when we got sick...so I had a bit of an in there...I had to get a good background on everything--on the neurology, the physiology...

Ben's use of plural therapies began with a combination of certain forms of biomedical drug treatment, and various forms of alternative therapies incorporated to boost his overall system. One of the main reasons he started to take the HIV drugs was due to the caution of his doctor, who warned him about his lowering white blood cell and rising virus counts. In addition to taking HIV drug therapy, Ben also uses sound therapy, vitamins, herbs, protein supplements, in addition to a well-balanced diet and proper exercise. In addition to these therapies, Ben practices Buddhist

meditation, which he believes helps his mind and spirit and lowers his anxiety and stress levels. As a part of his method, Ben further uses a computer graph to monitor his blood and the effects of how each therapy may be helping him. Talking about his combined approach, Ben explains:

> I was first introduced to [plural therapies] by my doctor--a wonderful doctor...because my counts had dropped so low they went down to 125...he said it's time to start this therapy [medical drugs]...so we started with the retrovirals, the pharmaceuticals...he prescribed them for me and then I had to go to the clinic...and I started taking the retrovirals and the protease inhibitors, and a prophylaxis for PCP pneumonia which I don't take anymore because my counts had gone up high enough I don't need them...and I was taking that along with my mega-vitamins...I was taking that along with the herbs...and I use herbs sparingly because...during flu season I'll start taking extra herbs to help my body...and I've had success with that...I don't get too many flu's...and I'll use herbs if I feel like...something coming on I'll start dosing myself with herbs that are appropriate or have been known to be appropriate for that condition...but I always take my supplements...I drink a powder as well...which is a supplemental powder for protein...and I work out...

Ben is very articulate about the effectiveness of the use of alternative therapies to promote healing. He believes that alternative therapies promote healing by strengthening the body's own systems on physical, mental and spiritual levels. This is different from relying on drugs to create the body's health. In the case of alternative therapies, it is the body which is being helped to establish its own equilibrium, rather than a sole reliance on an external source.

For example, Ben uses the more "material" alternative therapies such as herbal and vitamin supplements to strengthen his body's physical system, while therapies such as sound therapy and Buddhist meditation promote lower stress levels and spiritual healing. Furthermore, Ben believes that the therapies, while potentially working independently on a different level of the body, work together in a form of "synergy", each promoting or enabling the other. It is this focus on promoting healing on all levels of the body, rather than focusing on one level alone, that he believes is the key to maintaining healthiness in the face of a potentially fatal disease.

Ben also draws an important comparison to the difference between alternative and biomedical practitioners. In his opinion, alternative practitioners provide much more emotional and psychological support, which he believes is essential to the healing process. Rather than separating the two domains of alternative and biomedical therapies, however, Ben will often attempt to combine the two by using one to complement the other. For example, Ben uses a visualization meditation to attempt to strengthen his immune system. In accordance with his combined approach towards treatment, Ben further believes that it is a combination of therapies, rather than strictly biomedical or alternative, that has helped him to achieve his current level of health.

Ben describes how he understands the use of alternative therapies on multiple levels to promote healing:

> I think the alternative therapies, they've actually done what they are supposed to do which is strengthen my system--help me naturally to keep myself healthy...my immune system...my whole function as a whole...because I don't take just supplements just for my immune system...I take vitamins that work synergistically with each other so that they work together and they can work for the whole body because...I don't believe in just taking out one area and working on that...I think the secret to this is using the whole body...make the whole body healthy...as I explained to you before...mentally, physically, spiritually...you know...and I think the alternative therapies have helped much more than the allopathic help because you don't get...the psychological and emotional support from doctors that you can get from some of these practitioners...alternative therapists you know and that's certainly helps a lot when you...go with somebody that is genuinely wants to help and is generally out there to help you...you know...that can make a difference...with doctors you can sometimes be in and out and in and out and in and out and in and out!...but a lot of these people [alternative therapists] that I've dealt with and I've seen...they're just very genuinely concerned and genuinely want to help...

As mentioned earlier, there are certain aspects associated with the search for effective therapy which can be disruptive in one's life. Similar to Doug, Ben's use of HIV biomedical drug-therapy, despite his positive intent, had its price--he was not able to avoid the side-effects of the

powerful anti-HIV drugs. He experienced episodes of severe nausea and anxiety, accompanied by fatigue, in addition to violent sinus headaches. Interestingly, through the use of alternative therapies such as meditation, however, he has been able to overcome some of the side-effects of the HIV medication. Additionally, the drugs altered his sensory perceptions towards certain foods, and required that he completely exclude those foods from his diet. Commenting on the severe side-effects he experienced, Ben states:

> Oh! Nausea, unbelievable nausea--it was with you all the time...sometimes it wasn't always like you want to get sick but...I guess you could say it was like in the background you always felt crappy...fatigued and nauseated...and I know cause it did with my partner as well--I got turned off from some foods...like even now if I think of grilled foods I think of going to the bathroom...I used to love grilled steaks and chicken...it's altered my perception of certain foods...

Currently, despite experiencing certain side-effects, Ben is feeling very healthy, his virus counts are low, and he is not experiencing any chronic HIV symptoms other than mild fatigue. His use of a combination of both alternative and biomedical therapies, has, in his opinion, kept him at his current level of health. He continues to explore new therapies which may boost his immunity against HIV. When asked which therapies, in his experience, were the most beneficial in treating his illness, Ben replied:

> You know...it'd be hard to say right now...if I was to zero-convert I could never say which one was the best I honestly think it's going to be a combination of everything...I think a person who is...not just HIV+ but who has cancer or whatever...you have to look at the body as a whole...you have to treat the disease definitely...and when you keep the whole body healthy you have to think of the mental well-being, which a lot of doctors don't really do...they just sort of, "hey here take a pill"...and uh as well as a spiritual well-being because you become spiritual when you know you have a disease that can kill you...you become very...you know...introspective I guess...you look at your past life...

III – Greg's Story

Greg's narrative of living with HIV, while similar to Ben's story, is also strikingly different. I was introduced to Greg through Ben's Sound Therapist, who also happened to be treating Greg. Greg also lives in the same building as Ben, and it became clear that they were friendly neighbours when Ben led me to Greg's apartment. Different from the two previous narratives, however, upon first impression there was every indication that Greg was dealing with a serious illness, and that he had been for some time. His face had the drawn look of someone who was living with a disease, accompanied by a slight physique. Defying his weak physical appearance, however, Greg embarked on a very vocal, detailed and full narrative of his illness story.

The focus for Greg's narrative centres on his struggle with living with the HIV virus, and his search for effective therapy. Elements of the chaos narrative intermingle with the care-seeking narrative, as Greg's despair of living with the virus becomes strikingly apparent. Unique to Greg's search for therapy, however, is his almost complete avoidance of biomedical therapies, and his extensive use of alternative therapies, from the time he was first diagnosed with HIV. This additionally gives Greg's story aspects of the *manifesto* quest narrative, characterized by raising awareness through illness. Furthermore, aspects from *narratives about illness* become apparent in the detailed chronology of illness symptoms that Greg presents. Also unique to Greg's story is that he is a long-term HIV survivor. At the time of the interview, Greg had been living with the virus for at least ten years, and had not yet progressed to full-blown AIDS.

Background

Greg is 48 years old. He was born and grew up in a small town in Nova Scotia with a population of approximately 5,000. Greg left Nova Scotia for Ontario, where he studied Social Work at Ryerson University, followed by Theology at the University of Toronto. In addition to this education, Greg has trained in and practices the alternative therapies of reiki and therapeutic touch, and is a certified hypnotist and practitioner of time-line therapy and neurolinguistic programming (NLP). He also has a thorough knowledge of many other alternative and biomedical therapies.

Illness Genesis/Search for Diagnosis

In 1988, Greg was medically diagnosed with the HIV virus. As with Ben, due to fast biomedical tests, Greg's illness genesis and diagnosis were combined, and both were relatively short. Differing from Ben, however, Greg was uncertain as to how he had contracted the virus. According to his partner history, Greg could have been infected and living with the virus since 1981, at which time a partner he was no longer involved with passed away from an advanced stage of HIV. Thus, there was a potential seven year gap when Greg could have been living with HIV. Despite the fact that Greg could have been infected seven years prior to his medical diagnosis, he did not begin to experience symptoms until 1988. Greg's illness genesis and search for diagnosis, therefore, remains relatively short from when he first began to experience symptoms.

Greg was diagnosed with HIV when he was at the height of his career. As he explains, finding out he was HIV+ was to change his life dramatically:

"How did you feel when you were first told you had HIV?"

> Well I felt a lot of things...well initially I felt very comforted by the people who delivered the news, they were really very supportive...I had done pre-test counseling...I was well aware that it was a very real possibility that I was infected, so it wasn't so much a surprise, but the reality wasn't a very pleasant one...as a matter of fact, the doctor, I suggested to him that we have a little party, because there were quite a number of changes that I felt I needed to make in my life at that point--including nutritionally--so like let's have a little party with some of my friends, and sort of have a "last blast!" [laughs], and, so we did that...um, it was very frightening, scary...

From Illness Genesis to Life Disruption

Despite the fact that Greg would have much success with alternative therapies in controlling HIV, he could not avoid the detrimental and disruptive effects from living with the HIV virus. Greg's situation was clearly different from Ben's experience. Whereas Ben lives fairly comfortably on a settlement package from his previous company, Greg lives at the poverty line. By avoiding HIV drugs, however, Greg does not have to deal with the harmful side-effects that Ben must endure in addition to living with HIV. Nevertheless, both experienced life-disruption in terms of the inability to work. In the case of Greg, HIV prevented him from being able to maintain a standard of living above the poverty line.

For five years after diagnosis, Greg was still able to maintain full-time work. Shortly thereafter, however, Greg began to experience bouts of irritability and fatigue that could only be attributed to the HIV virus. It was at this point that Greg left for Toronto, in the hope of starting a private practice in therapeutic touch, which he hoped would require less energy. After several weeks in Toronto, however, he developed an episode of shingles, and experienced even more fatigue. This ultimately prevented him from developing a private practice, and forced him to return to Winnipeg, unemployed. It was not until four years later, with the help of alternative

therapies such as homeopathy and sound therapy, that Greg found the strength to start exploring part-time work. Commenting on this period in his life, Greg notes:

> when I would get up in the morning, I would have to see my feet on the floor, in order to be able to stand up, because my energy was so low that I didn't know that my legs--it was like--I had to concentrate on my feet being on the floor in order to know that my legs could hold me up so that I could walk...so I just became blottoed, and it took quite a number of months to be able to regain some strength, and so, while I did some work while I was there, I ended up not being able to have the energy to work on developing a private practice...

Greg is very vocal about what it is like to live in poverty with a serious illness. He states that he does not have the privileges that many of us take for granted, such as being able to travel, to visit with family, to see friends, going out to dinner, and pursuing creative activities. He also believes that it is his inability to pursue these activities which contributes significantly to his depression and lack of motivation. Commenting on what it is like to live in poverty with a serious illness, Greg notes:

> living in poverty is not any fun, it's very stressful--if I could be employed in some way and in some activity that didn't have a lot of stress, that could allow me some flexibility to function when I could function, and I could generate a decent income and living for myself, I'd be comfortable...

As will be seen in his search for therapy, not only is HIV preventing Greg from living the life he wants to lead, but his lack of financial resources ultimately restricts his use of alternative therapies. Thus, life-disruption and search for therapy is combined, as it is for all individuals dealing with a chronic and life-threatening illness.

Search for Effective Therapy

Faced with a chronic and often fatal illness, Greg was very aware of his options towards particular health care strategies. For reasons that will unfold below, he made an educated and conscious decision to completely reject most biomedical therapies such as biomedical drugs, and decided to pursue alternative therapies alone. Greg's reasoning for this decision, as he explains, is threefold. He believes that: (1) biomedical drugs, especially those used to treat HIV, are highly toxic; (2) the long-term side-effects of HIV drugs on the human body and on the HIV virus are as yet unknown; and (3) alternative therapies represent an equal or better chance of combating the virus and promoting well-being. Regarding his decision to pursue only alternative therapies, Greg explains:

> I went to a medical doctor in order to get tested...but by that time in my life I had been doing some exploring, I had already started, I had already been trained in therapeutic touch and was practicing with friends and others...I had begun to explore non-conventional understandings of health and disease and how to work with those conditions...I guess because of my reading and sort of re-thinking that part of my life, I'd already decided that if I ever was faced with a life-threatening disorder that I would primarily use alternatives, as my first line of attack, and I have continued to do that for nine years...

As mentioned, one of the main reasons Greg avoided biomedical drugs was his belief in their toxic side-effects, otherwise known as "iatrogenesis", or disease caused by biomedicine. He believes that by using alternative therapies to combat HIV, he may avoid causing his body to become more toxic. He details his argument:

> ...I don't experience side-effects from what I do [alternative therapies]...in the sense that my reactions to the medicines that I take or to the practices that I use do not cause me to become more toxic, therefore I don't have to deal with the toxicity level, but it does help to cleanse the body and keep things flushing out and moving, it does help the body to be more restorative, and, lots of the things that I do stimulate activity on other levels, psycho-spiritual levels...so, and I must say that, as I look out from my experience to other people,

> at times when others are becoming more and more fatigued, the work that I've been doing has been creating more and more energy for me.

Requesting a referral from the doctor who diagnosed him, Greg soon began a rigorous seven-year program with a naturopathic doctor (for a detailed definition of naturopathic medicine, please see **Appendix A -- "Definitions of Alternative Therapies"** below). He began with an informal meeting with the naturopath, where they negotiated a treatment program. The meeting involved taking an extensive medical history involving a psychological assessment. Greg then began a program which involved such alternative therapies as acupuncture, counseling, herbs, ozone therapy, vitamins and minerals, hydrotherapy and nutritional therapy (see **Appendix A**).

Despite his heavy reliance on alternative therapies, Greg explained that in order to maintain his mental well-being, including a balanced lifestyle, he ultimately had to incorporate other pursuits in addition to alternative therapies. By the end of the first summer of intensive treatment, Greg determined that while he may have been physically well, he was not mentally healthy. As a result, Greg took some time off his intensive treatment plan, and began some part time work. Nevertheless, he still continued using certain alternative therapies.

In his search for therapy, Greg discovered that he needed to find a therapy which stimulated both the physical, emotional and spiritual levels of his body. Bio-tuning, subtly different from bio-acoustics, is one such therapy which met all of those expectations. Using bio-tuning, Greg also became aware of his own symptoms and began to understand them more thoroughly. Regarding his healing process associated with the use of bio-tuning, Greg comments:

> ...and then I found out about bio-tuning, and what had led me to homeopathy and to bio-acoustics was that--it was just a hunch you know I'd been reading a lot about acupuncture, Chinese medicine, herbal medicine...so what I had come to realize was that I needed something that turned all of the systems on simultaneously, and that worked also on the psycho/spiritual level, and bio-tuning is the one therapy that does that, and it moves you through the physical level, by balancing all of the organs in the systems of the body, and then moves on to address the emotional/spiritual level...and of course while the body is being stimulated to be functioning at a normal level, it also is sort of percolating all of the psycho/spiritual things...

It was clear that Greg's decision to avoid biomedical therapies was influenced by his interactions with allopathic doctors, which, similar to Doug and Ben's experiences, on the whole were negative. Greg notes that his experiences with doctors were marked by doctor-defensiveness and physician coercion to use biomedical drugs, despite the fact that eventually he was able to find a supportive doctor.

For example, Greg was in need of a family physician to perform certain functions such as blood monitoring. Greg would approach the certain physician, and as with his naturopath, would negotiate an informal verbal contract in an attempt to establish the kind of treatment he wanted. His main needs were that the physician agree to perform basic physiological checks and tests, keep him updated on the latest biomedical treatment or treatments, but also recognize and respect Greg's use of alternative therapies, and thereby not coerce him to use HIV drugs.

Despite attempts to establish such a contract, Greg had many difficulties. One experience was marred by the particular physician being highly defensive towards establishing an open physician-patient relationship. Another physician, despite agreeing to the contract, continued to badger Greg to use HIV drugs, to the point where Greg simply outright left the physician. Talking about his experiences with doctors, Greg states:

> ...one of the frustrations for many years, has been that medical doctors have not generally supported [alternative therapies], and it took me a long time before I found medical doctors who would support that, because, as more and more drugs became available--of course every time I went to have my blood work done then they wanted me to consider this new drug or that new drug, or taking some kind of prophylaxis--and my reasoning for not doing that is, from the beginning, that what I'm doing is working...but what would happen is I'd go for visits and at the end of it I would be asked, you know, "was I ready, you know, to take the 'A'", you know, that 'A' word, what she was referring to was AZT...so that just happened more frequently, it became an every time occurrence, and, one day I just was in the wrong mood to hear it, and I just, literally got really pissed off at her and I walked out of her office. I said "if you can't serve me the way I need to be served, then you don't need to be my doctor!"...Then I went to the director of the clinic and I complained, and then I wrote the board of directors at the clinic, and I complained...because she really had overstepped her bounds. That put me in a place of really having little or no trust for doctors, for medical doctors. It also put me in a place of having to search for somebody else, and it took me as I said well over a year to be able to find somebody...

Greg is convinced that it was his reliance on a combination of alternative therapies, and the avoidance of toxic biomedical therapies, that has kept him at his current level of health. He also believes that it is the exclusive use of alternative therapies that has helped him to survive the HIV virus for a significant length of time. This is in clear contrast to Ben, who believes that biomedical drugs, seen as toxic by Greg, are also integral to maintaining health in the face of HIV. Commenting on his view towards the use of alternative therapies as opposed to HIV drugs, Greg comments:

> Well lets say that many of the people that I knew who were diagnosed [with HIV] at the same time that I was diagnosed, are dead now...you know...I have stayed, certainly have stayed as well as those people that are, who are taking drugs, and much better than most...

When asked what he thought were the major reasons for why he outlived other people he knew with HIV, Greg responded:

> Well, I've done an awful lot other than just relying on pills for my well being, you know. I and many other people that are infected you know we have grown up in a culture that says, you know, the "quick fix", and people look to that, it's the only thing that they know...

When asked if he thought medicine had failed in the treatment of chronic illness, and if for that reason people were choosing unconventional therapies, he responded:

> I don't know if people are choosing alternatives because they are chronically ill--some for sure--I think that what we can say about chronic illness in comparing the different systems is, that depending on the chronic disease, the alternative systems do as well or better, and the way it winds up is, on the acute side, the allopathic medical practices do a little bit better, and on the chronic illness side, the alternatives do a little bit better.

Currently, Greg is continuing with the healing process of bio-tuning, and has plans to draw on his current experiences by writing several books about coping with HIV and using alternative therapies. Despite his skepticism towards biomedicine, he is also exploring the potential of new allopathic therapies, and is participating in a current clinical study on alternative therapies. Greg remains, however, frustrated with his present-day existence:

> but what I've discovered is that...part of the pattern that I've lived with is living in the past, and living towards the future, but having difficulty being satisfied being here in the present, and I'm heavily into those past issues in terms of feeling stuck and changing them, and bound to be determined to do it, and looking forward to the future and things that I want to have happen, but I'm having difficulty just being here...

