

**The Social and Cultural Legitimation of
Complementary and Alternative Medicine
in Cancer Care: An Ethnography**

by

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ABSTRACT

This dissertation explores the question of how the legitimacy of different approaches to healing is socially and culturally constructed. Questions about the legitimacy of what has come to be called "Complementary and Alternative Medicine" or CAM have come to the forefront of both health policy and public discourses as the popularity of these non-biomedical approaches to healing has grown. The dissertation used an ethnographic approach to explore the complex issues related to the legitimation of CAM. This interdisciplinary research focused on the field of cancer treatment since a significant proportion of cancer patients use both conventional and unconventional treatments and since treatment decisions have important consequences. Fieldwork was undertaken in the Lower Mainland area of British Columbia over a period of three years. A total of 45 in-depth individual interviews were done with 17 cancer patients, six oncologists, three nurses who specialize in cancer care, and 11 professionals involved in CAM, including practitioners of traditional Chinese medicine, naturopathy, chiropractic, healing touch, and psychospiritual counseling. Eight people participated in more than one interview. A focus group with seven cancer patients was done to supplement the interviews. Participant-observation was done in a variety of relevant settings including a committee considering how to integrate CAM with conventional medicine, a healing group for patients, and public lectures, conferences, and events. Textual material from public media was analyzed. The dissertation uses the results of the fieldwork, particularly the experiences of patients, to formulate a model that elucidates the processes whereby emerging cultural models are linked with personal experience to form situated meanings about legitimacy that take root through social practices. The dissertation argues that underneath the growing use of CAM lie important changes in the way people are thinking about the nature of the body, the nature of health and healing, and relationships between patients and health care providers. In addition, the use of CAM is associated with the adoption of epistemologies that undermine the hegemony of scientific rationality. The implications of these findings for health care policy, practice, and research are discussed.

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PREFACE

The research reported here was driven by both intellectual curiosity and personal commitment. The question of whether complementary and alternative medicine is legitimate is a hot topic in the public arena. Despite the level of public interest, there has not been a great deal of social science research regarding this complex question. When I began my PhD program I knew that the area was ripe for investigation. Through my previous work as a researcher in a variety of health care settings I was aware of some of the challenges that stood in the way of resolving the question. Through my engagement with practices such as Tai Chi and meditation, I knew that underneath the question were profound differences between conventional medicine and some of the therapies and medical systems whose legitimacy was being contested. I believed I was in an ideal position to undertake an exploration of the issues. But it was the experience of some friends that made me realize that the issues were not only of academic interest.



The phone rings. "Hello?"

"Hi Margo, this is Doreen."

Something in her voice coupled with the fact it is 9:30 on a weeknight raises a subliminal alarm bell, but I continue with the usual ritual. "Doreen. Hi. How are you?"

"Oh Margo. I'm not good." She pauses, her voice shaky. I wait, now alert for the bad news.

"Camille has had this ear infection that wouldn't go away. We took her to the doctor and they did a blood test. We found out today she's got leukemia."

Doreen is one of those rare friends who have moved into the category of family. We even refer to each other as sisters sometimes. I have known her and her husband, Ted, for many years. Camille, their only child, was born six years ago not long after Doreen had a serious case of pelvic inflammatory disease. For Ted and Doreen, Camille is a miraculous gift.

We talk for some time. I get as many of the details as I can, but there is still a lot of uncertainty.

The next day I go to the hospital, unannounced. I can't stay away. Doreen sinks into my arms when she sees me. We hang on to each other for a while, me trying to provide strength. She gives me more information about the diagnosis and the intensive chemotherapy regime that is being recommended. Camille lies curled on a cot in the room. She is quiet, still, her skin ashen.

When adults I've known have been diagnosed with cancer, there has been an air of unreality about it because they don't look or feel sick. But Camille looks sick. I can't tell whether she really is as sick as she looks or whether her state is just a reaction to the cloud of trauma and distress that surrounds her.