Chapter Five: Analysis of Narrative Themes

The following analysis presents themes derived from the case narratives. The themes are presented and discussed by drawing analyses across the three narratives, thereby providing both comparison and contrast. In addition, extra narrative from the case studies not previously included is added where it becomes applicable and relevant to the particular themes. The analysis also links the two conceptual frameworks, that of the individual care-seeking narrative and medical dominance, as discussed in Chapters One and Two.

Themes Drawn from the Care-seeking Narrative

As previously mentioned, themes can be drawn from the narratives using two related conceptual frameworks. The individual care-seeking narrative reveals themes such as iatrogenesis, healing promoted by alternative therapies, spirituality, job loss, family history and self-reflexivity. Medical dominance, however, underlies many of these experiences, by providing a more global framework towards understanding these themes. Nevertheless, as will be discussed, the care-seeking narratives continue to engage the underlying medical dominance thesis.

Theme 1. The Chronic Patient in Biomedicine

It is clear that one of the main similarities between the three narratives is the experience of the chronic patient in biomedicine. As previously mentioned, biomedicine is often ineffective in treating the complexity of chronic illness, resulting in chronic patients facing many obstacles in the

biomedical health care system (Kleinman 1988). Contained within the experiences of the chronic patient in biomedicine, is one powerful sub-theme: iatrogenesis.

Iatrogenesis

"Iatrogenesis", originally derived from the Greek origin, literally means "of physician origin" or "physician-caused" (Illich 1976:3). More specifically, it means disease caused by any medical system. Illich breaks down iatrogenesis into three levels: clinical, social and structural/cultural. Illich, defines "clinical iatrogenesis" as meaning "all clinical conditions for which remedies, physicians, or hospitals are the pathogens, or 'sickening agents'" (1976:27). Illich states:

> The pain, dysfunction, disability, and anguish resulting from technical medical intervention now rival the morbidity due to traffic and industrial accidents and even war-related activities, and make the impact of medicine one of the most rapidly spreading epidemics of our time. Among murderous institutional torts, only modern malnutrition injures more people than iatrogenic disease in its various manifestations (1976:26).

Clinical iatrogenesis "includes not only the damage that doctors inflict with the intent of curing or of exploiting the patient, but also those other torts that result from the doctor's attempt to protect himself against the possibility of a suit for malpractice" (1976:32-33).

Illich further states that iatrogenesis cannot be understood unless it is seen as the "specifically medical manifestation of *specific counterproductivity*" (1976:8; emphasis in original). Illich defines "specific" or "paradoxical" counterproductivity as a "negative social indicator for a diseconomy which remains locked within the system that produces it" (1976:8). In other words, iatrogenesis is in itself a very real "side-effect" of the entire medical enterprise. Furthermore, medicine cannot exist without iatrogenic disease, nor can iatrogenic disease exist without

medicine. Each is encouraging the other, in a vicious circle where money is made from illness caused by the very system that was created to resolve it. Nor can iatrogenesis in Western medicine, as Navarro (1976) argues, exist outside of an inherently capitalist economic system.

"Social iatrogenesis", as defined by Illich, "involves medical practice as it "sponsors sickness by reinforcing a morbid society that encourages people to become consumers of curative [. . .] industrial, and environmental medicine" (Illich 1976:33). What Illich is referring to is the "quick fix" mentality that is proposed by biomedicine, which ultimately becomes ingrained in our Western society. This worldview is based on the "band-aid" treatment of symptoms rather than the cause, which glorifies the widespread use of medical drugs and technology as the first course of action in the face of illness. Moreover, social iatrogenesis is in itself disease-causing by nature. Whereas many forms of healing can have beneficial or "placebo"[3] effects regardless of actual effective or physical/material properties in the therapy, social iatrogenesis involves "nocebo", where the non-technical side-effects of biomedical interventions can powerfully damage health (1976:114). In other words, the side-effect of social iatrogenesis is that instead of mobilizing the self-healing powers of the individual, it invariably causes damage by default. An example of an iatrogenic nocebo is found in a study which demonstrated that patients who underwent mechanized hospital care had higher mortality, ultimately ascribed to fright (Mather 1971, in Illich

[3] "Placebo", or the medical term for physiological healing which cannot be attributed to biomedicine (Brody 1980), is a debatable term and will be discussed in more detail in Chapter Six.

1976:107).

"Cultural/structural iatrogenesis", as defined by Illich, encompasses both clinical and social iatrogenesis by incorporating deep-rooted cultural ideals of "better health" based on self-destructing notions of medical "progress" (Illich 1976:34).

Illich believes that each level of iatrogenesis is now medically irreversible, which is a feature "built right into the medical endeavor" (1976:34). Even new medical approaches aimed at stemming the iatrogenic process ultimately become "pathogens contributing to the new epidemic", in an "iatrogenic loop" (1976:34). Illich terms this loop *medical nemesis*, a "self-reinforcing loop of negative institutional feedback" (1976:34). *Nemesis* is derived from the Greek word for the Gods' punishment of mortals who attempted to acquire the god-like attributes called *hubris* (1976:34-35).

Clinical Iatrogenesis

There are many instances where the above narratives have demonstrated, in various examples, all three levels of iatrogenesis, clinical, social and cultural. Beginning with clinical iatrogenesis, Doug experienced physician/hospital-induced illness when he was first taken to hospital immediately after his car accident. As mentioned, the hospital attendants strapped him to a board while overlooking the glass embedded in his back. We may call this experience "biomedical neglect." He further experienced various toxic and damaging side-effects from doctor-prescribed medication ranging from a skin rash, oversleeping and fatigue, to a bleeding stomach ulcer, cessation of bowel elimination, and a heart attack. Talking about one experience immediately after his accident which was only made worse by drug-induced side-effects, Doug

describes:

> Well I just hurt all over--no matter what it was--I just didn't know where to go, what to do with myself--I was--in pain--constant, continuous pain...so my doctor sent me to a specialist, and...this specialist, he give me some...anti-inflammatory...Naproxin I think is what it was...and...Oh! Jee!...right away I felt better, I said "well why didn't you give me this sooner?"...well...you know...I hadn't finished saying that...hardly...when the Naproxin started to act, and it burnt a hole in my stomach...so...now I had two sets of pains...and so now I had to go back to a doctor and to another set of specialists where they put a hose down my throat to take a look at my stomach to diagnose what was happening...and...well then they put me on the medication for ulcers...and most of this time too I'm in extreme pain with the ulcers, and the joint pains and the back pains and whatever else I had...I was just hurting all over...so...as soon as that...the doctor found out that I was bleeding internally well then, then I had to stop that medication and go on another medication...well...I don't know how long that transpired but I remember it was a long time...

Ben, for the most part, suffers from the toxicity of the biomedical drugs he is taking to combat the HIV virus. He suffers from strong nausea which involves repulsion to certain food groups previously in his diet, violent sinus headaches and anxiety. Ben comments on one of these side-effects, for which he is prescribed additional medication with potentially harmful effects:

> ...one of the side effect of the AZT is...you get very violent...sinus headaches...and oh! that's!...you ever had one? oooof! you don't want that...when the weather change comes...barometric pressure...I will get one...but they give me medication for that...which works but which is very hard on your stomach...so I don't like to take it unless I absolutely have to...

Greg, on the other hand, was acutely aware of the high toxicity and damaging effects of biomedical HIV drugs, and chose to completely avoid them. He states that the frequency of iatrogenesis, such as induced in biomedical drugs, is reported in a high percentage in medical journals, which leads people to an early death. He maintains that 80-90% of all allopathic procedures are not proven according to scientifically required "double blind controlled studies", and the long-term effects of drugs on the human body in combating illness are not known. Greg

has seen many of his friends with HIV suffer iatrogenic effects from HIV drugs, and by relying on alternative forms of healing Greg has outlived many he knew who engaged in drug treatment. Reiterating his opinion towards biomedical drugs, Greg states:

> side-effects are in effect iatrogenic diseases...when drugs induce harm to the patient's body, say, for example, they screw up the liver--that's an iatrogenic disease...I see the guys around me and I see other people--well, one of the guys around here, who had just started a few months ago, I mean, he essentially slept all day long, and all night--the quality of his life went down hill--now, what we know about this particular group of drugs is that, they have a tendency to have certain kinds of side-effects for a period of time, and then most of the side-effects go away, but people still get, you know, nausea, people still get headaches, like all kinds of things that just are constant and re-occurring, and as a result of the drugs...

Social Iatrogenesis

Social iatrogenesis is also found in these narratives. As mentioned, Doug suffered from an internal head injury, something which should have been diagnosed in the hospital, but which was missed due to neglect and his early discharge immediately after his accident. It took two years before Doug received proper diagnosis that he had indeed suffered head trauma. By that time substantial recovery was impossible.

In the two years before he was diagnosed, Doug was referred to specialist after specialist, who prescribed a "smorgasbord" of medication which left him suffering from serious side-effects which may have contributed to a heart attack years later, almost taking his life. Despite being properly diagnosed, his search for therapy would continue for five more years before he found relief with herbal therapy. Doug feels that medical therapy did not help him at all, and that he suffered unexpected and often violent side-effects from any medical procedure he tried. Stating his opinion towards the use of herbs versus drugs, he states:

> Well, you know, the herbs--you can take them and there's no side effects, it's very gradual...you don't have pains or weird feelings usually...and if you take these drugs...there's always after effects or side effects and...you know, these side effects are probably greater than they're supposed to be...it's kind of what my feeling is and...the drugs never seem to do what you expect them to do...

Doug was never given a full and clear explanation from physicians as to the allopathic procedures or drug-treatments he received, even while he was in the hospital. Doug also suffered from the regimen of doctors' rigid schedules. For example, he almost collapsed one day in his effort to attend a doctor's early appointment. Additionally, Doug states that because he did not have any information to the contrary, he simply accepted the doctor's instructions to take the medication, despite suffering iatrogenic effects. Doug's health seeking behaviour could be interpreted as "addictive", as he initially had no other option but to keep using biomedical therapies (Illich 1976). Describing an incident regarding a particular medication he was prescribed, Doug comments:

> ...you know, he [the doctor] put me on the diabetic medication...and...the medication he put me on...I found out later...there's a book at the library...and it says "101 medications...the worst medications to be on"...and...he put me on the worst one...Chlorpropamide...and all the side-effects that they promised in that medication, I think I had them...including the heart attack

Similar to Doug's story, Ben also experienced social iatrogenesis with certain aspects of biomedicine. As mentioned earlier, despite his openness towards the combined use of alternative and biomedical therapies, Ben notes that he had significantly more to endure when interacting with physicians than with alternative practitioners. Ben notes that when dealing with biomedicine, he has had to face such things as the devaluation of his symptoms by physicians, withheld physician knowledge, physician hopelessness, and the lack of proper diagnostic procedures.

Ben has also endured frustration with the biomedical system with regard to the treatment of his now deceased partner. One of the first things that Ben noticed was that he had to struggle to get his partner proper medical care. For example, he believes that physicians gave up on his partner when he was in an advanced stage of the disease, and preferred to "let the disease take its course." Additionally, Ben's partner contracted a neurological disorder common in the terminal stages of HIV, which Ben believes could have been prevented with a proper diagnostic procedure, such as a CAT scan or MRI. Furthermore, Ben believes doctors became defensive when he would suggest information about certain courses of HIV treatment that he had learned from additional reading. Talking about his past experiences with physicians, which is largely different from experiences with alternative practitioners, Ben notes:

> ...with doctors I find you have to research and I do that--I used to do that with [my partner] I'd have arguments with doctors to get new treatment...and put my case forth and then...as soon as they realized, "this guy knows a little bit about what he's talking about", they'll usually give in...and do what you want...you don't have to do that with alternative doctors...if you show interest and you know something they'll say "yeah, that's right, well maybe we can try that"...you don't get that [with doctors]--I have to fight for what I get!

Greg, while avoiding biomedical drug treatment, still needed an allopathic physician to monitor his health status and to perform basic diagnostic procedures. His experiences with physicians were marked by extreme doctor defensiveness and skepticism towards his use of alternative therapies. In addition, he experienced physician coercion to take allopathic drugs. Greg believes that doctors are fearful of the effectiveness of alternative therapies, and that they maintain a false sense of power by prescribing powerful and toxic biomedical drugs. He further believes that Western society is characterized by a "quick-fix" mentality towards health, rather than promoting wellness and prevention through non-toxic means. Summing up his experiences

with physicians, Greg notes:

> so my experiences have been two-fold--the younger, the most recent ones [medical doctors] have been women; they've been very supportive; they respect my degree of knowledge and understanding of what I'm doing, and why I'm doing what I'm doing; they know that they have nothing better to offer; they understand that protease inhibitors are really unproven and the long term effects are not known, but they appear to be as toxic or maybe even more toxic than AZT; and so, they don't know like, when is their effectiveness? How long does it last, and what's all this toxicity gonna do? I have a number of people around me who live here, and others that are commuted in, they have just all kinds of stuff happening because of the toxicity levels...so I have a very comfortably working relationship with a couple of medical doctors in recent years, and I'm very happy with that...

Both Ben and Greg's experiences with doctors mirror Arthur Kleinman's case studies such as the profile of Mr. Steele, whose doctor was hostile to the use of alternative therapies or self-care (Kleinman 1988:127). Kleinman states: "The message the practitioner indirectly transmits to patients and their families is this: your view doesn't really matter much; I am the one who will make the treatment decisions; you do not need to be privy to the influence and judgements that inform those decisions" (1988:130).

Cultural Iatrogenesis

Cultural iatrogenesis can be also be seen in these narratives. As will be demonstrated below, however, these individuals do not follow the exact definition of cultural iatrogenesis as defined by Illich, in that despite each experiencing periods of dependency on the medical system, they each maintain a strong sense of individual autonomy in their choice for health care.

For example, Doug was never referred to a holistic or alternative practitioner by a physician. In the face of biomedical failure over seven years, physicians never relinquished their "power" by admitting that perhaps there was something else to offer Doug in the form of less-

invasive alternative measures. Doug believes that doctors essentially "gave up" on his condition, and instilled in him a sense of "hopelessness." He also had to self-educate himself about effective alternative therapies, as there was no support infrastructure in the health care system to direct him to any therapies that might have been beneficial for his condition. Doug is further convinced that while there is a place for biomedical diagnostic procedures, doctors do not aid in maintaining a healthy lifestyle. Commenting on these experiences, Doug states:

> in fact I don't think there was anybody...even...particularly interested in my case...like that's the way I felt anyhow...and...if I was to receive any particular therapy...I was gonna have to...come up with the bucks for that and.....from what I understand there was no therapy available in Winnipeg...

Ben believes that doctors and the medical system deal poorly with death and dying, and that doctors will attempt to keep people alive even when a person does not want technical or life-support measures, and is ready to die. He also believes that doctors do not want to hear about the effectiveness of alternative therapies. Ben believes that people are eager to be "cured" by alternative therapies, but he states that people must realize that alternative healing involves a long-term process of preventative measures and boosting the body's overall healthiness through slow-acting means. Talking about his perceptions towards the establishment and recognition of alternative therapies by the biomedical community, Ben states:

> I can see it coming about, but it's going to be very difficult...a lot of doctors just will not open their eyes to see that this can...a lot of doctors do not want to hear this stuff, this has no basis in the way they were taught, even though it is the basis of medicine to start with, they just don't want to hear this...it's not to replace them...but, lets look at the whole person...a lot of doctors just don't do that--here I go again!--you go to some doctors and tell them you're taking vitamins they'll tell you to stop, they don't do any good...they do do a lot of good!

Doctor De-valuation

Related to social iatrogenesis, is a recurring theme found in both Doug and Ben's illness stories. The theme may be termed "doctor devaluation of patient complaints." Simplified, it means that both Doug and Ben consistently had experiences with allopathic physicians, who would "devalue" or question their experiences of particular side-effects from drug-treatment.

For example, Ben has had repeated experiences where physicians would question his own perception of certain drug-induced side-effects. The main reason for this questioning, Ben explains, is due to the fact that the particular side-effect may not be contained within the formal list of side-effects for that drug. This upsets Ben greatly, as he believes he knows his body better than any physician. Talking about this experience, Ben explains:

> I tell them [doctors] symptoms that I'm having--and they kind of wonder if you're actually having them! But I'm the one who's taking these pills! A lot of these doctors don't take these pills, I'm taking them because I know what I'm having I know how I feel...and I think some doctors maybe think it's just me but no, I know it's the pills...

Doug has had similar experiences with physicians. When put on two different heart medications after his heart attack, he complained of symptoms of fatigue and lack of energy. Not only were Doug's complaints not validated by his physician, but he was asked to accept these side-effects as the only option to avoid a future heart attack, and was strictly told not to stop taking the medication. As Doug explained earlier:

> Well I've been complaining ever since I...started taking this stuff...that it creates...a feeling of tiredness...you know your full energy isn't there...but they say "well, you weigh one against the other and, you know, would you sooner be tired?", and then they scare you with the threat of...of heart pains or something like that...and you talk about quitting these pills...well...everybody throws up their hands and says "don't you dare!"...so...that's why I'm still with these pills as recommended by the doctors...

Justifying Illness

Doug's experience of being told by physicians to continue taking his medication under threat of a future heart attack, despite enduring iatrogenic side-effects, leads us to an interesting moral and/or philosophical dilemma: can we justify enduring one illness to prevent another? Or put differently, can we say that one form of illness should be artificially imposed and endured to prevent another? One may argue that ideologically (in the sense that this is not the norm and may never be), no additional illness should be imposed on an individual to prevent another illness or disorder, and certainly not be imposed under any form of "threat." Furthermore, the fact that doctors devalue iatrogenic illness as an acceptable part of the healing experience only reinforces how deep and integral iatrogenic disease is in biomedicine.

Predictably, doctors readily acknowledge that side-effects always exist in any drug, and druggists state that side-effects are something that simply must be "accepted" as part of "reality" (Illich 1976). As some doctors readily admit, "All drugs are a poison." This does not, however, justify iatrogenic disease as necessary for all healing experiences, nor does it make it valid by any means. Furthermore, biomedicine fails to acknowledge that perhaps there are other ways of healing the body which do not involve iatrogenic disease. These narratives are testimony to the fact that illness sufferers can, and do heal their illness through alternative and non-toxic means.

Theme 2. Alternative Healing

In direct contrast to iatrogenesis, the occurrence of "alternative healing", or a healing experience promoted by alternative therapies, is a second key theme which is integral to these narratives. As can be seen in the narratives, individuals faced many problems in attaining

therapeutic care which could effectively treat their condition. Their conditions necessitated treatment on various levels, both physiological, psychological, and spiritual. Different types of alternative therapies, for various reasons, had the capacity to provide the treatment needed by these individuals.

When Doug finally learned about the positive healing effects of herbs and began herbal therapy, his symptoms and healing improved significantly. Through the use of herbs, Doug reduced the swelling in his abdomen and resumed a fairly normal bowel elimination, something which was hindered from the side-effects of drugs he was taking. His blood circulation, digestion and general pain level also improved. Most importantly, Doug's head injury, which caused detrimental memory loss, stammering and general confusion began to improve, resulting in his self-sufficiency. He also achieved considerable success in aligning his spine and improving his mobility with the use of a chiropractor. I asked Doug about his use of herbs:

> *"Do you remember any immediate impact from the herbs? Did anything change dramatically?"*
>
> Well, yes...you know I started to have bowel movements...and the pain started to, you know, subside slightly...you know it's taken a long time but...you know you can't expect these things to clear up over night either...but things are much better than they were...you know, and I got to the point where I could walk, and I could talk with less difficulty...you know I sometimes still get a little mixed up and frustrated...

Interestingly, Doug explained that in his use of alternative therapies, not all were beneficial, at times were even harmful. Describing a harmful experience with acupuncture which he ultimately had to combat with chiropractic, Doug explained:

> about three weeks ago, I had acupuncture, and...it just didn't agree with me...I've just been feeling rotten and my whole left side tightened up...so I've been spending extra time with my chiropractor...and he says, "well, it's coming along", but he says fortunately I didn't wait too much longer to get it looked at...and he says he had several instances

> where...acupuncture had been recommended by...I think he said Autopac [Winnipeg automobile insurance]...and people had come just all hunched over and...I guess that's probably the kind of thing that happened to me...just didn't seem to agree...so I've been trying to...get over that...in the last while...and...well hopefully...this is the start of it...

Ben, while also using biomedical therapies, has maintained a high level of health using a combination of alternative therapies. Using things such as vitamins, minerals, herbal and protein supplements, Buddhist meditation, sound therapy and a well-balanced diet and proper exercise, Ben is keeping his immune system strong and his HIV virus counts low. He also believes that alternative therapies extended the life of his now-deceased partner by an extra two years, and that alternative therapies can significantly help in the overall host-resistance to virulent viral or bacterial infections. As Ben previously stated:

> I think the alternative therapies have actually done what they're supposed to do which is strengthen my system--help me naturally to keep myself healthy...my immune system...my whole function as a whole...because I don't take just supplements just for my immune system...I take vitamins that work synergistically with each other so that they work together and they can work for the whole body...

Greg is a key example of a person who has maintained optimum health and survived the often fatal HIV illness by relying solely on alternative therapies. Greg began a seven year healing program with a naturopathic doctor which involved alternative therapies such as acupuncture, herbal therapy, homeopathy, nutrition, ozone therapy, psychological counseling, and vitamin and mineral supplements. Following his work with the naturopath, Greg began another alternative therapy called bio-acoustics/tuning. He believes that these therapies help to cleanse the body's systems, and encourage healing on deeper levels of the body, both physical and psycho-spiritual.

Greg is convinced that his reliance on a combination of powerful alternative therapies has kept him alive today. He has outlived many people he knew who were diagnosed with the virus at the same time he was diagnosed, and who relied solely on biomedical drug-therapy. He further believes, similar to Ben, that alternative therapies can and do play a significant role in the life-extension and immunity of HIV sufferers, particularly at the terminal stages of the illness. For example, Greg believes that the HIV sufferer at the terminal stage, who has boosted his body with alternative therapies, may avoid the quickly fatal bacterial or viral infections common at this stage of the illness. In contrast, the HIV sufferer who has not used any alternative therapies may succumb quickly to these infections. Additionally, Greg states that allopathic medicine has a place when dealing with acute illness, while alternative medicine is particularly suited to chronic illnesses such as HIV. Commenting on how alternative therapies have helped to manage his condition, Greg states:

> I believe that for the seven years that I worked predominantly and primarily with the naturopath, he kept me alive, I really--well, let me re-phrase that, because I believe that we keep ourselves alive, and that there are other people that we may be blessed to come into our lives and help use along the way--but he, both from the perspective of his personal support, as well as from his skill as a physician, and my willingness to do the best that I could do with those things that he was asking, you know, directing me and helping me--and plus many other things that I did on my own--that that combination of my commitment to working at it, and his commitment to helping me work at it, kept me alive, kept me productive...and so, I mean that's a lot of things, that's acupuncture, and herbs, and homeopathy, and bach flower remedies, and nutrition, and clinical, you know the use, the clinical use of nutrition and supplements and minerals, and a whole bunch of things, and the naturopathic system of medicine--it worked, in my estimate...it has had a great deal to do with me feeling physically well, energetically I have more energy; I used to suffer daily from fatigue, and once I no longer was feeling fatigued I finally understood...

It is clear that each individual as represented in this study is using a combination of many different therapies to promote healing, biomedical included. As documented in previous Canadian studies by Kelner and Wellman (1997a; b) on alternative medicine use, individuals use certain

therapies as they help their condition. This explains the use of many different alternative therapies by these individuals, in addition to some biomedical therapies. For example, each individual in this study used a combination from as little as two, to as many as nine different alternative modalities. Despite the widespread use of alternative therapies, these individuals did not *totally* reject the use of certain biomedical elements. Indeed, each individual remained in the service of a family physician for basic health care needs such as annual check-ups, blood monitoring and certain drug therapy. This co-incides with Kelner and Wellman's conclusions, and suggests a "plural" nature to health care.

As will be discussed in Chapter Six, however, the case narratives indicate that the underlying reasons for alternative therapy use run much deeper than postmodernist "calls to order" based on notions of "romanticism", "nature worship", "reintegration with antiquity" and ultimately, "neoprimitivism" (Hook 1993:161). Indeed, alternative medicine users as represented in this study are not choosing alternative health care based on a "pick and mix" mentality, but base their decisions on positive experiences with healing promoted by alternative therapies.

For example, it is clear that the above individuals suffer from chronically acute ailments (head injury; HIV/AIDS), which at various times in their life have been life-threatening. As documented in previous studies (Kelner and Wellman 1997; Pawluch et al. 1994; Sharma 1992) the majority of alternative medicine users suffer from chronic illnesses, which forms the basis for their choice to use alternative therapies. Furthermore, as evidenced in this study, it is through the use of certain alternative medicines, as opposed to biomedical, that the resolution of these individual's chronic symptoms has been most successful.

Moreover, it is apparent that the individual illness conception plays an important role in the choice and continual use of therapies. This coincides with Kleinman's findings, who states that

"physiological aspects of chronic illness shape explanatory models and the meanings they encapsulate" (1988:45). For example, Ben perceives the human body using a combination of both biomedical and holistic concepts. Accordingly, his choice of therapies combines both alternative and biomedical, in that he uses meditation and herbs in combination with HIV drug-therapy. Greg, in another example, is very focused on psycho-spiritual elements, and thus has drawn heavily on therapies oriented towards spiritual healing such as therapeutic touch and bio-acoustics/tuning.

Theme 3. Spirituality in Illness

A third common theme that was found throughout all three narratives was the concept of "spirituality." That is, Doug, Ben and Greg exhibited particular conceptual ideas which hinted at their belief in the nature of the Universe as "ordered", outside of any structured religious context. This occurrence also coincides with previous research showing that a notion of "spirituality" is common among alternative medicine users (Kelner and Wellman 1997a; b).

Doug, for example, feels a strong sense of cause and effect, that there is a reason he ended up using herbal therapy, and that there are many inter-related factors which leads an individual to different life-events. For example, he believes that if the medical system had not failed as it did, that he would not have learned about the healing effects of herbal therapy.

In his search for therapy, Ben has found a strong spiritual connection with the world philosophy of Buddhism. Buddhism is derived from an historic individual Siddartha Guatama known as "Buddha" in approximately the fifth century B.C.E., in what is today Southern Nepal (Powers 1995). The entire development of Buddha's teachings and the volumes of knowledge

that were produced after his time is far too complex and detailed to discuss here. Generally, however, Buddhism involves attaining a higher consciousness by which one learns to endure suffering though life, leading to breaking the cycle of rebirth in the Karmic or "physical" world, called "Samsara." An additional Buddhist concept is "non-violence" and the respect of all living things, expounded by Tibet's current spiritual leader his Holiness the Dalai Lama. Ben also does a form of yoga (meaning "connection") meditation, derived from Hinduism.

Ben believes that living with a potentially fatal illness has led him to become a more spiritual person. He believes that his spiritual notions have helped him to deal with many factors associated with his illness, such as death and dying, and the loss of his partner. Ben is not afraid of death, and he has come to terms with the fact that he may soon die from the HIV virus. Furthermore, he believes in a form of "afterlife" which is a positive and beautiful place filled with friends and family, and believes that he was put on this earth for a reason. Buddhist spirituality has led him to see life as illusory, which has helped to relieve the stress associated with his current life and illness. More pragmatically, Ben combats anxiety, a side-effect caused by one of the drugs he is taking, by using a relaxing meditation. Should Ben reach the terminal stage of HIV, he hopes he will be spiritually advanced enough to be able to die peacefully and without much pain.

Ben believes that when it comes to dealing with death and dying, doctors do not have the same philosophy. He believes that doctors do not understand death as a natural process, and do not recognize spiritual aspects towards death and dying. He explains:

> They're [doctors] so dedicated to keeping you alive at whatever cost, they don't see death as being the natural process that we go through, that a person has fulfilled whatever he has to fulfil and now it's time for them to go on...uh, no, they don't see that, no, they will look at the machines, because they've got this thing that they will never do any harm to you, but, you know, they are doing harm when they're keeping you alive when you shouldn't be alive...that's stressful--it's got to be stressful on the person whose trying to pass over...

Similar to Ben, Greg's narrative also contains significant spiritual elements. Whereas Ben discovered a specific spiritual philosophy in Buddhism through his search for alternative therapies which he uses to promote healing, Greg focuses more on issues which are both psychological and spiritual in nature, and which are fundamental to his existence. When discussing his work with the naturopath, Greg hinted at his own deep psychospiritual issues that were an integral part to his healing experience. When asked to expand on this issue, Greg indicated that he was dealing mainly with two separate yet interrelated issues. First, Greg believes that his upbringing in an abusive family environment contributed significantly to the psychological issues he developed. Greg's father was an alcoholic, and because of this Greg endured both physical and psychological abuse. This contributed to Greg's own "self-abuse", by fostering behaviour and mental attitudes such as anger, rage, and homophobia.

Second, Greg believes he came into his body as a form of spiritual consciousness, bringing with him certain unresolved issues. As a result, he feels a constant pull between the side of him that wants to keep living, and the side of him that does not. Commenting on his psychospiritual issues, Greg explains:

> the interesting thing is the conflict that goes on inside between what I know is the truth, what I think is the truth, and this other aspect which hasn't been healed yet, the part that doesn't want to be here. I mean those two things are constantly clashing, and that just sets up a system within myself for not succeeding...it makes it difficult for me to fundamentally say "yes, I want to be here", and it makes it difficult for me to fundamentally say, "yes, I am committed to following through on what I know my purpose to be"...and, frequently,

> means that I go through periods of time even doubting that I know what my purpose is...although I love a statement that I heard the last few months: "we spend too much time wondering and worrying about what our purpose is, or trying to find it; if you haven't found it, then choose it!", and there's a lot of wisdom there...so, as much as I know that that's wise and that's a good thing, I still sabotage my efforts to do that...

Asked whether he thought spiritual issues were important in the context of illness, Greg responded:

> Fundamentally all disease is a spiritual disease, and therefore, provided my body hasn't gone, hasn't deteriorated to such an extent that it can't recoup, I assume that if I can get right with myself spiritually, that my body will recuperate and I'll be fine...does that mean that the HIV's gonna be gone? Not necessarily...but, if it's possible for the scientist to come up with drugs that supposedly might be able to keep people alive with the disease for a very long time, I see no reason why using very powerful alternative methods can't do the same...so whether I live with the actual virus in my body or not, isn't important...

Theme 4. Job Loss/Illness poverty

A fourth key theme which touched all three individuals was job loss due to illness, or what may be called "illness poverty." The effects of job-loss due to illness leading to a low income has not, as some studies suggest, *completely* prevented these individuals from using alternative therapies (Kelner and Wellman 1997a; b). Job loss does, however, play an integral role in the use and continued use of alternative therapies, particularly in light of the fact that in the current (1998) Canadian health care system, few alternative therapies are covered by mainstream or private health care. Thus, as Navarro argues, the facets of inequality as linked to a capitalist class system also come into play here (1976).

Doug's work forced him to retire from his longstanding job as manager, due to the debilitating effects of his head injury. Although not included in the above narrative, Doug indicated that he had to legally pursue compensation from his company which was not offering

any monetary package. Doug now survives on long-term disability payments, including the money he received form his settlement. This is just enough to cover his living expenses and payment for herbal therapy and chiropractic. Doug indicates that he spends a significant amount of money to support his use of alternative therapies, and that he was forced into paying for certain therapies due to the cessation of work compensation:

> my herb bill for a month is probably twice what my medication bill is! [laughter]... worker's compensation cut me off on the chiropractic...they told me I couldn't go anymore...and then it got to the point I couldn't walk anymore...so...I dragged myself in to another chiropractor...I've been paying it on my own ever since...

Ben also is prevented from working due to his illness. As previously mentioned in the life-disruption section of his narrative, the fatigue associated with HIV prevents him from being able to maintain full- or part-time work. Fortunately for Ben, however, he pursued a retirement/settlement package and was fully compensated by his company.

Greg is very clear about the hardship of living in poverty while dealing with a serious illness. Formerly working at demanding organizational and managerial jobs, Greg is now unable to keep up this pace while living with HIV. As previously discussed in the life-disruption section, Greg attempted to open up his own private practice in alternative medicine, but was forced to cancel his plans due to a serious bout with shingles. As mentioned, Greg states that living at the poverty level restricts him from pursuing creative activities, contributes to negative emotions, and ultimately prevents him from using much-needed alternative therapies unless practitioners withhold charge. Despite Greg's hardship, he has managed to keep relying on alternative therapies by using the little money he has, and by accepting certain therapy sessions from certain alternative practitioners. As previously mentioned, Greg believes that income level and the choice

to use alternative health care are ingrained within a warped biomedical system:

> [people] who I know who are HIV+, they would say that [it] was probably most important to them that they should have a choice of treatment--they don't--they don't have a choice because it's not part of the system of medicine that's practiced here, there's not the money, and also, they don't know what choices they have other than drugs--most people don't--and most people don't wanna know...

Theme 5. Family History

An important contributing factor in the lives of Doug, Ben and Greg in the context of their illnesses and healing was the impact of their families and social histories, which ultimately influenced their use of alternative therapies.

Doug, for example, notes that when he was growing up on a rural Canadian farm, the first course of action for remedying minor health afflictions, including broken bones, was to see the local chiropractor. While different from chiropractic therapy today, the chiropractors of old provided much needed health care when medical doctors were few and far between, and when they were available, were only within reach of the elite class. Describing rural health practices, Doug notes:

> Chiropractic had always been in the family...I guess it may not have been chiropractic in the way that we know it now...but it was, you know, the old traditional or chiropractic that the...the old people used...I remember years ago as a small kid going to see the chiropractor lady and...and she would bandage you all up with hot towels...and rub you down with Vicks...and then she would proceed to manipulate or whatever...and sometimes you would come away with a cloth bandage around you ...and...hopefully things would settle down from whatever was bothering you...I guess years ago if you had to go to a doctor it was probably a ten mile drive with horse and buggy...and the chiropractor wasn't as far...but still sometimes we may have gone once every couple of months...if somebody...fell off a hay wagon somewhere and...dislocated a bone...well...that would be the first course of action...

Ben, on the other hand, directly grew up with herbs, as his mother was a trained pharmacologist schooled in herbal therapy. Growing up with herbal therapy, Ben learned valuable knowledge that he still applies today, such as the knowledge of the effectiveness and different healing properties of herbs. As he previously mentioned:

> having been brought up with herbs my mother, when she was in England, she studied pharmacology but in those days it was mainly herbal pharmacology they studied, so we were raised on herbs when we got sick...so I had a bit of an in there...

Growing up in the 1950s, Ben also faced considerable homophobia which he had to deal with as a gay man. This ultimately influenced his lifestyle to the point where he could not pursue this lifestyle openly.

Greg experienced a damaging childhood marked by physical, emotional, psychological and spiritual abuse, which stemmed mainly from his father. Like Ben, Greg was also a victim of rampant homophobia that was ingrained in him, his family, the local church, and the community. Commenting on his upbringing, Greg explained:

> in my case my father was addicted to alcohol--I lived with, what I think of as minor physical abuse, it was the minor of all of the abuse, but the psychological and the spiritual abuse that comes from a family that's sorely lacking in those things takes its toll and creates a series of patterns that become self-abusive--I don't mean that in the sense of, you know, "slash and burn and cut"--but, just in the sense of not following through on things that I know that are good for me...and it generates a lot of fear and anxiety and anger and rage, and add to that all of the homophobia--some of which I believe I brought with me, when I came into this body--and which was just very strongly re-inforced, in my family, and in the church, and in the communities in which I grew up and lived, in just daily life, you know...

Theme 6. Physician Satisfaction

One interesting theme which appeared shortly in Doug's narrative was the fact that physicians should have a vested interest in being personally satisfied with the treatment of the patient, regardless of the fact that the therapy may be damaging to the individual. For example, when seeing a psychiatrist, Doug stated that his treatment was not satisfying him *or* the psychiatrist. This kind of comment hints at the fact that physicians exhibit a certain kind of "power" in being personally satisfied with the progress of the patient, regardless of how the patient might be feeling, or if the treatment is contributing to iatrogenic effects. This often results in the patient feeling obliged to take biomedical treatments rather than having a choice not to take the therapy. Describing this experience, Doug explained:

> ...and the psychiatrist--well I don't know--he give me pills and I pop pills until I--well, at that time too I had to go home and went on sick leave, and this psychiatrist give me a bunch of pills and I ate these pills and as I ate them, you know I would sleep for three days at a time! And finally he decided that, you know, this wasn't getting anywhere--*it wasn't helping me, or, it wasn't helping him*...

Theme 7. Alternative Therapy Self-education

Another important theme which was found in all three narratives was that Doug, Ben and Greg self-educated themselves with regard to alternative therapies. For example, Doug referred to his large library of books on herbal therapy, which, while he cannot mentally retain in detail, still provides useful reference material. Ben indicated that he had taken courses in biochemistry, which, while allopathic, helped him to understand the effects of the alternative therapies on his body. Lastly, Greg is an expert on many alternative therapies, and has even trained in several forms of alternative medicine such as therapeutic touch and neuro-linguistic-programming (NLP).

Similar to conclusions drawn in Kelner and Wellman's research (1997a; b), prior to their illnesses the above individuals were highly educated. For example, each had pursued education in a least a post-secondary institution, while one of the participants in this study (Greg) had two university-granted degrees. It is, however, debatable how the precise role of education plays in the choice for alternative therapies, and how this contributes to the awareness of these therapies, as (a) each individual pursued different forms of education, and (b) these forms of education did not specifically deal with alternative therapies. One explanation that may be pursued in future studies is the role that family upbringing may play in the shaping of health-seeking behaviour. For example, it is clear that in this study, both Doug and Ben had direct family influence for the use of alternative forms of medicine (e.g. Doug's family used a chiropractor; Ben's mother was a herbalist).