Ted arrives. He is agitated. His usual calm, grounded manner is completely missing. Ted and Doreen talk about the treatment regime that is being recommended. Not long ago, Ted qualified as a doctor of traditional Chinese medicine (TCM). Both he and Doreen have been involved in alternative approaches to healing such as bodywork and meditation for years.

Doreen just wants to save Camille's life. But Ted is aware of some of the side-effects of chemotherapy and knowledgeable enough about medicine to know that, even though short-term survival rates for kids with leukemia are now pretty good, the long-term effects of the strong drugs that are used are not known. He does not want to agree to chemotherapy. I can see that the conversation is only upsetting everyone, so I suggest that Ted and I go for a walk.

We leave the hospital and march into Queen Elizabeth Park. We wind our arms around each other's bodies, the way lovers do. It seems the only way to keep Ted from exploding. It's a warm, sunny day. Tourists and locals stroll through the gardens, laughing, taking pictures. But every child I see suggests loss. The bright, vibrant flowers are an insult.

"How can I let them put poison into my baby's veins?" says Ted, almost shouting. "If it was me, I wouldn't agree to chemo. I love her more than I do myself. Why would I make her submit to something that I wouldn't have?"

We talk about alternative treatments for cancer. Ted's already been on the Internet. He's talked to the TCM doctor who trained him. He's collating information about herbal remedies that help to detoxify the organs after chemo. But he doesn't want to go there. He fundamentally disagrees with the premises of the medical model. He does not see cancer the way the oncologists do. He does not want to spend the next several years at the mercy of a system he has no respect for. But he's caught.

Over the course of the next days and weeks, Ted and Doreen reached agreement about Camille's treatment: some chemotherapy, but no participation in clinical trials, so her treatment could be individualized; fewer rounds of chemo than recommended; a regime of herbal remedies and supplements to strengthen her immune system and cleanse her organs; the creation of a network of social support for Doreen and Ted; and monthly meditation sessions on Camille's behalf.

In the ensuing two years, Ted, Doreen, and Camille suffered through the ups and downs of conventional treatment and all that this entails. Camille became bloated from the prednisone. She missed a lot of school and had to avoid sports and other activities. She lost all her hair. Her classmates teased her. There were scares because of unexplained fevers and infections. And other reasons for fear—one of Camille's oncologists inadvertently gave another child an injection in the wrong site and the child died. Ted's medical expertise was dismissed by the conventional doctors and nurses. Not only did they not recognize any merit in TCM but they felt it was not appropriate for him to be treating a family member, so they refused to engage in Ted's attempts to play a role in the management of Camille's care. Ted and Doreen felt even their personhood was dismissed. They were one of "the cancer families" so the professionals kept their distance.

Today, Camille is a strong, talented girl on the verge of adolescence. She is like most other almost-teenaged girls except for the occasional sign of precocious wisdom that surfaces—the result of hardship experienced too young.

Camille Paloma Thomas, this dissertation is for you.

ACKNOWLEDGEMENTS

I would like to express my appreciation to the many people who contributed to the research on which this dissertation is based and who supported me through my PhD program. First, my profound thanks go to the individuals who participated in my fieldwork. The stories and thoughts of the people I met who used complementary and alternative treatments for cancer and the perspectives of the health professionals I interviewed are the foundation on which the dissertation rests. I hope I have been able to adequately convey the significance of the experiences and understandings with which I was entrusted.

I also want to extend my sincere gratitude to the members of my supervisory committee: Tannis MacBeth, Ken Bassett, and Simon Sutcliffe, and especially to the co-chairs of my committee: William McKellin and Joan Bottorff. Their guidance through the various stages of the PhD program, their help in identifying authors and ideas that would further the evolution of the research, and their constructive feedback on drafts of the dissertation were invaluable.

I was fortunate to have received a scholarship from the British Columbian Health Research Foundation. I am very grateful for the financial support that enabled me to focus on the research during the critical stages of my program.