Theme 8. Patient as Healer

Related to the theme of "alternative therapy self-education" is an important theme illustrated by Greg: that of "patient as healer." While Greg is a regular user of many different alternative therapies, he is also a trained practitioner in therapeutic touch, reiki, and neuro-linguistic-programming. One might argue that this kind of dual interaction between patient and healer would provide much understanding of both the practice and healing effects of alternative therapies. Greg describes an important experience which combined many aspects of his knowledge as an alternative healer and patient, and indicated the interconnectedness of many forms of alternative therapies that deal with energy forms of healing:

> a couple of people who were taking therapeutic touch from me, somehow got interested, in learning bio-acoustics...now I was one of those people that [the sound therapist] first

> worked with, with bio-acoustics, and then when bio-tuning came along, and she learned that, and it seemed that it was going to be even more effective in helping me, then we changed from bio-acoustics to bio-tuning. But before we finished bio-acoustics, one of the things that happened was we were starting to work with it, for the energy system around the body. In particular, we were working with the chakras, so the energy centres in the front and the centre of body along the spine...What we uncovered is--I mean I've known about the meridians and I've known about chakras, and I've known about auras, and worked with all of that, so that wasn't new--I guess I had thought that they were interconnected but I'd never felt the interconnection, until one day when we were experimenting with using frequencies of the chakras, and what happened was, I started to feel the associated meridians in my body opening up, so I ran home to my meridian charts to see if what I was feeling had any relationship to where those meridians were on the body and they were exactly where I had felt the sensations of the opening taking place...so that was kind of interesting so that's really changed--You know it's not maybe a grand insight--but it just certainly proves to me that when you work on any one of the energy systems you're working on all the others, they're interconnected...

Theme 9. Therapy Interaction

As Greg indicates above excerpt, therapies can interact on multiple levels, not only with the body, but with other forms of therapies.

For example, Ben is combining alternative and biomedical therapies, and states that each is important for maintaining the entire health of the body. He combines things such as herbal and vitamin supplements, with allopathic drugs, in combination with meditation. Ben believes that this combination of plural therapies has kept him at the level of health he has today.

Greg most clearly demonstrates that each therapy interacts with another and also affects the body on all levels. As he states above, this is exemplified by his work with chakra (Hindu energy centres) balancing which also helped the meridians (Chinese energy channels) to open up. He further states that each therapy has a kind of "synergy" which can promote the other, such as with the combination of homeopathy and bio-tuning/acoustics. Greg notes, however, that he had to stop homeopathy as it was making the effects of bio-tuning too strong.

Theme 10. Self-reflexivity

It was clear that each individual had a strong sense of his illness and healing processes throughout his entire experience. This coincides with Arthur Kleinman's (1988) statement that the chronic illness sufferer is acutely aware of symptoms and is constantly monitoring bodily processes. For example, Doug was acutely aware of how each allopathic therapy affected him in terms of side-effects, healing provided by alternative therapies, and in keeping written and filed documentation of each therapy that he has tried. Ben is also aware of his symptoms, and constantly monitors his virus and cell counts including graphing his blood work on a computer. Greg, while also constantly aware of symptoms, potential illnesses, and the effects of different therapies, is also very aware of his mental/emotional states, and refers to them in detail.

Themes Drawn from the Medical Dominance Thesis

Theme 11. Medical Dominance

Returning to the discussion at the end of Chapter Two, one might argue that while the medical dominance thesis may remain hidden on an individual level and remain in a so-called "larger" structural context, it is certainly evident that it underlies the care-seeking narratives. Whereas the narratives can reveal many aspects surrounding the search for therapy, one may suggest that one of the main theoretical foundations which underlies even these experiences is the occurrence of the rise and fall of medical dominance. It is here that the link between individual narrative conceptions and structural elements can be consolidated.

Interestingly, as suggested in the discussion in Chapter Two, it appears that individuals are illustrating both aspects of medical dominance and collapse, supporting Coburn's (1993) thesis

that while medical power has declined, certain elements have remained. Moreover, as previously discussed, the fact that individuals continue to exhibit certain aspects of medical dominance supports the argument that while medical dominance may have declined on the medical professional level, the dominance of the biomedical paradigm to define notions of health and disease remains powerful. Thus medical dominance remains complex in the lives of individuals.

Structurally, the rise of medical dominance can be seen to affect societal elements such as the establishment of "medical elitism" and the consolidation of "medical power", whereby medicine became the dominant form of health care in Western society. In this process medicine also came to dominate the vehicle through which health and well-being was achieved, namely that of strictly allopathic or biomedical therapies. Medicine furthermore eliminated non-allopathic or "alternative" therapies as they represented a means of health care.

How can structural elements be seen to affect individual experiences? Before proceeding to the narratives, Frank (1998b), by drawing on Foucauldian concepts, suggests a concise way to understand power within illness stories. Frank states that while stories of illness are told to empower the teller and readers who share the story, there are additional aspects of power which come into play, and thus necessitate an "ethics" of storytelling (1998b:331). Frank suggests that the concept of structural power contained within stories may be best exemplified by an analogy put forth by Foucault in the last years of his life, drawing on the concept of the "panopticon"--"a prison design that allowed an unseen guard to exercise perpetual surveillance of each cell" (1998b:331). Frank states that the panopticon concept illustrates how power operates through micro-strategies, which can turn the self into its own agent of disciplinary practice (1998b:331). Summarizing this concept, Foucault writes:

> He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself, he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection (1979:202-3).

Foucault further states that "it is not that the beautiful totality of the individual is amputated, repressed, altered by our social order, it is rather that the individual is carefully fabricated by it, according to a whole technique of forces and bodies" (1979:217).

Frank suggests that by putting Foucault's concepts together, one arrives at Foucault's basic insight: "the genius of the social fabrication of the individual is to make that individual the principle of his or her own fabrication, thus guaranteeing the sense of authenticity in what is fabricated" (Frank 1998b:331). Thus, while individuals may be only partially aware of aspects of medical dominance in the health care system, not only may they be shaped and fabricated by these forces, but they may be in the process of directly fabricating these forces themselves. Frank writes: "To ignore how the ill person is affected by institutional medicine is as much an error as the medical negation of contextual and existential factors that affect ill people" (1997:145).

Therefore, on the individual level, the consolidation of medical elitism and power, thereafter appropriated by the state, has led to the establishment of what may be termed a "hegemonic biomedicine" (see **Figure 3**, Chapter Two). A hegemonic medicine, in turn, is defined by "allopathic health", which is defined by biomedical therapies. "Allopathic health", in turn, has led to the control over the definition of disease and what it means to be "healthy", in addition to defining the parameters around which this health is established. Individually, these factors have partially led to a reliance on allopathic therapies as the only means to establish health and healing, and has resulted in the "marginalization" of any existing non-allopathic therapies.

Taking Doug as one example, for seven years he had no option but to rely on biomedicine in his search for therapy. Furthermore, while alternative therapies were available in Doug's search, they were largely marginalized and were not supported by existing health care structures. This "dominative" biomedical structure is confirmed by the fact that Doug had to "self-educate" himself with regard to his awareness of alternative forms of healing, and also explains why Doug had to endure seven years of ineffective biomedical treatment until he chanced upon herbal therapy.

In a second example, despite being fortunate to have the opportunity to consult freely with a naturopath, Greg's choice for alternative health care was not without its problems. Greg believes that on a fundamental level, people suffering from illness do not have power or free choice to use alternative forms of health care. He states that this stems from the dominant and competitive nature of our current biomedical health care system, which has led to the overall poor accessibility of alternative therapies, their high cost, and stigma against their effectiveness.

One of the main reasons for the inaccessibility of alternative therapies, Greg suggests, has to do with alternative therapies not being part of the current biomedical system. He believes that although people may have a certain amount of choice in using aspects of biomedicine, such as which particular physician to attend, ultimately people do not have the *freedom* of choice in health care. As a result, Greg believes that alternative health care users ultimately do not have power. Furthermore, Greg states that due to the marginalization of alternative medicines, the necessity for ample financial resources also plays an integral role in a person's ability to access alternative health services. For example, because he is unemployed due to his illness, Greg is restricted in his use of alternative therapies and relies on the charity of alternative practitioners.

This occurrence has strong links to a capitalist system, in which unequal access to resources restricts the ability to maintain health. Commenting on his viewpoint, Greg states:

> I think generally that we don't have choices; I have a choice as to which allopathic doctor I may go to. I may have the choice to go to one allopathic doctor, and then go to another and another, just to get a couple of opinions...I don't have the choice to seek out the advice--well, the system doesn't enable me to have the power or the choice; if I have the money, where alternatives are concerned then I have power, and then I have choice, you know...if I'm fortunate enough to know people or to find therapists or alternative doctors who will give me free service or who will negotiate with me for service, then I have some power and some choice, but the health care system that we have does not give us that...

Expanding on the issue of medical dominance, Greg notes that many allopathic physicians are fearful of the effectiveness of alternative therapies over allopathic therapies, and assume false notions of power. He further draws links between the marginalization of alternative therapies, and biased biomedical research. Referring to these issues, Greg states:

> there's nothing rational about [it]--they're [the doctors] just scared--because they know that in some areas, naturopaths and other brands of medicine do as well and better than they do; things that they can't cure, or that they can't manage, alternatives can do better, and uh, that's very frightening, it's very frightening that they don't wanna see that...but I think that those doctors are just as hopeless about HIV as they ever were, and I think that really affects the way in which they prescribe, it gives them a sense of power, to give somebody a prescription for these powerful toxic drugs, and it makes them feel like they're doing something, and they're not really looking at what the drugs aren't doing...and, now, I mean, at this stage, we don't know what naturopathic medicine or ayurveda or any of those others are doing either, but we might know if all the money weren't going in to research on these drugs, as if drugs were the only answer, and it's clearly not; you know, certainly the alternatives, can do as well at helping people to have a quality of life as stay as well, you know, well as the people on drugs...

In a third example, Ben makes clear reference to the role that pharmaceutical companies, which can be seen to be aligned with a medically powerful state, have played in the systematic elimination of important herbal remedies essential for boosting his immunity against infection. Commenting on these issues, Ben states:

> ...I'm sure the government are big against this kind of thing [alternative therapies]...that's how I feel...they took licorice off the shelves...I mean I can go down I can get a licorice root and make the same thing myself but they took the extract off the shelf...and...that was one of the main things I used to use in the Winter to help me get through because it is very much an immune stimulant and...now I have to go make my own or get it from the States...every time you do something good, the government seems to want to just take it off and say "no"...but I put that down to a very powerful lobby with the pharmaceuticals...you know there's a lot of things that they've taken off the shelf that...people have been taking for years and years...I mean, they say "oh, yeah, so and so has died, or this many people have died from it", but more people die from over the counter drugs--o.ding on them--than actually ever been killed on herbal drugs, I mean, the statistics bear that out...

There are also elements of medical dominance on the individual level which are related to the above themes of social and cultural iatrogenesis as defined by Illich (1976). For example, Doug's reliance on a dominative medical system led to a misdiagnosis of his internal head injury, while limiting his choice to pursue additional and perhaps non-allopathic therapies. Ben, while attempting to combine allopathic and alternative therapies, was confronted with the dominative nature of medical doctors, such that he had to fight to obtain medical information concerning himself and his partner. He also found it difficult to negotiate with physicians his views towards alternative ideologies of death and dying. Greg endured a sense of "mockery" and was ridiculed by biomedical doctors for using alternative therapies. He was furthermore coerced by medical doctors into taking HIV medication such as Protease inhibitors and AZT, something which Greg had made explicit he did not want, based on the effectiveness of the alternative medicines he was using.

As discussed in theme #4, "job loss/illness poverty", "choice" is particularly relative when it comes to the use of alternative therapies by individuals living in a dominative biomedical health care system in Canada, and which is ultimately ingrained in a capitalist system (Navarro 1976).

As mentioned, not only are alternative therapies marginalized by the existing health care structure in terms of support networks such as medical care, but because of this many non-allopathic therapies are simply out of the financial reach for many individuals who could benefit from them. As Greg stated earlier:

> I think generally that we don't have choices; I have a choice as to which allopathic doctor I may go to; I may have the choice to go to one allopathic doctor, and then go to another and another, just to get a couple of opinions...I don't have the choice to seek out the advice--well, the system doesn't enable me to have the power or the choice; if I have the money, where alternatives are concerned then I have power, and then I have choice, you know...if I'm fortunate enough to know people or to find therapists or alternative doctors who will give me free service or who will negotiate with me for service, then I have some power and some choice, but the health care system that we have does not give us that...

As was discussed earlier, "financial reach" also has to do with the ability to maintain an occupation, which in turn affects alternative therapy use. Thus, the use of alternative therapies marks individuals as venturing beyond the conventional medical system, where they are not making neutral decisions, and face overwhelming capitalist processes such as the loss of control over the means of production (Kelner and Wellman 1997; Navarro 1976).

In sum, one argument which can be drawn from the above examples is that medical dominance contributes to individual experiences in the search for therapy, such as iatrogenesis and marginalized alternative health care services. Furthermore, it is evident that while individuals are having experiences which may be seen to be attributed to medical dominance, they are also aware of these larger structural factors which are contributing to their experiences.

Theme 12. Medical Collapse

"Medical collapse", or the "fall" of medical dominance can also be illustrated on both structural and individual levels, despite the fact that individuals continue to exhibit certain aspects of medical dominance and a dominant biomedical paradigm.

Structurally, the relative decline of medical dominance on the medical professional level where the control of medicine was appropriated by the state, can be seen to have contributed to the overall decline of medical "elitism" on the medical interprofessional level. The decline of medical elitism, in turn, can be seen to have contributed to the decline of the medical monopolization over the means to achieve health through strictly allopathic means. The decline of "allopathic health", in turn, has led to the resurgence of non-allopathic or "alternative" therapies, which are defining different notions of health and disease by using different health modalities.

Individually, the decline of medical elitism and power has given room for the rise of what may be called "counter-hegemonic" health movements, illustrated by individuals exploring different therapies apart from allopathic (see **Figure 3A**, Chapter Two). The decline of the medical monopolization over definitions of health and disease has further led to the resurgence of alternative health ideologies or worldviews towards defining health and illness. Emerging and differing health ideologies may also be termed the "democratization" of knowledge (Hook 1993). The resurgence of alternative therapies has additionally led to the widespread use and availability of particular alternative therapies, whereas previously they were unavailable. The fact that individuals may be using widely available alternative therapies does not, however, negate the fact that these therapies remain unsupported by existing biomedical health care structures.

It is evident that the individuals presented in the above narratives are clearly representative of a decline in medical dominance, with regards to particular factors. For example, upon the failure of the biomedical system to treat his chronic symptoms, Doug was able to explore additional non-allopathic therapies in the form of herbal and chiropractic therapy. Ben, in another example, has had the freedom to combine aspects from both allopathic and alternative therapies. Lastly, Greg has had the choice to reject sole reliance on allopathic drug-therapy, and has had the option to pursue many different alternative therapies and modalities to treat his condition. When asked about his opinion concerning the use of alternative therapies and the current state of the Canadian health care system, Greg replied:

> ...it's gonna change, it's gonna change because pharmaceuticals are killing people; people are increasingly aware of the profiting that goes on with the pharmaceuticals, and drug companies; even the doctors' medicines are going to catch up with them because I mean there are increasing numbers of researchers who are looking at this very issue of iatrogenic disease--and the high rate--Oh! God! the high rate of iatrogenic disease, and I mean, we're not just talking about people getting sick we're talking about people dying there's a high death rate from, you know, the therapies, and there are other means that are less harmful and just as effective...

Summary

Aspects from both the rise and fall of medical dominance can be seen to contribute to both structural factors, and to individual factors in the course of the illness experience. The plural nature of health care that exists today illustrates the fact that while medical dominance has declined, it has certainly not disappeared (see **Figure 3B**, Chapter Two). The complex nature of medical dominance becomes most clear at the individual level, despite structural barriers. One might argue, for example, that medical dominance has led each individual in this study to become dissatisfied with the "authority" and ineffectiveness of biomedicine. This has ultimately resulted in

each individual pursuing alternative forms of health, or what were earlier called "counter-hegemonic" health movements, which in turn contributes to the decline of medical dominance. Furthermore, while biomedicine may be maintaining its hegemony through a health care system dominated by the biomedical paradigm, the above individuals are one example pointing to the fact that medicine is losing its hold not only on certain types of health care, but on even the ability to maintain and promote health with regard to chronic illness. Thus, medical dominance is at the root of both medicine's failure to promote health and well-being for chronic ailments, and is the inspiration for the use of alternative forms of healing by individuals.

FIGURE 5: SUMMARY OF NARRATIVE THEMES

Themes Drawn from the Care-seeking Narrative

Theme 1. **The Chronic Patient in Biomedicine**
- **Iatrogenesis**
  - Clinical Iatrogenesis
  - Social Iatrogenesis
  - Cultural Iatrogenesis
- **Doctor De-valuation**
- **Justifying Illness**

Theme 2. **Alternative Healing**

Theme 3. **Spirituality in Illness**

Theme 4. **Job Loss/Illness Poverty**

Theme 5. **Family History**

Theme 6. **Physician Satisfaction**

Theme 7. **Alternative Therapy Self-education**

Theme 8. **Patient as Healer**

Theme 9. **Therapy Interaction**

Theme 10. **Self-reflexivity**

Themes Drawn from the Medical Dominance Thesis

Theme 11. **Medical Dominance**

Theme 12. **Medical Collapse**

Chapter Six: Discussion

The Choice for Alternative Health Care

It is evident that the individuals as represented in this thesis, while clearly not representative of a large sample, are nevertheless choosing alternative therapies for reasons similar to those outlined in previous studies (Kelner and Wellman 1997; Pawluch et al. 1994; Sharma 1992). The individuals in this thesis suggest that the use of alternative medicines in the course of their search for therapy involves many factors.

First, it is clear that these individuals are choosing alternative therapies based on significant negative past experiences with the biomedical system. These individuals have suffered from various levels of iatrogenesis, physician dominance and coercion, and have faced the power of a dominative biomedical system. Moreover, these individuals have found no relief from their chronic symptoms while using conventional medicine, something which has been shown to be a clear and influential factor in the choice for alternative health care (Kelner and Wellman 1997; Kleinman 1988; Sharma 1992). Despite completely rejecting biomedicine for failing to resolve their chronic symptoms, these individuals nevertheless remain in the service of allopathic physicians for specific functions, such as an annual checkups and certain diagnostic procedures, including some forms of medication.

The individual use of alternative therapies in this study further involves clear ideological factors. For example, following models as defined by Furnham (1988), Pawluch et al. (1994), and Sharma (1992), these individuals are committed to a proactive and preventative role in their own health care as evidenced by their search for effective relief, and they assume responsibility for

health care decisions. These individuals furthermore have a unique holistic understanding of health as encompassing both physical, mental, emotional, and spiritual well-being. Additionally, they have a belief in the positive value of alternative care, and are concerned about the adverse side-effects of conventional medical care.

Using Andersen's model for health seeking behaviour (previously discussed in the literature review), Kelner and Wellman's study (1997a) document influential predisposing and enabling factors in the choice for alternative health care. While it was not the aim of this study to assess these factors in detail, certain conclusions can be drawn here. As evidenced by Kelner and Wellman, the ability to pay for alternative medicines is a key predisposing factor in the ability to choose and use alternative therapies.

It is interesting to note, however, that two individuals in this study, Doug (despite his settlement package) and Greg, were not financially predisposed to using alternative medicines, yet they were clearly relying on them for relief from their symptoms. This does not negate, however, that financial factors are clearly influential in the choice for and use of alternative health care, but simply points out that capitalist processes are not universal in their power to influence health care choices. Other factors that were clearly apparent in the individual choice for alternative care were the level of education and income. Again, however, factors such as employment did not adversely affect the use of alternative therapies by individuals in this study. Despite each individual being unemployed due to disability (only Ben received a substantial settlement package), they continued to use alternative therapies. Education, nevertheless, remains an important factor with regard to comprehensive awareness of alternative therapies as a viable health care option.

In addition to examining past experience, ideological and predisposing/enabling factors, an examination of the potential positive benefits of alternative therapies in the context of chronic illness, as opposed to the effectiveness of biomedical therapies, can also be drawn. One may argue that alternative therapies represent for the most part a non-toxic means towards health and healing, as opposed to iatrogenic biomedical therapies. As stated earlier, this does not, however, negate the fact that in any improperly administered medical system, alternatives included, iatrogenesis can occur. Rather, it is evident that iatrogenesis appears to be much more established in contemporary biomedicine than in alternative medicine.

Alternative therapies furthermore promote the body's own "natural" healing process, and includes it as an integral part of the healing experience, as opposed to the biomedical reliance on the therapy alone. The term "natural" is used here not in the sense of a "romantic" notion, but by engaging what has been called "mind-body" healing (Chopra 1989). Additionally, non-biomedical therapies take into account important contextual factors by valuing them as an integral part of the healing process. Contextual factors, for example, involve such things as examining an illness on the individual level rather than population level, and emphasizing emotional and lifestyle factors as part of the illness context. One might argue that alternative therapies, as evidenced by individuals in this study, are effective in eliminating chronic symptoms and in promoting healing in the context of chronic illness. One might argue that this is something that biomedicine has yet to achieve.

Lastly, a popular argument often discussed today by avid postmodernists suggests the use of alternative medicine by individuals stems mainly from the nature of our postmodern society. While it is not the intent of this thesis to explore in detail the relationship between postmodernism and alternative health care as has been done elsewhere (Hook 1993), certain conclusions can be

drawn based on the above case narratives. This thesis does not dispute that we live in a postmodern and fragmented society; however, the choice for alternative health care cannot be purely attributed to postmodernist factors. For example, one may argue that in contrast to some arguments (e.g. Hook 1993), the choice for alternative health care can neither be attributed to: (1) the shift from one monolithic framework to another, manifesting in another search for "truth"; (2) the evolution of postmodernist society characterized by malaise and uncertainty, ultimately resulting in "calls to order" defined by either (a) romanticism, (b) nature worship or (c) reintegration with antiquity also known as "neoprimitivism." On the contrary, as previously mentioned, the choice for alternative health care involves both experiential, ideological and predisposing/enabling factors, in addition to the positive healing benefits of alternative therapies in the context of chronic illness.

Taking into account all of the above factors, the message becomes clear: chronic illness sufferers are choosing alternative therapies not only because they may have experienced limited options for improved health in the biomedical world, but because alternative therapies have demonstrated the means for resolving their chronic suffering and promoting healing. Alternative therapies can resolve chronic illness over time, and in the process provide an open-ended relationship by valuing the individual. Furthermore, where biomedical therapies often leave the individual to cope with sometimes devastating side-effects, alternative medicines provide a means to resolve even iatrogenic disease. Thus, unilateral statements such as proposed by Hook (1993) which claim that patients "do not abandon biomedicine in favour of alternative medicine when a crisis arises", have not only ignored important contextual factors, but have failed to account for the complexity of alternative health care use.

Has Biomedicine Failed in the Treatment of Chronic Illness and in the Ability to Promote Health and Well-Being?

One cannot deny the fact that modern biomedicine has, and has had, a very real place in the maintenance of health. There are many instances where innovations in biomedicine have saved millions of lives. For example, immunization has virtually wiped-out the paralytic poliomyelitis, while vaccines for infectious diseases such as measles, and whooping cough have prevented millions of deaths worldwide (Illich 1976:23-24). Drug treatment has helped to reduce the mortality and morbidity of diphtheria, malaria, pneumonia, scarlet fever and tetanus. Biomedical diagnostic procedures such as the papanicolaou vaginal smear ("pap-smear") have prevented many potentially acute diseases, by signalling the early stages of disease and providing the individual an opportunity to overcome the disease before it advances (Illich 1976; Kleinman 1988:175). Emergency medicine such as surgery has saved many lives in the face of immediate life-threatening factors. Two-thirds of all deaths in "First World" countries are now associated with the diseases of old age (Illich 1976:13). Medicine is also gaining an ever-increasing and intricate knowledge of how the body works, through anatomy, physiology, genetics, and cell-signalling systems. New discoveries in neurology, or the structure of the brain and nervous system, are increasing at a rapid pace.

Just as biomedicine has saved millions of lives in light of particular diseases, in the rise and practice of medicine so too has it destroyed or damaged lives due to a myriad of factors which are tied to political, economic and socio-cultural contexts. For example, early allopathic medicine in nineteenth century Europe and North America sided with the popular philosophy of the times which viewed women as "irrational creatures", their emotions "out of control" and rooted in their

sexual organs, and to be remedied by "ovariotomy" or the surgical removal of the ovaries (Ehrenreich and English 1973; Findlay and Miller 1994; Mitchinson 1991; Moscucci 1990). Jumping to twentieth-century medicine, experimental procedures on women such as misguided reproductive and bio-technology[4] have accounted for countless deaths and/or unforeseen side-effects, due to the lack of long-term knowledge of the effects of these procedures, and due to links between capitalism, patriarchy, science and technology (Mies 1993:174-197; Martin 1994).

Furthermore, research has demonstrated that seven percent of all hospitalized patients in the United States suffer injuries while hospitalized, and incredibly, the frequency of reported accidents in hospitals is higher than in all industries excepting mines and high-rise construction (Illich 1976:31). One out of every five patients admitted to a research hospital acquires a hospital induced disease from drug or diagnostic procedures, which in turn requires additional treatment, while one in thirty of these cases leads to death (1976:31). Moreover, three-quarters of the diseases in the late twentieth century in the Western world are now chronic in nature, thereby replacing the acute diseases of the past, and it is the chronic form illness which biomedicine is at present ineffective in treating (Kleinman 1988).

I would like to argue here that despite some advances in the *preservation* of health, biomedicine does not *promote* health or well-being on a large-scale. My arguments partly stem from conclusions drawn from the case-narratives and particular literature references. In addition,

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[4]Dalkon Shield; Deprovera; the new IC's or Injectable Contraceptives; "Third World" sterilization of women; female foeticide based on the diagnostic knowledge of amniocentesis; rampant cesarean sections.

the following discussion also represents my viewpoints as a researcher on the interpretation of illness in the context of biomedicine and alternative health care.

Some readers, especially those with a medical background, may partially or strongly disagree with the arguments presented below. I anticipate that the main criticism, among others, will be directed towards claims to efficacy of alternative medicines based on the case-narratives. It is not my intent, or the intent of this thesis, to claim clinical validity based on biomedical notions of "proof." I believe, however, that the combination of explanatory models as represented by both myself *and* individual narratives is a valid means for constructing illness meaning, and in assessing the efficacy of alternative medicines using a non-biomedical paradigm. This perspective is also clearly supported by other researchers such as Kaufert in his research of First Nations' explanatory models in the context of clinician/client communication, and by current research directions in complementary medicine (Anthony 1987; Kaufert 1990:214-15; Kleinman 1988; Sharma 1992; Vincent and Furnham 1997).

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It is clear that biomedicine has a place in the larger picture of health such as in the prevention of acute diseases, but falls short in maintaining daily well-being of a preventative nature, particularly in the case of chronic illness (Kleinman 1988:175). Ivan Illich states: "The fact that modern medicine has become very effective in the treatment of specific symptoms does not mean that it has become more beneficial for the health of the patient" (1976:81). Moreover, taking into account the historical factors in the rise of medical elitism and dominance discussed in Chapter Two, biomedicine has assumed false truths as to the preservation of humanity such as the

elimination of all disease and the extension of the human life-span (Illich 1976). While biomedicine has achieved particular successes in reducing the morbidity and mortality of certain health problems, there is a strong argument which suggests that world-wide changes that are not medical principles (e.g. public health developments in the nineteenth century may not necessarily be attributed to biomedical techniques but may be associated more generally with science and technology) are the real and underlying causes of change in human health patterns (Illich 1976:15-20; Waldram et al. 1995). These include better housing and nutrition, enhanced treatment of water and sewage, environmental factors such as changes in the eco-system and the effects of pollution and environmental contamination, socio-cultural factors such as socio-political inequality, and the overall epidemiological changes in disease virulence and genetic patterns in populations over time (Illich 1976:15-20; Waldram et al. 1995). For example, medical treatments for cholera, dysentery, plague, tuberculosis and typhoid came many years after these diseases had reached epidemic proportions and subsequently declined in 19th and early 20th century times (Illich 1976; Frank 1995). Ivan Illich (1976:15-17) states:

> The study of the evolution of disease patterns provides evidence that during the last century doctors have affected epidemics no more profoundly than did priests during earlier times. Epidemics came and went, imprecated by both but touched by neither [. . .] two things are certain: the professional practice of physicians cannot be credited with the elimination of old forms of mortality or morbidity, nor should it be blamed for the increased expectancy of life spent in suffering from the new diseases.

One may argue that the underlying reasons for illness sufferers choosing non-biomedical therapies mirrors the reasons that biomedicine has become ineffective in treating certain types of illness. Thus, there are four main influential factors, which will be discussed further, which have led to the ineffectiveness of biomedicine in treating certain types of illness. These factors

encompass: (1) iatrogenesis; (2) capitalist processes and class inequality associated with medical dominance; (3) biomedicine's inability to treat chronic illness, and (4) biomedicine's critical view of non-allopathic therapies. While the first two points have been thoroughly reviewed in the body of this work, I will focus on points three and four for the majority of the discussion.

Beginning with the first factor of iatrogenesis, the narratives presented above are testimony to the fact that biomedicine, to use Ivan Illich's words, has created an "epidemic" of iatrogenic disease, which cannot be separated from medicine (Illich 1976). As previously outlined in Chapters Four and Five, particular aspects of biomedical treatment, such as the use of toxic drugs, have contributed more to the damage than health of the individual. Second, medicine cannot be separated from capitalist processes and class inequality, as evidenced by Navarro (1976). As discussed in previous chapters, capitalist processes associated with the rise of medical dominance have contributed to both structural and individual health inequalities.

Third, it is clear that biomedicine, as it stands today, is ultimately ineffective in treating the entirety of chronic illness, which as stated, now forms the majority of illnesses in the late twentieth century by replacing the acute diseases of the past (Kleinman 1988). Kleinman argues that one of the main reasons for the inadequacy of medical care to treat chronic illness stems from biomedicine's failure to assess the social environment in which illness is experienced (1988:180). Kleinman states:

> Chronicity is not simply a direct result of pathology acting in an isolated person. It is the outcome of lives lived under constraining circumstances with particular relationships to other people [. . .] To understand the contribution of the social environment to chronicity, to the swings of symptoms and disability, we must be able to see the patient suspended, as it were, in the web of relationships that constitute a life world, including relationships with the health care and disability systems that frequently impede the transition from impaired role back into normal social statuses (1988:180-1).

Rather than simply being "peripheral tasks", Kleinman states that the interpretation of illness meanings, and the handling of deeply felt emotions within intimate personal relationships is, or should be, the central tenet of biomedicine (1988:253). "The failure to address these issues", Kleinman argues, "is a fundamental flaw in the work of doctoring" (1988:253). Strauss et al. (1984:7) further state:

> [. . .] to treat medically the problems of any chronically ill patient, one has to supplement the strictly medical knowledge with psychological and social knowledge--about the patient's family and other intimates, as well as the patient himself. That knowledge will include not only how he or she and they handle the disease and the associated medical regimens but how the disease, regimens, and symptoms affect his or her and their lives--and so possibly, or even probably, the ultimate progress of the disease.

Biomedicine treats chronic illness not as an *illness* full of a web of interconnected social and physiological meanings to be worked through, but as an isolated *disease* to be cured. In medical training, students are encouraged to believe that disease is more important than illness, and that a purely biological understanding of the body is sufficient to understand aspects of illness (Kleinman 1988:255). Furthermore, the majority of medical research on chronic illness has not focussed on the experiential aspects of illness sufferers (Strauss et al. 1984:10). A problem arises upon the realization that chronic illness cannot be cured, as the very existence of chronic illness indicates that curative notions are utopian in nature: "[. . .] human problems cannot be reduced to simplistic formulas and stereotyped manipulations that treat patients and their families as if they were overly rational mannequins" (Kleinman 1988:228). The goal, however, should be to reduce the frequency and the severity of exacerbations, and to minimize life difficulties associated with illness (1988:229).

To understand chronic illness, Kleinman states, "we must inquire into the *structure* of illness meanings: the manner in which illness is made meaningful, the processes of creating meaning, and the social situations and psychological situations that determine and are determined by the meanings" (1988:185; original emphasis). "Without understanding a great deal about how the chronically ill get through their days outside of health facilities (and inside them, too), health personnel will never understand what they really need to know to give effective care at the facilities--and to ensure that patients will not return more quickly than they should" (Strauss et al. 1984:9).

Supporting Kleinman's position, the Australian philosopher Paul Komesaroff (1995), calls for a "mircoethics" towards the professional treatment of the ill and personal illness experiences (in Frank 1998a). Komesaroff writes, "The job of the clinician [. . .] cannot be formulated in terms of broad principles, bioethical or otherwise, but only as a series of practical tasks" (1995:63). These tasks involve "the most appropriate way to approach the patient, to talk with him, to allay his fears, and to establish the common ground on which mutual decisions can be taken" (1995:63). Frank (1997:134;140) furthermore proposes the development of a new "potential consciousness" of illness, which involves pushing the "cultural limit of the imagination of who the ill person might rise to the occasion to become", by redrawing "moral maps." The potential consciousness of illness also suggests the capacity to imagine new ways of being ill, what Frank calls "rising to the occasion" of an illness (1997:135). Frank writes:

> [the] potential consciousness imagines disease not as a pathology to be cured in an individual body. Instead, symptoms are openings to a recognition that a pattern of relationships is out of balance. Disease is not the absence of health; rather, health and illness are the complementary cycles of the world (1997:140).

Kleinman argues that it is the nature of biomedical training which seems to disable practitioners from giving effective care to the chronically ill, and that the only solution to resolve these inherent problems is to restructure medical training from bottom to top, however unfeasible this may sound (1988:225;255). Students must be taught to interpret the illness narrative and illness experience, by drawing on courses in the medical social sciences and humanities. New ways of teaching must be employed, and even teachers must be reschooled to value the illness narrative and life history in addition to orthodox measures. These forms of learning must be supported by medical school faculty, in order for students to value what they are learning. In order for this medical training to be preserved, health care structures and funding agencies must ultimately change, by emphasizing physician-sensitive interviewing, outpatient care and community services (1988:258). Only then will the epidemic of chronic illness be effectively addressed by the biomedical community.

The care-giver, in learning the above approaches, must overcome professional masks and interpreting chronic symptoms as personal failure, in order to meet the needs of the chronically ill (Kleinman 1988:228). In addition to the above-mentioned issues, Kleinman (1988:227-245) outlines a specific framework for meeting these needs that the care-giver can employ in the context of chronic illness: (a) the development of a mini-ethnography which constructs the patient's narrative; (b) the identification of psychological problems associated with the illness and its treatment; (c) the solicitation of a life history; (d) the elicitation of the patient's explanatory model, accompanied by the practitioner's explanatory model, and (e) establishing a therapeutic relationship between the care-giver and patient. It is through the use of this framework that chronic symptoms can be resolved.

The fourth and last underlying reason as to why biomedicine has become ineffective in treating certain types of illness is that biomedicine has fervently opposed and/or criticized any other kind of medical system which is not deemed to be "allopathic." Regarding this matter, Kleinman states: "Here we see exposed the profession of medicine's mischievous mind-body dichotomy, which assumes that only biological aspects of illness are "real" and only biological treatments are "hard" enough to produce biological change [. . .] Respect for the patient's viewpoint should include a willingness to learn about the use of so-called alternative practitioners" (1988:128;262). In addition to biomedicine's failure to address effectively chronic illness through its own means, it has ignored the possibilities and potential successes of other healing systems.

It is clear that there has been *some* success in the melding of allopathic and alternative healing systems. For example, new complementary medicine curriculum implemented in some American medical schools, and the use of "hands-on" healing for pre- and post-surgery in leading American hospitals, suggests a new cooperative venture (Crellin et al. 1997). In addition, a new community of allopathic physicians who recognize the drawbacks of biomedicine, and the strengths of other forms of healing is slowly emerging (Coburn et al. 1983). For the most part, however, biomedical and alternative healing systems have remained diametrically opposed. While there appears to be antagonism from both sides of the fence, it appears that biomedicine is much more structured in its resistance.

For example, when conducting research in Vancouver in June of 1997, I interviewed the Clinic Coordinator for the newly established Tzu Chi Research Centre for Alternative and Complementary Medicine. The Centre houses approximately 16 waiting rooms and provides a Traditional Chinese pharmacy. The Coordinator informed me that despite being set up for many

months, prepared to conduct even clinical trials of certain alternative therapies, and being open to cooperation from the medical community, they had not been able to start research due to the scathing criticism and poor cooperation from the British Columbia Medical Association and College. At the last news update over a year later, the Institute still claimed to be "almost ready to begin research." I also interviewed one of the leading complementary physicians in Eastern Canada, who discussed his fight to save his practice from being closed down by the Provincial Medical College for no reason other than offering alternative forms of healing (Dr. William LaValley, personal communication 1997). One may conclude that one of the main reasons that biomedical and alternative medicines have failed to merge is due to unjust and negative medical criticism and fear, combined with outright medical antagonism in some instances. Related to the above issues, as will be discussed below, is that not only is biomedicine highly critical of non-conventional medicine to treat illness, but it has a clearly misconstrued perception of alternative therapies.

One of the important and popular arguments that often arises from the skeptical doctor or individual regarding the use of alternative medicine to combat illness is: How can one be certain that the alternative therapies are actually doing what they claim to do? Phrased differently, physicians or medical researchers alike often argue that because the healing mechanism or mechanisms of alternative therapies is not known, there is no way of telling if the alternative therapy is actually promoting healing, or if it is simply an arbitrary factor such as the "placebo effect." This kind of medical reasoning is often used negatively to stigmatize alternative therapies as doing "nothing" and as simply part of the patient's "imagination" (Vincent and Furnham 1997). Medical doctors also label alternative therapies as "dangerous" because they are not understood

and viewed as "unregulated." Due to the above factors, many alternative medicines are viewed by medical doctors as avoidable at all cost, if at least not approached with extreme caution and apprehension (Crellin et al. 1997).