Dennis Pavlich, UBC's Vice-President of External and Legal Affairs, and my colleagues at the UBC Learning Exchange have given me strong support over the past few years. They have never complained about my attention being divided between my work with them and my writing of the dissertation.

I have also received enormous support from my close friends of many years, Ted and Rosemary Cragg. The countless times they provided nourishment for both body and soul sustained me when I needed it most. Finally, my deep appreciation goes to my dear husband, Richard Piers. He listened when I needed to talk in order to find out what I was thinking and shared the celebrations of the various milestones along the way. Without his unwavering support, the dissertation would not have been done.

Chapter One

The Research Problematic: the Legitimation of Complementary and Alternative Medicine

Introduction

This dissertation explores the question of how the legitimacy of different approaches to healing is socially and culturally constructed. The dissertation focuses on the experiences of cancer patients and health professionals who are struggling to make sense of difficult issues. Questions about the legitimacy of different medical treatments have come to the forefront of both popular and academic discourses with the public's use of a variety of healing techniques, practices, and substances that exist outside the institutionalized scope of professional medicine. This diverse array of non-biomedical approaches to healing has come to be known as Complementary and Alternative Medicine or CAM. Since many of the treatments and medical systems that are being used are unknown by biomedicine and some are inconsistent with conventional medical concepts and practices, their use by patients is creating tensions within health care. For cancer patients, the situation is difficult. Their lives depend on the decisions they make about what treatments to undergo. Rarely can conventional medicine offer guarantees of treatment outcomes. Some conventional cancer treatments have side-effects that influence quality of life.

There are many CAM treatments available but relatively little research has been done about their safety or efficacy and little is known about how they interact with conventional treatments. For professionals and policy makers, too, the questions are challenging: Which of these CAM treatments are safe and effective? Should their value be assessed according to the same scientific standards biomedicine is expected to meet? If these treatments are of value, should they be incorporated into the health system?

This dissertation attempts to bring clarity to the complex issues surrounding the legitimacy of CAM by elucidating the processes by which individual patients and health care practitioners come to see different approaches to healing as legitimate. In using the word "legitimate" I am referring to the usual meanings of the word: sanctioned by law or custom; reasonable; logically correct; justifiable or justified; or conforming to established rules, standards, or principles (Guralnik 1980). The focus of the dissertation is on the ways in which individuals legitimize different cancer treatments through their engagement with cultural and social influences. The focus is not on the ways that social groups or institutions legitimize different medical approaches or practitioners, e.g., through professionalization or government regulation. The dissertation also does not attempt to answer questions about whether any particular treatment or the field of CAM in general is or is not legitimate. Rather, the research focuses on the processes whereby conceptions of legitimacy are socially and culturally constructed.

I explored the nature of these legitimization processes by investigating the experiences of people with cancer who use alternative treatments and by eliciting the perspectives of professionals who care for cancer patients, including those who are aligned with biomedicine and those who practice various CAM approaches. The

dissertation describes the results of ethnographic fieldwork undertaken in the Vancouver area which relied on qualitative interviews, participant-observation and analyses of textual material to develop an in-depth understanding of the issues raised by the convergence of different approaches to cancer treatment. The research focused on cancer because questions about medical legitimacy are highly salient in this area. A significant proportion of cancer patients use both conventional medicine and CAM. Since cancer is a potentially life-threatening disease, treatment decisions have important consequences. The research was interdisciplinary in that it combined the literature and theoretical concerns of three different disciplines: anthropology, sociology, and health policy. Relevant literature from the fields of medicine and nursing also contributed to the investigation. Integrating these disciplines has been crucial to the achievement of an understanding of the issues that is broad enough in scope to encompass all the relevant issues.

The dissertation uses the results of the fieldwork, particularly the experiences of patients, to formulate a model that describes the processes whereby legitimacy comes to be attributed to different approaches to healing through the interaction of cultural models (culturally constructed beliefs or stories about how things are) with personal experience. The model describes the important role played by social settings in the construction of legitimacy since this is where ideas about legitimacy can be tried out and either confirmed or rejected. The dissertation argues that, underneath the public's use of CAM techniques, lie important changes in the way people in Western cultures are thinking about the nature of the body and the mind, the nature of health and healing, and the kinds of relationships that patients should have with health care providers. In addition, the use

of CAM is associated with the adoption of epistemologies that undermine the hegemony of scientific rationality. The dissertation argues that the understanding of legitimization processes derived through the fieldwork provides a foundation for the clarification of the complex issues raised by the debates about CAM's legitimacy.

Overview of the Dissertation

This first chapter of the dissertation sets the stage for the exploration of the research issues by providing a guiding framework for the health care system, a description of the primary differences between biomedicine and CAM, and a summary of previous research regarding the issues raised by CAM use. In chapter 2, I draw on literature from the social sciences to outline the social and cultural aspects of the question of CAM's legitimacy.

Chapter 3 provides a detailed description of the research methods used. Chapter 4 presents in-depth portraits of the decision-making processes of six of the 17 people with cancer who participated in individual interviews. Chapter 5 focuses on the perspectives of biomedical practitioners who specialize in cancer care. Chapter 6 presents the thoughts and opinions of practitioners of a variety of healing approaches, including traditional Chinese medicine, healing touch, and psychospiritual counseling. This chapter also includes descriptions of social settings where the legitimacy of CAM techniques and ideas is being both promoted and contested. Chapter 7 provides examples from popular media, including the Internet, that show the kinds of cultural models that are being promulgated by CAM proponents as well as the contentiousness of the debate about CAM's legitimacy. The concluding chapter presents my analysis of sociocultural legitimization processes and their implications.

The Health Care Context: A Guiding Framework

Since this dissertation focuses on the socio-cultural construction of the legitimacy of Complementary and Alternative Medicine, it is important to provide a conceptual framework for the comparison of medical systems that explicitly recognizes the importance of social and cultural factors. Kleinman (1978) has outlined a model that describes the structure and functions of health care systems as cultural systems. In his elucidation of his model, Kleinman notes that medical systems are both cultural and social, i.e., they include systems of meaning and behavioural norms as well as connections between these cultural systems and particular social relationships and institutional settings.¹ Kleinman conceives of culture as mediating between the external aspects of health care (i.e., social, political, economic, historical, epidemiological, and technological factors) and its internal aspects (i.e., psychophysiological, behavioural, and communicative processes). Kleinman defines culture as a system of symbolic meanings that shapes both social reality and personal experience; it mediates between the external and the internal and thereby determines the contents of different medical systems, their effects, and the processes of change they undergo.

Kleinman (1978) identifies three social arenas within any health care system: the popular; the professional; and the folk. The popular arena is where the influence of the family, informal social networks and other community connections predominates.

Kleinman points out that in both Western and non-Western societies, between 70 and 90% of health problems are managed solely within this arena. The professional arena consists of conventional Western ("scientific") medicine as well as other healing

¹ The strength of Kleinman's model is that it emphasizes social and cultural factors. One of its weaknesses is that it does not explicitly consider political and economic factors.

traditions that have become professionalized (e.g., chiropractic and traditional Chinese medicine). The folk sector consists of non-professional healing specialists (e.g., faith healers and teachers of mind-body practices such as meditation, yoga or tai chi).

Kleinman asserts that health care systems perform several core tasks that allow individuals and groups to respond to illness. The core tasks that are most relevant to this dissertation are: the social and cultural construction of the illness experience; the social and cultural construction of strategies and evaluative criteria to guide treatment decision making; and the cognitive and communicative processes involved in attaching personal and social meanings to illness episodes. Kleinman sees the attribution of personal and social meaning to illness as a central aspect of any healing process. In fact, he and other medical anthropologists believe that the successful explanation of an illness episode alone can be seen as signifying healing, regardless of the fate of the ill person. In such situations, there is a fit between expectations, beliefs, behaviour and evaluations of outcome. Healing then, has different aspects: physiological, psychological, social, and cultural (Kleinman 1995).