The counter-argument to this criticism is complex, and therefore needs to be outlined in detail. Beginning with broader levels, as discussed in detail in Chapter Two, medicine has been characterized by an historic process of dominance and elitism whereby medicine attempted to eliminate or limit all competing health occupations. Funding for research was focused strictly on allopathic forms of medicine, such as in the early days of "Rockefeller Medicine" (Brown 1979). Subsequently, clinically-based scientific research has until recently completely avoided exploring non-biomedically based therapies, and has monopolized research on strictly allopathic or "acceptable" forms of healing. This focus has also avoided valuing the nature of the illness experience (Kleinman 1988). Furthermore, medical fear of the effectiveness of alternative therapies combined with medical dominance has contributed to the misunderstanding of alternative medicine and the avoidance of clinical research on these therapies. Thus, one of the main reasons that alternative healing mechanisms are not understood scientifically is because there has been virtually no scientific research aimed at trying to understand them.

A second argument as put forth by Patel (1987), on a theoretical level, suggests that even if scientific medicine were to focus all of its efforts on researching alternative therapies, it might show some significant results, but it would ultimately fail due to core differences between scientific and alternative paradigms. Medical researchers, in contrast, commonly argue that "everything" in the natural world can be understood using a "controlled" study. Patel (1987), however, suggests that differences in alternative and scientific paradigms or worldviews are so

diametrically opposed that while scientific research may achieve some understanding of alternative therapies according to the scientific paradigm, it will ultimately not be able to comprehend the mechanism of their success. Therefore, based on Patel's argument, one may argue that not all things in the natural world may be understood according to the scientific paradigm.

Patel's argument does not propose, however, that because alternative therapies may not fit within the parameters of the scientific paradigm they are "unscientific", and are therefore inferior. On the contrary, many alternative forms of healing such as homeopathy and traditional Chinese medicine (TCM) grew out of logical scientific principles[5], but ultimately developed a system of medicine which did not fit within the scientific paradigm. There have also been some scientific studies which, while largely unknown in the scientific and medical communities, have shown significant results with regard to some alternative therapies such as homeopathy[6] and TCM (see footnote five).

Furthermore, one reason which may explain why most alternative therapies do not fit the parameters of a scientifically controlled study is that a key component of many forms of alternative medicine involves relevant social, cultural, and personal contextual factors. These are something that controlled studies attempt to eliminate above all cost, or labels as "bias" which ultimately "taints" the data. Many alternative therapies also value the individual, and treat the illness by taking into account holistic factors such as personality and lifestyle. In the case of

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[5]Samuel Hahnemann, the originator of Homeopathy, had a rigorous allopathic education; Traditional Chinese Medicine evolved over many years using the now rational principle of trial and error, and underwent literally thousands of clinical studies in the 1950s documenting clinical efficacy (Kaptchuk 1983:20).

[6]See for example Fisher et al. (1989), *British Medical Journal*:p365; Gibson et al. (1980), *Journal of Clinical*

alternative treatments, one individual's illness may require a completely different therapy as compared to another individual suffering from a similar condition.

The argument, therefore, is the following: while some alternative therapies may be understood according to the scientific paradigm, others may not be understood following the "tried and true" clinical trial (Crellin et al. 1997:42). Furthermore, alternative therapies which are not scientifically "proven" can still remain as an equally valid system of medicine. Moreover, it is evident that there are some new forms of allopathic treatment, such as HIV drugs for example, which remain misunderstood by the biomedical community, but nevertheless are authorized for use by HIV sufferers (e.g. new protease inhibitors and DNA vaccines). It would appear that alternative therapies may be strictly judged by the medical community without a recognition of the flaws apparent in biomedicine.

Expanding from this point is a related concept which suggests that what is going on in the body concerning all forms of healing including biomedical therapies, is so complex that it simply cannot be understood in its entirety. For example, many suggest that healing involves a complex interaction between physiology, mental/emotional states, spirituality, matter, and ultimately, consciousness (see for example Chopra 1989). Concepts such as these are at present beyond our full understanding, despite their current exploration in fields such as Psycho-neuro-immunology and in Quantum Physics (see Talbot 1991).

Pharmacology 9:p453; Kleijen et al. (1991), *British Medical Journal* 302:p316; Reilly et al. (1986), *Lancet*:p365.

In light of the above arguments, a scientist may argue that because many alternative therapies remain scientifically unproven, speculation is irrelevant. Contrary to this argument is the fact that, first, all human innovations, including those of scientific value, have come from human imagination and speculation (Frank 1995). Second, the role of a paradigm is such that if it encounters something in the natural world that it cannot understand, for example the occurrence of "spontaneous" or "miraculous" healing, the paradigm must change and modulate to fit the parameters of that particular natural event (Dr. William LaValley, complementary physician; personal communication 1997). This leads us to the concept of "placebo", which, one might argue, is biomedicine's poor attempt to label and "explain away" something it does not, and cannot, fully understand (Vincent and Furnham 1997). Third, despite claims to the contrary one may argue that up to 80% of all practiced allopathic therapies, surgery for example, have not been clinically tested according to the "double-blind" study (Vincent and Furnham 1997). Moreover, even the cellular mechanisms for early biomedical drugs such as acetycalicylic acid (contained in Aspirin), including many current therapies, are not fully comprehended by the medical community. Ironically, these examples speak for themselves--biomedicine assumes a "double-standard" whereby for alternative therapies to be accepted and deemed "scientific", they must first conform and "prove" themselves to scientific protocol. Further, alternative therapies must then conform to strict and regulated procedures which are not even fully applied to allopathic medicine.

Regardless of the fact that alternative therapies may not be "scientifically" understood, many come from a rich background which is just as complex as biomedicine, and which involves detailed conceptual and explanatory models for these therapies. For example, traditional Chinese medicine (TCM) (labeled as "alternative" in the West), while rooted in centuries-old concepts, is a

coherent and independent system of thought developed over two millennia (Kaptchuk 1983:2). TCM, while predating Western science and therefore "pre-scientific", is nevertheless grounded in "conscientious observation of phenomena, guided by a rational, logically consistent, and communicable thought process [. . .] It has a body of knowledge with standards of measurement that allow practitioners systematically to describe, diagnose and treat illness" (1983:18). This is not to state, however, that because certain forms of alternative therapies predate biomedicine by hundreds to thousands of years that they are necessarily "better" forms of healing (Crellin et al. 1997:42). Rather, many of these therapies have been developed through trial and error on living human beings, which in itself is a scientific principle. Many of these therapies, such as naturopathic medicine, have regulated schools and training certificate programs on par with biomedical schools (Kleinman 1988).

Doctors, however, often argue that alternative therapies are not understood and are therefore "dangerous" and less effective than clinically-tested biomedical therapies. For example, some doctors argue that there is simply no way of knowing what compounds are contained in herbs, and as they are not synthesized, pose potential risk to the individual (Hook 1993:83). Doctors also argue that alternative therapies are assumed to pose no threat to the individual because they are seen as "natural", when they should really be seen as harmful (Hook 1993; Wasner 1991).

Contrary to this medical criticism, however, is that as practiced by an experienced and well-trained alternative practitioner, the therapy is understood and therefore not dangerous to the individual. This does not negate the fact that in any improperly administered or unregulated medical system, alternatives included, damage can occur to the individual. Rather, the argument

is as follows. Considering that some allopathic therapies may be less understood by doctors than alternative therapies are understood by alternative practitioners, and taking into account the high level of iatrogenesis propagated by physicians who prescribe concentrated and powerful medicines with potentially misunderstood side-effects, biomedicine has significantly higher ramifications in terms of damaging individuals than alternative medicine. Furthermore, in the case of herbs, for example, contrary to some arguments which claim there is no recognizable difference between organic and synthesized molecules (e.g. Hook 1993:82), one may argue that herbs in raw form often contain key trace-elements which are lost or overlooked in the biomedical molecular synthesis. Additionally, rather than being "natural" therapy, the relative low-potency of herbs in contrast to biomedical drugs is a key factor in the prevention of iatrogenesis using herbal therapy.

An additional criticism often arising from the medical community is that many alternative therapies are not regulated by any monitoring board, and therefore they cannot be trusted for the quality of care they provide. While at first an easy criticism to accept, the underlying issues surrounding alternative medicine regulation point to the fact that alternative medicines are not to blame for any lack of regulation. In fact, there are certain therapies which are regulated. For example, as discussed in Chapter Two, chiropractic, midwifery and massage therapy have recently been accepted by the Ontario Health Professions Legislation Review as having their own governing bodies and peer review committees (Coburn 1993). Acupuncture is now regulated in Alberta and Quebec, while in Alberta acupuncture is now officially accepted by the College of Physicians and Surgeons of Alberta (Greg Elgert, acupuncturist, personal communication 1998). Naturopathic medicine in Canada also has provincial and national regulatory boards and examinations (Dr. Chris Turner, naturopathic doctor, personal communication 1997).

Outside of North America, there are many countries in Europe, and some countries such as China and provinces in India which have far more integrated plural health care systems and regulated alternative medicines than in North America. This is something that North American doctors are quick to overlook. For example, China, while biomedical health care may soon dominate, still hosts integrated traditional Chinese medicine with Western biomedicine (Greg Elgert, acupuncturist, personal communication 1998). Further, some parts of India claim a three-tiered health care system comprised of ayurvedic medicine, homeopathy and biomedicine, while England has well-established homeopathic schools, regulatory boards and homeopathic hospitals.

Furthermore, one might argue that the underlying cause for many alternative medicines which remain unregulated in North America is the nature of the North American health care system, which has historically been competitive and dominated by biomedicine. Additionally, due to the nature of medical dominance which eliminated therapies such as homeopathy through co-option or "assimilation", alternative therapies have a tendency to be wary of meeting regulatory guidelines specified by the medical colleges. Indeed, alternative therapies almost completely eliminated in the early twentieth century, have only recently begun to overcome the damage that they incurred from early allopathic medicine. Moreover, many alternative therapies, while they may not be "officially" regulated, have their own system of informal peer review, policy-making and maintenance of quality of care provided.

As stated, the majority of doctors will agree that because the scientific mechanisms of alternative therapies are not known or scientifically "proven", any number of factors could be responsible for the healing of the alternative medicine user ranging from the patient's own "natural healing process" to the patient's "imagination." Therefore, doctors argue, one will never know if

the alternative therapy had a healing effect, should be relegated to the commonly doctor-used term "quackery", or resigned to be a therapy which exploits the patient and their resources while doing nothing beneficial for the patient. A central issue which needs to be addressed is: if alternative therapies cannot be proven "scientifically", does this mean that these therapies are "useless" and have no healing properties, and should be disregarded? Again, there are several more-specific counter-arguments to this form of medical criticism.

First, in clear contrast to biomedicine, it is evident that one of the basic mechanisms of alternative therapies is to stimulate the body's own healing mechanism or immune system to affect healing by using non-toxic and non-invasive measures (Patel 1987). Therefore, the body's natural healing process is an integral part of the use of alternative therapies. On a very deep level the body's system is "kick-started" to address the imbalance which has indirectly caused illness ("imbalance" as the root cause precipitating illness, usually understood as an imbalance of "energy", is a common theoretical explanation in many alternative therapies) (Vincent and Furnham 1997). Thus, biomedicine is taking a very positive aspect of alternative medicine, that of stimulating the body to affect healing using non-invasive measures, and criticizes it because this kind of healing, for the most part, does not exist in biomedicine. In a field characterized by "attacking" or directly "manipulating" the body's cellular processes using outside means, the fact that the body may achieve this with the help of non-invasive measures would indeed seem very foreign to medicine (Frank 1995).

Weighing these two opposing forms of medicine, it is clear that the use of non-toxic and non-invasive measures to heal illness would far outweigh the value of resorting to toxic and invasive procedures. Again, this type of thinking is diametrically opposed to the biomedical

paradigm. One might further argue that medicine's critique of alternative medicine for these very reasons is not actually doing alternative therapies a disservice. On the contrary, by stating that alternative therapies promote the body's own healing process and mental attitude, which are integral factors to the healing process, medicine is actually supporting the use of these therapies.

Second, and more specifically, by shifting the focus away from trying to "prove" scientifically that alternative therapies are actually doing "something", much becomes revealed. Complementary practitioners and researchers alike are suggesting that the classic experimental methodology of the biomedical randomized controlled trial may not do justice to complementary medicine, thus requiring a new methodological approach (Anthony 1987; Heron 1986; Vincent and Furnham 1997). One might argue that it is not necessary or appropriate to use clinical trials to assess alternative therapies at the individual level (Patel 1987). Rather, the focus should be on the overall healing experience of the individual. Factors that may be explored are the benefits of the particular therapy with regard to resolving the illness and in comparison to other therapies, and the explanatory models of both patient and therapy (Kaufert 1990; Vincent and Furnham 1997:151). Additionally, questions should be raised as to: How did the individual feel after using alternative therapies? How did the therapy promote the healing process, both physically, mentally and spiritually? Only then should the therapy's effectiveness be determined (Vincent and Furnham 1997).

The answers to the above questions can be clearly found in what are medically called "retrospective studies." These are often devalued and labelled "purely anecdotal" by the scientific community, but can form valid testimony to the perception of biomedicine (see Hunter 1986). Moreover, anecdotes may form valid testimony to the effectiveness of alternative therapies. One

might argue that there are different kinds of "proof", and that it is less important to understand the specific molecular mechanism at hand, which arguably cannot be fully understood at this point in time, than to understand how alternative therapies promote healing on the individual level. The narratives provided by Doug, Ben and Greg are excellent examples of illness stories which give "oral" and personal testimony to the positive healing effect of alternative therapies. These illness histories furthermore form a new body of evidence beginning to assess the efficacy of complementary therapies in a non-biomedical format (Vincent and Furnham 1997:152).

Regarding medicine's critique of alternative medicine as a form of exploitive "quackery", it is only fair to state that quackery exists in both the domain of alternative *and* biomedical therapies. While there certainly do exist certain alternative therapies which do "nothing" and capitalize on the financial resources of the individual, there are many alternative therapies which in fact do much good and do not exploit the individual. Furthermore, as previously demonstrated some forms of biomedicine have done much damage to individuals, arguably more so than the sum of all alternative therapies put together, and this damage certainly involved exploitation and violation of individual rights on many levels. Ethically speaking, one can argue that the general nature of alternative medicine is structured to protect the rights of the individual by respecting confidentiality, consent and the open sharing of information and awareness, whereas some areas of biomedicine do not. Again, referring back to the historic rise of allopathic medicine, it becomes clear that medicine was born from exploitive and elitist parents, and that the level of exploitation that occurs and has occurred in biomedicine far outweighs the so-called "quackery" going on in the domain of alternative medicine (Hamowy 1984). Moreover, and as previously stated, biomedicine would seem to win its own contest in "quackery", as one may argue that 80%

of medicine is presently not "proven" according to its own standards.

An additional criticism often heard from the medical community is the following: an individual faced with a serious or life-threatening illness should not "fool around" with alternative or "unproven" therapies. While it is clear that biomedicine is effective in dealing with acute or emergency situations, it certainly does not have a monopoly on treating these types of illnesses. In certain contexts, some alternative therapies have demonstrated successful treatment of acute illnesses. A good example is the homeopathic "first-aid" remedy kit that can be obtained from most homeopathic clinics or pharmacies, and which is directly applicable for many acute first-aid situations, ranging from minor injuries such as cuts and bruises, to more serious afflictions such as broken bones, burns, food-poisoning, shock and even drowning (Panos and Heimlich 1980).

Furthermore, although contrary to many doctor's opinions and actions, an individual has the right to choose the form of therapy s/he may want to use. As Greg indicated in this study, it is the biomedical drugs such as currently being used to treat HIV which are not fully understood, and therefore pose potential risk to the HIV patient. Taking into account the high level of iatrogenesis contained in these drugs, on the contrary, it would seem that individuals faced with a life-threatening illness should not "fool-around" with biomedicine. This does not negate the fact that some forms of potent drug treatment, for example, while iatrogenic in nature, do have beneficial effects in combatting the illness. Rather, it is the risk that these drugs pose to the individual which is the focus for debate, as the side-effects may overshadow any beneficial effects that the drugs induce.

Lastly, a common medical argument used to justify the use of toxic biomedical drugs to treat illness is that because the illness, cancer for example, is so destructive, that only toxic drugs can be used to defeat or "kill" it (Frank 1991). As previously stated, this kind of medical reasoning is then used to justify iatrogenic disease as simply "part of the therapy." What is often failed to be included in this statement is that while these drugs may be killing the illness, they may also be killing the body in the process (Frank 1991). For example, while chemotherapy for cancer treatment kills cancer cells, it also destroys the body's immune system, leaving it open for other illnesses and different forms of cancer to develop (Chopra 1989). Additionally, the forms of chemotherapy-based drugs being used today are so toxic, and administered in such large quantities, that the patient runs the risk of having their coronary artery collapse from "toxic overdose" (Frank 1991).

As stated, the main issue then comes down to a philosophical argument in which biomedicine claims authority to value one illness over another. For example, recent breast cancer drugs such as Tamoxifen are currently being defended by doctors who can be interpreted as stating: "Which would you prefer, breast cancer at age 60 or the risk of uterine cancer and/or fatal blood clots?" If one assumes that rampant iatrogenesis does not exist in every medical system as it does in biomedicine, and taking into account the above illness narratives as represented in this study, it is clear that there are other ways of treating serious and chronic illness than resorting to toxic and iatrogenic-causing drugs. Whether the majority of biomedical doctors will realize this remains to be seen.

In sum, biomedicine's incapacity to treat certain forms of illness and maintain overall health and well-being stems from many interrelated and complex factors. While there certainly

exist a variety of other factors, it becomes clear that iatrogenesis, medical dominance, capitalist processes, biomedicine's inability to treat chronic illness, and unfounded medical criticism towards alternative therapies form the basis towards explaining biomedicine's weakness to promote healing.

Conclusion

The aim of this thesis was to use illness narrative stories to document the processes of illness and healing among chronic illness sufferers. Particular emphasis was given to highlighting the use of alternative and/or biomedical therapies in the search for therapy, and how these therapies fit into the illness context. Contained within the illness meanings, it became apparent that chronic illness sufferers, while using particular aspects of biomedicine, were becoming particularly disenchanted with the effectiveness of biomedical therapies to heal their illnesses.

As became revealed, this dissatisfaction with biomedicine stemmed from many factors, encompassing iatrogenesis, medical dominance, dissatisfaction with physicians, devaluation of personal socially contextual factors and explanatory models, a devaluation of the illness experience, and ultimately, an overall ineffectiveness of biomedicine to resolve chronic symptoms. In the course of this research, it became apparent that where biomedicine had failed, individuals were turning to outside means to resolve their illnesses--alternative medicine. It was the conviction of each of the individuals as presented in this study, that certain forms of alternative medicine, for various reasons, helped to resolve the chronicity of their symptoms.

This study presents a strong avenue for hope. There *are* options for those who have been damaged by biomedicine and for chronic illness sufferers that can simply find no relief using biomedical therapies. This study represents documentation of real individuals who have found positive relief with alternative medicine, who are very clear about how they experienced this process. Furthermore, these stories communicate the message that there always exist alternative ways of thinking about illness and healing for those who wish to hear. Whether biomedicine will begin to "hear", only time can reveal.

REFERENCES CITED

Aday, L.A. and R.M. Andersen.
1974 A Framework for the study of access to medical care. Health Services Research 9:208-220.

Andersen, R.M.
1995 Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? Journal of Health and Social Behaviour 36 (1):1-10.

Andersen, R.M. and J.F. Newman.
1973 Societal and Individual Determinants of Medical Care Utilization in the United States. Milbank Memorial Fund Quarterly 51:95-124.

Anthony, Honor M.
1987 Some Methodological Problems in the Assessment of Complementary Therapy. Statistics in Medicine 6:761-771.

Baer, Hans A.
1989 The American Dominative Medical System as a Reflection of Social Relations in the Larger Society. Social Science and Medicine 28 (11):1103-1112.

Bakx, K.
1991 The 'Eclipse' of Folk Medicine in Western Society. Sociology of Health and Illness 13 (1):20-38.

Berg, Bruce L.
1989 Qualitative Research Methods for the Social Sciences. Boston: Allyn and Bacon.

Berger, E.
1993 The Canada Health Monitor. Survey No. 9, March, p.123. Toronto: Price Waterhouse.

Blore, Shawn.
1997 Ancient Medicine: Has A Century of Dismissal Ended with the Opening of the Tzu Chi Institute? The Georgia Straight, January 23-30, Vancouver:13-18.

British Medical Association
1986 Alternative Therapy: Report to the Board of Science and Education. BMA, London.

Britten, Nicky.
1995 Qualitative Interviews in Medical Research. British Medical Journal 311, July 22:251-253.

Brody, Howard.
1980 Placebos and the Philosophy of Medicine: Clinical, Conceptual, and Ethical Issues. Chicago and London: The University of Chicago Press.

Broom, Dorothy H. and Roslyn V. Woodward.
1996 Medicalisation Reconsidered: Toward a Collaborative Approach to Care. Sociology of Health and Illness 18 (3):357-378.

Brown, E. Richard.
1979 Rockefeller Medicine Men: Medicine and Capitalism in America. Berkeley: University of California Press.

Bury, Michael.
1982 Chronic Illness as Biographical Disruption. Sociology of Health and Illness 4 (2):167-182.

Canadian Medical Association Journal.
1991:144; 469.

Chapman, Carleton B.
1974 The Flexner Report by Abraham Flexner. Daedalus 103 (1):105-117.

Charmaz, Kathy.
1983 Loss of Self: A Fundamental Form of Suffering in the Chronically Ill. Sociology of Health and Illness 5 (2):168-195.

Chopra, Deepak.
1989 Quantum Healing: Exploring the Frontiers of Mind/Body Medicine. New York: Bantam Books.

Clarke, Juanne N.
1983 Sexism, Feminism and Medicalism: A Decade Review of Literature on Gender and Illness. Sociology of Health and Illness 5 (1):62-82.

Clark, Jack A. and Elliot G. Mishler.
1992 Attending to Patient's Stories: Reframing the Clinical Task. Sociology of Health and Illness 14 (3):344-372.

Coburn, David.
1988 Canadian Medicine: Dominance or Proletarianization? The Milbank Quarterly 66 (2):92-116.

1993 State Authority, Medical Dominance, and Trends in the Regulation of the Health Professions: The Ontario Case. Social Science and Medicine 37 (2):129-138.

Coburn, David, Susan Rappolt and Ivy Bourgeault.
1997 Decline vs. Retention of Medical Power Through Restratification: An Examination of the Ontario Case. Sociology of Health and Illness 19 (1):1-22.

Coburn, David, George M. Torrance and Joseph M. Kaufert.
1983 Medical Dominance in Canada in Historical Perspective: The Rise and Fall of Medicine? International Journal of Health Services 13 (3):407-432.

Connor, J.T.H.
1991 'A Sort of Felo-de-Se': Eclecticism, Related Medical Sects, and their Decline in Victorian Ontario. Bulletin of the History of Medicine 65:503-27.

Creswell, John W.
1994 Research Design: Qualitative and Quantitative Approaches. Thousand Oaks: Sage Publications.

Crellin, J.K., R.R. Andersen and J.T.H. Connor (eds.).
1997 Alternative Health Care in Canada: Nineteenth--and Twentieth--Century Perspectives. Toronto: Canadian Scholars' Press Inc.

Csordas, Thomas J.
1994 Embodiment and Experience: The Existential Ground of Culture and Self. Cambridge: Cambridge University Press.

Ehrenreich, Barbara and Deirdre English.
1973 Complaints and Disorders: The Sexual Politics of Sickness. Glass Mountain Pamphlet No.2. New York: The Feminist Press.

Eisenberg, D., R. Kessler, C. Foster, F. Norlock, D. Calkins, and T. Delbanco.
1993 Unconventional Medicine in the United States: Prevalence, Costs and Patterns of Use. New England Journal of Medicine 328:246-252.

Elgert, Greg.
1998 Personal Communication.

Findlay, Deborah A. and Leslie J. Miller.
1994 Medical Power and Women's Bodies. In Women, Medicine and Health. B. Singh Bolaria and Rosemary Bolaria (eds). Pp. 155-139. Halifax: Fernwood.

Foucault, M.
1979 Discipline and Punish. New York: Pantheon.

Frank, Arthur W.
1991 At the Will of the Body: Reflections on Illness. Boston: Houghton Mifflin Company.

1995 The Wounded Storyteller: Body, Illness, and Ethics. Chicago and London: The University of Chicago Press.

1997 Illness as Moral Occasion: Restoring Agency to Ill People. Health 1 (2):131-148. London, Thousand Oaks and New Delhi: Sage Publications.

1998a First-Person Microethics: Deriving Principles from Below. Hastings Centre Report. July-August:37-42.

1998b Stories of Illness as a Care of the Self: a Foucauldian Dialogue. Health 2 (3):329-348. London, Thousand Oaks and New Delhi: Sage Publications.

Freidson, E.
1970 Profession of Medicine. New York: Harper and Row.

1994 Professionalism Reborn: Theory, Prophecy, and Policy. Chicago: The University of Chicago Press.

Fulder, S.J.
1988 The Handbook of Complementary Medicine. Oxford: Oxford University Press.

Fulder, S.J. and R.E. Munro.
1985 Complementary Medicine in the United Kingdom: Patients, Practitioners, and Consultations. Lancet 2 (8454):542-5

Furnham, A. and C. Smith.
1988 Choosing Alternative Medicine: A Comparison of the Beliefs of Patients Visiting a General Practitioner and a Homeopath. Social Science and Medicine 26 (7):685-689.

Garro, Linda C.
1992 Chronic Illness and the Construction of Narratives. In Pain as Human Experience: An Anthropological Perspective. M.J. Good, P.E. Brodwin, B.J. Good and A. Kleinman (eds). Pp. 100-137. Berkeley: University of California Press.

Gevitz, N. (ed).
1988 Other Healers: Unorthodox Medicine in America. Baltimore: The Johns Hopkins University Press.

Good, M., P. Brodwin, B. Good, and A. Kleinman.
1992 Pain as Human Experience: An Anthropological Perspective. Berkeley: University of California Press.

Gordon, D.
1988 Tenacious Assumptions in Western Medicine. In Biomedicine Examined. M. Lock and D. Gordon (eds). Holland: Kluwer.

Goldstein, Michael S. et al.
1987 Holistic Physicians and Family Practitioners: An Empirical Comparison. Family Medicine 19 (4):281-286.

1988 Holistic Physicians and Family Practitioners: Similarities, Differences and Implications For Health Policy. Social Science and Medicine 26 (8):853-861.

Goldstein, Michael S.
1992 The Health Movement: Promoting Fitness in America. New York: Twayne.

Goldszmidt, et al.
1995 Complementary Health Care Services: A Survey of General Practitioners' Views. Canadian Medical Association Journal 153 (1):29-35.

Hahn, Robert A.
1995 Biomedicine as a Cultural System. In Sickness and Healing: An Anthropological Perspective. Robert A. Hahn. Pp. 132-172. New Haven and London: Yale University Press.

Hammersley, Martyn and Paul Atkinson.
1983 Ethnography: Principles In Practice. Routledge: London and New York.

Hamowy, Ronald.
1984 Canadian Medicine: A Study in Restricted Entry. Canada: The Fraser Institute.

Harden, Bonni L. and Craig R. Harden.
1997 Alternative Health Care: The Canadian Directory. Toronto: Noble Ages Publishing Ltd.

Helman, C.G.
1985 Communication in Primary Care: The Role of Patient and Practitioner Explanatory Models. Social Science and Medicine 20 (9):923-931.

Heron, J.
1986 Critique of Conventional Research Methodology. Complementary Medical Research 1:12-22.

Hook, Kerry P.
1993 Medical Pluralism in Postmodern Society: A Postmodern Analysis. Masters Thesis, Department of Anthropology, University of Calgary, Calgary, Alberta, Canada.

Hyden, Lars-Christer.
1997 Illness and Narrative. Sociology of Health and Illness 19 (1):48-69.

Hunter, Kathryn Montgomery.
1986 "There Was This One Guy . . .": The Uses of Anecdotes in Medicine. Perspectives in Biology and Medicine 29 (4):619-630.

Illich, Ivan.
1976 Limits to Medicine: Medical Nemesis: The Expropriation of Health. London: Marion Boyars.

Jackson, J.
1994 Report of Fieldwork in Chronic Pain Treatment Settings. Manuscript.

Kaptchuk, Ted J.
1983 The Web That Has No Weaver: Understanding Chinese Medicine. Chicago: Congdon & Weed.

Katon, W.
1982 Depression and Somatization, parts 1 and 2. American Journal of Medicine 72:127-35, 241-47.

Kaufert, Joseph M.
1990 Sociological and Anthropological Perspectives on the Impact of Interpreters on Clinician/Client Communication. Sante, Culture, Health 7(2-3):209-235.

1998 Personal Communication.

Kelner, Merjoy and Beverly Wellman.
1997a Health Care and Consumer Choice: Medical and Alternative Therapies. Social Science and Medicine 45 (2):203-212.

1997b Who Seeks Alternative Care? A Profile of the Users of Five Modes of Treatment. The Journal of Alternative and Complementary Medicine 3 (2):127-140.

Kleinman, A.
1980 Patients and Healers in the Context of Culture. Berkeley: University of California Press.

1986 Social Origins of Distress and Disease: Depression, Neurasthenia and Pain in Modern China. New Haven: Yale University Press.

1988 The Illness Narratives: Suffering, Healing and the Human Condition. New York: Basic Books, Inc.

Komesaroff, Paul A.
1995 From Bioethics to Microethics: Ethical Debate and Clinical Medicine. In Paul A. Komesaroff (ed.). Troubled Bodies: Critical Perspectives on Postmodernism, Medical Ethics and the Body. Durham, N.C.: Duke University Press.

Kunitz, Stephen J.
1974 Professionalism and Social Control in the Progressive Era: The Case of the Flexner Report. Social Problems 22 (1):16-27.

Larkin, G.V.
1988 Medical Dominance in Britain: Image and Historical Reality. The Milbank Quarterly 66 (2):117-133.

Larson, Magali Sarfatti.
1977 The Rise of Professionalism: A Sociological Analysis. Berkeley: University of California Press.

LaValley, W.J. and M.J. Verhoef
1995 Integrating Complementary Medicine and Health Care Services Into Practice. Canadian Medical Association Journal 153 (1):45-49.

LaValley, W.J.
1997 Personal Communication.

Lips, Jan.
1998 Personal Communication.

Lyotard, J.F.
1984 The Postmodern Condition. Minneapolis: University of Minnesota Press.

Martin, Emily.
1987 The Woman in the Body: A Cultural Analysis of Reproduction. Boston: Beacon Press.

Mather, H.G.
1971 Acute Myocardial Infarction: Home and Hospital Treatment. British Medical Journal 3:334-8.

Mies, Maria.
1993 Feminist Research: Science, Violence and Responsibility; New Reproductive Technologies: Sexist and Racist Implications. In Ecofeminism. Maria Mies and Vandana Shiva. Pp. 34-56; 174-197. Halifax, Nova Scotia: Fernwood Publications; London and New Jersey: Zed Books.

Mitchinson, Wendy.
1991 The Nature of Their Bodies: Women and Their Doctors in Victorian Canada. Toronto: University of Toronto Press.

Montbriand, M. and G. Liang.
1991 Alternative Health as a Control Strategy. Journal of Advanced Nursing 16:325-332.

Moscucci, Ornella.
1990 The Science of Woman: Gynaecology and Gender in England, 1800-1929. Cambridge: Cambridge University Press.

Navarro, Vincente.
1976 Medicine Under Capitalism. New York: Prodist.

OBCIEP
1994 Ontario Breast Cancer Information Exchange Project (OBCIEP).

Powers, John.
1995 Introduction to Tibetan Buddhism. Ithaca, New York: Snow Lion Publications.

Patel, Mahesh S.
1987 Problems in the Evaluation of Alternative Medicine. Social Science and Medicine 25 (6):669-678.

Panos, M. B.and J. Heimlich.
1980 Homeopathic Medicine at Home: Natural Remedies for Everyday Ailments and Minor Injuries. New York: Putman Publishing Group.

Pawluch, D., R. Cain, and J. Gillett.
1994 Ideology and Alternative Therapy Use Among People Living with HIV/AIDS. Health and Canadian Society 2 (1):63-84.

Rankin-Box.
1992. European Developments in Complementary Medicine. British Journal of Nursing 1 (2):103-105.

Raso, Jack, and Stephen Barrett, ed.
1994 Alternative Healthcare: A Comprehensive Guide. New York: Prometheus books.

Rogers, Roger.
1997 Personal Communication.

Schudson, Michael.
1974 The Flexner Report and the Reed Report: Notes on the History of Professional Education in the United States. Social Science Quarterly 55 (2):347-361.

Sharma, Ursula.
1992 Complementary Medicine Today: Practitioners and Patients. Routledge, London.

1993 Contextualizing Alternative Medicine: The Exotic, the Marginal and the Perfectly Mundane. Anthropology Today 9 (4):15-18.

Silverman, Paul.
1993 Interpreting Qualitative Data. Sage Publications:30-58.

Spencer, M.H.
1995 Physicians Should Keep an Open Mind on Complementary Health Care, Congress Says. Canadian Medical Association Journal 153 (12):1796-7.

Stoppard, Janet.
1990 A Suitable Case for Treatment? Premenstrual Syndrome and the Medicalization of Women's Bodies. Source reference unavailable.

Strauss, Anselm and Juliet Corbin.
1990 Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park: Sage Publications.

Strauss, Anselm L., J. Corbin, S. Fagerhaugh, B. Glaser, D. Maines, B. Suczek, and C. Weiner.
1984 Chronic Illness and the Quality of Life. Second Edition. St. Louis, Toronto: The C.V. Mosby Company.

Talbot, Michael.
1991 The Holographic Universe. New York: Harper Perennial.

Townsend, Joan.
1998 Personal Communication.

Turner, B.S.
1990 The Interdisciplinary Curriculum: From Social Medicine to Postmodernism. Sociology of Health and Illness 12 (1):1-23.

Turner, Chris.
1997 Personal Communication.

Unschuld, Paul U.
1980 The Issue of Structured Coexistence of Scientific and Alternative Systems: A Comparison of East and West German Legislation. Social Science and Medicine 14 (1B):15-24.

Verhoef, M.J.
1997 Personal Communication.

Verhoef, M.J. and L.R. Sutherland.
1995 General Practitioners' Assessment of and Interest In Alternative Medicine in Canada. Social Science and Medicine 41 (4):511-5.

Vincent, C. and A. Furnham.
1996 Why Do Patients Turn to Complementary Medicine? An Empirical Study. British Journal of Clinical Psychology 302 (26):207-210.

1997 Complementary Medicine: A Research Perspective. Chirchester, New York, Weinham, Brisbane, Singapore, Toronto: John Wiley & Sons.

Visser, G.J. and L. Peters.
1990 Alternative Medicine and General Practitioners in the Netherlands: Towards Acceptance and Integration. Family Practice 7 (3):227-32.

Waldram, James B., D. Ann Herring and T. Kue Young.
1995 Aboriginal Health in Canada: Historical, Cultural and Epidemiological Perspectives. Toronto, Buffalo, London: University of Toronto Press.

Wasner, C.K.
1991 The Art of Unproven Remedies. Rheumatic Disease Clinics of North America 17 (2):197-202.

Appendix A –Definitions of Alternative Therapies[7]

Acupuncture

Acupuncture originated several thousand years ago as part of a Chinese medical system that included herbs, massage, moxibustion, exercise and diet. Traditional Chinese medicine is a holistic system of health care that brings body, mind and spirit into balance. Acupuncture itself refers to the process of inserting thin needles of various shapes into the skin to stimulate "acupoints" or "meridians" in the body, which may be understood as nerve or energy pathways, and to stimulate the life-energy force of "Qi" or "Chi" (pronounced "Chee"). Qi is a balance of opposites--hot and cold, moist and dry, yin and yang--and also involves the five elements of fire, earth, metal, water and wood. In the Chinese system, illness results when the Qi is imbalanced within the body. Acupuncture is often used to relieve physical pain in the body, and has been recently used to help with drug addictions. It also promotes the body's natural healing abilities and restores internal regulation systems. "Medical Acupuncture" is another form of acupuncture performed by medical doctors, physiotherapists, and chiropractors. Acupuncture is currently regulated by the provinces of Alberta, British Columbia, and Quebec, and while it is not supported by Canadian health care, is covered by some private health insurance companies. There are several Canadian national acupuncture associations, including a new national Canadian acupuncture body established in 1996 to meet national standards. There are also several Canadian acupuncture colleges located in Victoria, Vancouver, Montreal, and London, Ontario. Acupuncture is practiced in all Canadian provinces (Sources: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997; OBCIEP 1994; Raso 1994).

Ayurvedic medicine

A system of medicine dating back 3,000 years and developed in India. Ayurvedic medicine is a holistic philosophy, based on restoring balance in an individual's energy systems. Meaning "the science of life", ayurvedic medicine is based on the concept of three "doshas" or body types (vata, pitta, kapha) and treats the unique individual by using a combination of herbs, minerals, diet, massage, exercise and meditation. Ayurvedic medicine in India is taught in more than 100 colleges with five- to six-year programs, and is practiced in the United States, Britain and Canada. It is currently not regulated in Canada, despite having a national Canadian association. In Canada ayurvedic medicine is practiced in Alberta, British Columbia, Ontario, Quebec and Saskatchewan (Source: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997).

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[7]These definitions include those therapies referred to in the above study. They do not represent the full spectrum of alternative therapies.

Appendix A --Definitions of Alternative Therapies (Continued...)