While Kleinman's model includes conventional medicine and alternative medical systems in the same category of the "professional" sector, it is important, especially given the topic of this dissertation, to point out that there are significant differences between conventional biomedicine and alternative medical perspectives. Kleinman (1995) asserts that while biomedicine is a pluralistic collection of practices and practitioners, it does have defining features. For Kleinman, biomedicine includes monotheistic ontological and epistemological commitments that distinguish it from other medical systems, especially those rooted in Asian traditions. Biomedicine differs from

other medical systems in its dualistic separation of mind and body, its reductionism, its materialism and the corresponding requirement for pathogenesis to be explained by single causal chains (D Gordon 1988b; Kleinman 1995).

Several authors have attempted to describe a generalized paradigm for CAM that includes fundamental tenets that can be contrasted with those of biomedicine (e.g., Lowenberg 1989; Vincent and Furnham 1997; Goldstein 1999; Kelner and Wellman 2000). While these descriptions of the putative CAM paradigm vary, some tenets that are commonly contrasted with those of biomedicine include a holistic view of the mind–body–spirit, individualized rather than standardized treatment regimes, and an acceptance of non–scientific sources of knowledge such as textual accounts of the observations of previous generations of clinicians. While later sections of the dissertation suggest that it is overly simplistic to view CAM and biomedicine as being on opposite ends of the medical spectrum, it is important to note that there are significant differences among different medical systems. These differences underlie the complexity of the issues that are being raised with the convergence of CAM and biomedicine.

Complementary and Alternative Medicine: Definitions and Taxonomies

One of the strengths of Kleinman's model of health care as a cultural system is that it reminds us that health and illness are not just the domain of professional medicine. So far, however, professional perspectives on the public's use of CAM and the resulting issues have been the primary focus of most of the social science and medical literature. This literature will be summarized in the next sections of this chapter.

The use of non-biomedical approaches to health and healing is not new. But the public awareness and use of unconventional treatments in the last decade has been reflected in a growing academic literature related to such therapies. Since the early 1990's, researchers in the medical and social sciences have struggled to bring clarity to the field. Attention has been paid to nomenclature, definitions, and taxonomies.

Some authors have used terms such as "holistic medicine" to highlight the emphasis in some alternative therapies on the presumed unity of body, mind, and spirit. This holistic view is described as opposed to biomedicine's focus on materialistic and mechanistic conceptions of the body and disease (e.g., Lowenberg and Davis 1994; Cohen 1995). Descriptors used by authors who contrast alternative therapies with the biomedical status quo have included "unorthodox," "unconventional," or "non-proven" (e.g., Northcott 1994; Sheard 1994; Risberg et al. 1998). While some authors have made a distinction between alternative therapies (i.e., therapies used *instead of* conventional medicine) and complementary therapies (i.e., therapies used *in combination with* conventional medicine) (e.g., Kaegi 1998), the validity of this distinction was called into question by research that revealed that only a small minority of patients (approximately 5%) use alternative therapies to the exclusion of conventional medicine (Eisenberg et al. 1998; Astin 1998).

With the establishment of the U.S. National Institute of Health's Office of Complementary and Alternative Medicine and its subsequent elevation to the status of an independent Center in 1998, the term "complementary and alternative medicine" or simply "CAM" has become widely used (Cohen 2000; Baer 2002; Pizzorno 2002), although some authors continue to use terms such as alternative medicine (e.g., Burstein

et al. 1999) or unconventional therapies (e.g., Fitch et al. 1999). Proponents of complementary and alternative approaches have begun using the term “integrative medicine” (Best 1998; Baer 2002) or “integrative health care” (e.g., Cohen 2000; Tataryn and Verhoef 2001). These terms explicitly signal the desire to bring complementary and alternative therapies into the biomedical mainstream. As is obvious with the term “integrative medicine,” the name used to refer to non-biomedical therapies often reveals a particular position with respect to the legitimacy of these therapies.²

Just as there have been differences in nomenclature, there have been differences in the way complementary and alternative medicine is defined. For the purposes of their surveys, Eisenberg et al. (1993 and 1998) operationalized “alternative therapies” as interventions that are not widely taught in medical schools and not generally available in U.S. hospitals. Other authors have used minor variations of this definition (e.g., Chez and Jonas 1997; Crellin et al. 1997). The strength of this definition is that it clearly indicates that the dividing line has been drawn according to what is considered acceptable within the medical mainstream. However, this definition has weaknesses. First, it encompasses a heterogeneous collection of techniques and medical systems (e.g., chiropractic, homeopathy, traditional Chinese medicine [TCM], massage, meditation, biofeedback, spiritual healing, and macrobiotics) whose only shared characteristic is that they lie outside the mainstream. Second, this definition obscures the reality that some alternative therapies are more acceptable than others. For example, although chiropractic and massage are generally included in the category of alternative medicine, they have already

² In the dissertation I will usually use the term “complementary and alternative medicine” or “CAM.” I do so because both the academic and popular discourses have coalesced around this term and it is now the most widely used. My own position with respect to the issues surrounding CAM is outlined in chapter 3.

been integrated into conventional health care systems to varying degrees, e.g., through the creation of professional colleges and/or coverage by private insurance companies.³ Third, the boundaries established by the definition are not stable: the majority of U.S. medical schools now offer courses in alternative medicine (Wetzel et al. 1998), some hospitals are creating complementary and integrated medicine programs (Jonas 1998), and some health insurers offer benefits packages that include CAM practitioners and services (Pelletier et al. 1997).

The Office of Alternative Medicine in the U.S. National Institutes of Health has defined CAM in a more abstract way that explicitly acknowledges the fact that the definition of CAM is context-dependent and that the term is perhaps inherently ambiguous:

Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities and practices and their accompanying beliefs, other than those intrinsic to the politically dominant health systems of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed (NIH 1997 cited in de Bruyn 2001:II.18).

The conceptual ambiguity in the academic discourse about complementary and alternative medicine can also be seen in the variety of attempts that have been made to develop taxonomies of alternative therapies. "CAM" comprises a wide variety of substances, techniques, and medical systems. Table 1 presents a summary of five different taxonomies that reflect a range of perspectives. The latest version of the U.S. National Center for Complementary and Alternative Medicine's taxonomy puts CAM

³ British Columbia has professional colleges for massage therapists, chiropractors, naturopaths, and traditional Chinese medicine practitioners. Some private extended medical plans provide full or partial

into five categories (<http://nccam.nih.gov/health/whatiscam/#4>; accessed May 2003).

This categorization is based on the external characteristics of different CAM techniques. Other biomedically-oriented taxonomies that have been proposed use similar criteria for categorization but differ in the way specific therapies are grouped (e.g., Yates et al. 1993; Northcott 1994).

As Table 1 shows, some other taxonomies use very different criteria as a basis for categorizing CAM. For example, Joseph Pizzorno, the former President of Bastyr University (which trains naturopaths) categorizes CAM according to practitioners' degree of legitimacy. As a proponent of CAM, Pizzorno sees the inclusion of the last two categories of practitioners (minimally educated practitioners and medical mavericks) within CAM as problematic (Pizzorno 2002).

Tataryn (in Tataryn and Verhoef 2001) proposes a system that includes both conventional medicine and CAM and categorizes therapies on more theoretical grounds, i.e., their underlying assumptions about the nature of health and disease. While Tataryn's theoretical focus is potentially more coherent than those based on external characteristics of therapies or practitioners, all these taxonomies fail to satisfactorily make unambiguous distinctions among types of therapies or ontological assumptions.