Bio-tuning/Bio-acoustics:

A relatively new therapy which uses sound tone and frequency to affect healing and promote well-being on both physiological and psycho-spiritual levels of the human body. Initially developed by a chiropractor in the United States, bio-tuning/acoustics uses sound-tone to detoxicate the body, and to balance the human energy centres such as the Hindu chakras and the Chinese meridians. Sound-frequency is also used to heal soft-tissue and bone damage. New innovations in the therapy are constantly being discovered, such as the use of a specific tone to inhibit the proliferation of the HIV virus. Bio-tuning/acoustics is currently being practiced in Winnipeg, Manitoba and in the United States.

Chiropractic Therapy

Derived from the Greek meaning for "treatment by hand", chiropractors focus on the spine in relation to the body and specialize in the understanding and treatment of its component bone structures, muscles and nerves. Chiropractors do not use drugs or surgery, but most commonly use manual adjustment or manipulation, which involves the subtle re-aligning of the spinal column, resulting in a balanced nervous system. It also involves the use of diet and exercise. Founded in 1895 by Canadian born Daniel David Palmer (1845-1913), some forms chiropractic therapy also integrate the notion of a "vital force" within the body. Chiropractic therapy can alleviate musculo-skeletal disorders, including headache, migraine, neck and back pain, and pain radiating to legs, shoulders, and arms, and can alleviate disorders caused by spinal disfunction. It can also help sports and work-related injuries, hip problems, and can treat insomnia, menstrual cramps and the symptoms of multiple sclerosis. To date, there are approximately 4,500 licensed chiropractors in Canada. Chiropractic is regulated, licensed and practiced in all 10 provinces, and is partially or fully covered by provincial health care systems in Alberta, British Columbia, Manitoba, Ontario and Saskatchewan, and is covered by most private health insurance companies. There are several Canadian chiropractic colleges in Toronto and Quebec. (Sources: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997; Raso 1994).

Appendix A --Definitions of Alternative Therapies (Continued...)

Herbalism

Herbal medicine refers to the use of plants for healing and preventative medicine. This therapy uses plants to treat health problems, by causing neurochemical responses in the body. Herbal products are derived from roots, stems or leaves and are frequently sold in raw form, ointments, liquid extract, pill form or teas, douches, enemas or suppositories. The main difference between herbs and biomedical drugs is that whereas 25-30% of all drugs extract the single active constituent from a plant and synthesize it in a chemical compound, herbs use remedies extracted from a part of the whole plant, while preserving all of its biochemical constituents. The practice of herbal medicine also traces its origins to the earliest forms of healing. Herbs may be used as diuretics, laxatives and blood purifiers, to stimulate the body's own self-healing, and to tone organs and to nourish tissues and blood. Herbs can also be used to treat skin problems, digestive disorders, heart and circulation problems, gynaecological problems and allergic responses. Herbal medicine is a part of many different healing systems from around the world. While herbal remedies are not commonly prescribed by Canadian physicians, they are frequently prescribed by doctors in Britain and Germany. There is currently no Canadian regulation for herbal practitioners, aside from the use of herbs by naturopaths. There does exist, however, some controversial Federal regulation of herbs using drug identification numbers (DIN), including some proposed regulation by the Health Protection Branch of Health Canada. There are several Canadian herbal colleges in British Columbia and Ontario, while herbal therapy is practiced in Alberta, British Columbia, Manitoba, Nova Scotia, Ontario, Quebec and Saskatchewan. (Sources: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997; OBCIEP 1994).

Homeopathy

Homeopathy refers to the use of highly diluted traces of botanical, mineral, animal and other natural substances to stimulate the body's self-healing abilities. Developed in the nineteenth century by German physician Samuel Christian Friedrich Hahnemann (1755-1843), homeopathy is system of "energy medicine" based on the principles of "like cures like" and "less is more." Homeopathy follows the philosophy that substances which cause symptoms in a healthy person can cure disease which causes similar symptoms in an unhealthy person, if used in a very dilute nature. The overarching homeopathic theory, as proposed by Hahnemann, is that a "vital force" is the source of all biological phenomena, that it becomes "deranged" during illness, and that appropriate homeopathic remedies restore health by restoring the "vital force." Homeopathic remedies are drawn from varied flora and fauna, including minerals and both diseased (nosodes) and healthy (sarcodes) tissues (Jan Lips, DiHom.; personal communication, 1998). Remedies are prepared through a complex process of processing (called "succession") the substance by grinding it repeatedly, and then diluting it with alcohol and/or water to various concentrations of dilute solutions. For example, a 1CH dilution will consist of 1 drop from the "mother tincture", and 99 drops of alcohol or water. This dilution would be represented as 0.01 or 1/100. Dilutions range

Appendix A –Definitions of Alternative Therapies (Continued...)

from 1X (0.1) to 1000CH (1M). Homeopathy can treat almost all disorders in the human condition, ranging from chronic to acute symptoms. Although once regulated in British Columbia, Quebec and Ontario, homeopathy is no longer regulated by any provincial or federal body. There are currently two new homeopathic schools in Winnipeg and Toronto, and many schools in other countries such as in the United States and in Britain. Homeopathy is practiced in Alberta, British Columbia, Manitoba, Ontario, Quebec and Saskatchewan. (Sources: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997; Jan Lips, DiHom, Personal Communication 1998; Panos and Heimlich 1980).

Hypnosis

Hypnosis is the process of entering a trance or meditation state and the providing of positive suggestions to one's unconscious or subconscious mind, which represents 90% of potential brainpower. Hypnosis can be used successfully to end chemical addictions and resolve psychological and physiological problems. (Source: El Paso NLP Help Centre).

Meditation

Meditation is the process of entering subtle trance to positively affect mind and body. Similar to hypnosis, although meditation can involve guided meditation from another practitioner, it usually involves the training of the mind by the individual. Meditation is found in many world-philosophies, and can be used to relieve insomnia, anxiety and promote overall healthiness.

Naturopathic Medicine

A system of medicine which involves diagnosing, treating and preventing disease without the use of drugs or surgery. It is a philosophy founded on the healing power of nature, which combines a variety of natural methods and substances to support and stimulate the body's inherent self-healing ability. Naturopathic medicine as a profession was first established in North America by Benedict Lust, a German immigrant, who established the first school of naturopathic medicine in 1905 in New York. Naturopathic medicine is regulated in British Columbia, Manitoba, Ontario and Saskatchewan. Naturopaths train for three years in allopathic medical training, and then pursue up to five years training in additional alternative therapies such as acupuncture, herbs, clinical nutrition, homeopathy and lifestyle counseling. Naturopaths can diagnose and treat acute and chronic illnesses, and recognize conditions which require allopathic treatment. Illnesses treated by naturopaths range from the common cold and flus to food sensitivities, chronic fatigue, depression, anorexia, diabetes, and HIV. British Columbia is currently the only province that provides health care funding for naturopathic treatments, while many private health care insurance companies will cover naturopathic treatment. Naturopathic medicine is practiced throughout Canada. (Source: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997).

Appendix A –Definitions of Alternative Therapies (Continued...)

Neuro Linguistic Programming (NLP)

Neuro Linguistic Programming (NLP) is the study of how language and cognition of external events affect behaviour. NLP defines how we communicate internally with ourselves and how these communications affects us. This body of knowledge offers techniques for permanently changing behaviour and producing positive results. (Source: El Paso NLP Help Centre).

Nutritional Counseling

Nutritional consultants assess nutritional imbalances and offer suggestions for improvement. Nutritional assessments takes into account the individual's intolerances, allergies, degree of exposure to environmental poisons, lifestyle, eating habits, and symptoms of nutritional imbalance. Nutritional consultants, different from regulated dieticians, make suggestions regarding a balanced approach to food, the eating of whole foods, and the use of vitamin and nutritional supplements. Benefits of proper nutrition assists the body in maintaining and building physical strength and good health, which can prevent many health problems such as insomnia, diabetes, arthritis, fatigue, digestive problems, skin problems, circulation problems, heart and kidney disease, and cancer. Nutritional consultants are not regulated in any province in Canada. There does exist, however, a national nutritional consultants' organization of Canada, and there are several nutritional schools in British Columbia and Toronto. Nutritional counseling is practiced throughout Canada. (Source: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997).

Ozone Therapy

The process of infusing Ozone into the bloodstream to hinder the development of deadly viruses such as HIV. Ozone therapy is a controversial and unregulated therapy in Canada, but with potentially curative powers.

Reiki

Reiki is a healing system which was founded in late nineteenth-century Japan by Mikao Usui (1802-1883), a Christian minister and Zen Buddhist Monk. The term "reiki" refers to both "spirit energy" and to a method in which many forms involve the "laying on of hands" on the body. Reiki healing involves the laying on of hands by the healer to transfer a "universal energy" to specific parts of the body. The healer is not transferring his or her own energy, but that of the universal energy. The energy is said to discover and fulfil the body's own requirement for healing illness, which may be physical, emotional or spiritual. Further, the reiki method involves touching parts of the body and "brushing" the body's "aura" or energy field with the hands, without the healer's direct physical touch. There are different schools of reiki, as well as different levels of training (eg. Level I, Level II). Reiki is unregulated in Canada, but there are many certificate and training programs available. (Source: Raso 1994).

Appendix A –Definitions of Alternative Therapies (Continued...)

Therapeutic Touch

Therapeutic touch, while similar to reiki in principle, does not always involve the physical laying on of hands on the body. Rather, therapeutic touch involves mainly the "brushing" of the body's "aura" or energy field, and directing energy to certain parts of the body without direct physical touch on the body. Therapeutic touch was developed in the 1980s by Delores Krieger, Ph.D., R.N. There is currently no regulation of therapeutic touch practitioners in Canada, except where nurses and other regulated practitioners are trained in the technique. There are, however, networks in Alberta and Ontario, and courses are offered in community colleges and hospitals. Therapeutic touch is practiced throughout Canada. (Sources: Alternative Health Care: The Canadian Directory, Harden and Harden, 1997; Raso 1994).

Time-Line Therapy

Time line therapy is a recent development of Tad James and Wyatt Woodsmall. It is a body of new techniques for achieving fast and long-lasting healing results. This therapy specifies that all of our memories are stored on a "time-line" in the unconscious mind, where fantasy and reality are blurred. The unconscious mind is then used to try to change the past and create a desired future, such as promotions, peaceful living, happiness and health. (Source: Time Line Therapy Institute, El Paso).

Yoga

Derived from the Hindu teachings, yoga, meaning "connection", is a general term for many different kinds of stretching, meditation and breathing exercises.

Appendix B--Consent Form

CONSENT FORM FOR PARTICIPATION IN INTERVIEWS AND RELEASE OF INFORMATION

In signing this consent form, I _____,
am aware of and agree to the following conditions:

-- I will voluntarily participate in a 30-40 minute interview given by Daniel Hollenberg concerning my experience and opinions towards my use of plural therapies as an individual suffering from serious or chronic illness.

-- I will agree to participate in the interview and research under the following conditions:

(1) I will allow the interview to be tape recorded. The purpose for this is so that the interviewer can ensure that nothing is misinterpreted and/or misconstrued. As a participant, I have the right to turn off the tape recorder at any point in the interview, and I am free to withdraw from the interview or research project at any time without consequence or penalty.

(2) I will allow Daniel Hollenberg to use the information in helping him to complete his investigation of the use of plural therapies by serious or chronic illness sufferers. The information will be incorporated into a written thesis document that will be presented as partial requirements for the Masters in Anthropology, Department of Anthropology, University of Manitoba. I understand that Daniel Hollenberg will not use my name or any directly traceable information unless I want this information released. Pseudonyms will be assigned to any proper or place names or settings which may be identified in this interview or research. This will protect my identity and ensure anonymity and confidentiality.

(3) I understand that upon request, Daniel Hollenberg will give me access to all my transcribed and/or taped materials used in the interview or research, and that I will be able to review any final information before it is presented in the final document. Quotations will not be attributed to my name without my expressed consent and review of the quotation. After reviewing the information, I have the right to discuss any areas of the interview or research which I am uncomfortable with and have the right to suggest modifications and to clarify any discrepancies.

(4) At any time throughout the course of this interview or research, I have the right to modify or add to any issues not discussed in the above-mentioned consent form. I am encouraged to ask questions now and throughout my participation in the project.

Signature _____ Researcher's Signature_____
Date _____ Date _____

Appendix C – Example of Code Notes

D-Interview #1–Theme #1: Iatrogenesis

P.3 p.1

D–They hauled me to the hospital in an ambulance...I spent the night strapped to a board of some sort (laughter)...and I don't really remember what time they–well I think it was early in the morning that they untied me from the board–and they found out that all night I had been strapped to this board, no one had ever thought to take the glass out that was still under me...and so I was strapped to this board in the panic–I guess when they were going to change shifts in the morning--the nursing staff or doctors I don't know what they were–they suddenly someone realized that I still had all this glass under me...and so I guess there was a panic to pick the glass out of me (laughter)...they untied me and turned me over and picked all this glass out...and then the next morning I guess the doctors come in and they did a bunch of tests and they x-rayed me, and then they give me a set of crutches and said "Go home!"...they said I would probably be back to work in six weeks or so...and it was considerably longer than six weeks

P.3 p.2

...and the psychiatrist–well I don't know–he give me pills and I pop pills until I–well, at that time too I had to go home and went on sick leave, and this psychiatrist give me a bunch of pills and I, ate these pills and as I ate them, you know I would sleep for three days at a time!

DH–*"So, when they released you out of the hospital and you say you were on crutches, and they diagnosed that you had some internal bleeding, did they try and prescribe anything for you in terms of drug therapy?"*

P.4 p.4

D–Oh! Yeah...well they tried all sorts–well I just hurt all over–no matter what it was–it was just–I just didn't know where to go, what to do with myself–I was just–just–
in pain–constant, continuous pain...so my doctor sent me to a specialist, and...this specialist, he give me some...anti-inflammatory...yeah, Naproxin I think is what it was...and...Oh! Jee! And I...right away I felt better I said "Well why didn't you give me this sooner?"...well...you know, I just...hadn't finished saying that...hardly...when the Naproxin started to act, and it burnt a hole in my stomach...so...now I had two sets of pains...there were three! or more! or whatever it was...and so now I had to go back to a doctor and to another set of specialists where they put a hose down my throat to take a look at my stomach to diagnose what was happening...and uh...well then they put me on the medication for ulcers...and uh...and most of this time too I'm in extreme pain with the ulcers, and the joint pains and the back pains and whatever else I had...all my...I was just hurting all over...so...as soon as that...the doctor found out that I was bleeding internally well then, then I had to stop that medication and go on another medication...well...I don't know how long that transpired or how long that I was on that but I remember it was a long time...some kind of whitish chalky tasting stuff...I don't really remember what it was...

IMAGE EVALUATION
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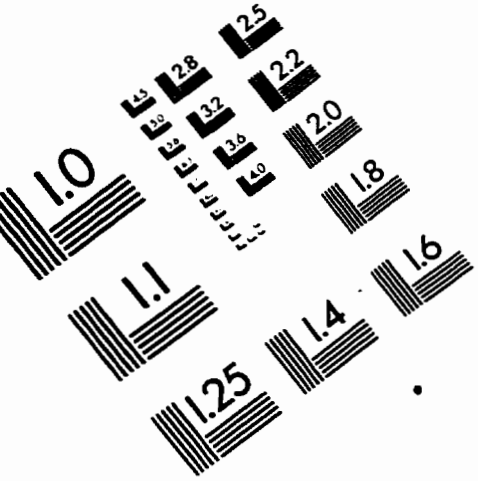

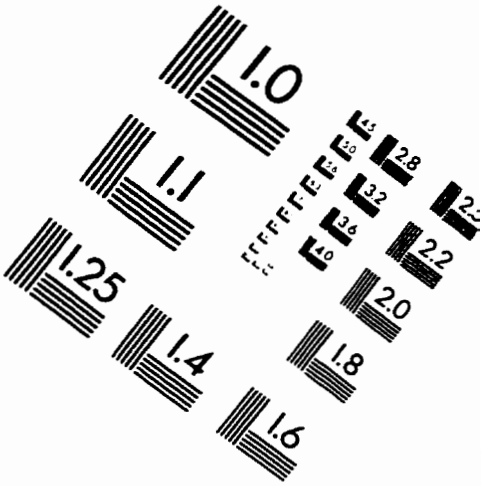

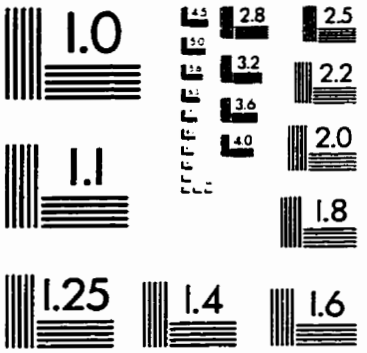

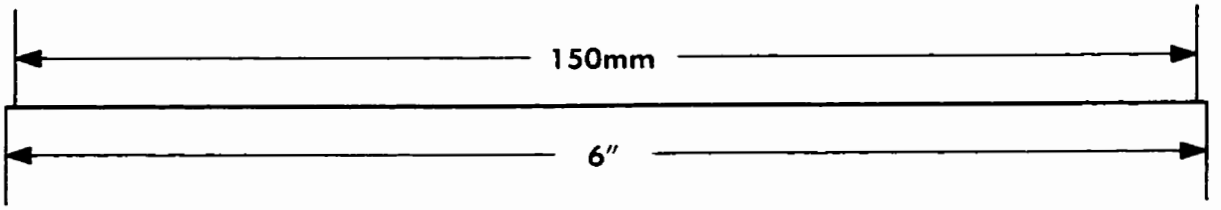

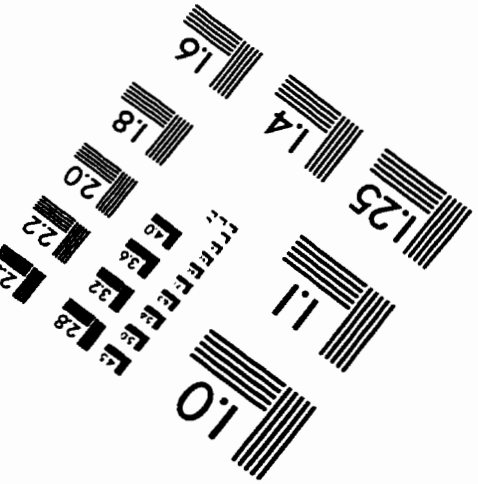

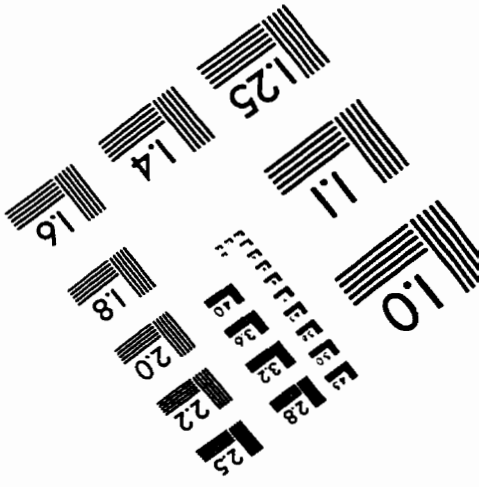

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