Another attempt to include both conventional medicine and CAM in the same conceptual framework uses a model developed by Ken Wilber. This model has been used to map a variety of phenomena according to their placement on a grid formed by two opposing axes: the individual vs. the collective and the interior vs. the exterior (Wilber 1995; 1998; 2000). Astin and Astin offer this model as a "powerful heuristic tool for conceptualizing health and illness, investigating the efficacy of different treatment

reimbursement for some or all of these CAM services.

modalities, exploring the multifactorial nature of disease, and informing research methodology and medical education” (Astin and Astin 2002:74). While this model provides a map that is holistic and comprehensive, Astin and Astin fail to include an aspect of the model that Wilber considers crucial, i.e., that the map not only has horizontal dimensions but vertical ones as well. Wilber’s integrative models all include a developmental or evolutionary aspect, usually portrayed as movement from the centre of the grid outwards or from the bottom upwards (e.g., Wilber 1995; 1998; 2000).

In contrast, Larry Dossey’s model of three eras in medicine clearly includes an assumption of evolutionary change. This model, too, applies to both conventional medicine and CAM. It is similar to Tatarzyn’s model in that it is based on underlying ontological assumptions. Dossey describes public and professional interest in CAM as evidence of an evolution of consciousness and the dawn of a new era in healing (Dossey 1999).

These taxonomies shed some light on the range and diversity of healing approaches subsumed under the CAM label and reflect the variation in the ways different authors are thinking about CAM. Four of the five taxonomies in the table were developed by authors who are at least sympathetic to CAM, if not outright advocates of alternative approaches to healing. The last three models use less instrumental, more theoretical criteria as the basis for their models than the more biomedically-oriented taxonomies. While a taxonomy based on fundamental qualities such as ontology or epistemology is likely to be more robust than more superficial models, it is unfortunately the case that none of these taxonomies has so far managed to bring significant conceptual clarity to research or theory related to CAM.

Table 2: Taxonomies of CAM

Source	NCCAM 2003	Pizzorno 2002	Tataryn 2001	Astin & Astin 2002	Dossey 1999
Criteria for classification	External characteristics of techniques	Legitimacy within CAM	Assumptions regarding the nature of health and disease	Individual vs. Collective and Interior vs. Exterior	Historical evolution of medicine (and consciousness)
Categories	<ol style="list-style-type: none"> 1. Alternative medical systems (e.g., homeopathy, TCM, Ayurveda) 2. Mind-body interventions (e.g., meditation, prayer) 3. Biologically-based therapies (e.g., herbal remedies, dietary supplements) 4. Manipulative and body-based therapies (e.g., chiropractic, massage) 5. Energy therapies (e.g., Biofield therapies such as Qi Gong, Reiki, Therapeutic Touch and Bioelectromagnetic-based therapies that manipulate electromagnetic fields, e.g., using magnets) 	<ol style="list-style-type: none"> 1. Professional practitioners with a cohesive healing philosophy, practice standards, accredited education, licensure or registration (e.g., naturopathy, chiropractic, acupuncture) 2. Holistic medical doctors, with conventional training and varying degrees of competency in CAM 3. Traditional healers (e.g., Native American healers) 4. Lay practitioners in emerging professions (e.g., lay homeopaths and herbalists) 5. Self-proclaimed or minimally educated practitioners without apparent standards or oversight 6. Medical mavericks who are conventionally trained but use controversial therapies 	<ol style="list-style-type: none"> 1. Body: Substances (e.g., dietary supplements, extracts, and synthetic drugs) and physical manipulation (e.g., massage, chiropractic, surgery) 2. Body-Mind: (e.g., counselling, hypnosis, meditation, support groups, psychotherapy) 3. Body-Energy: (e.g., acupuncture, TCM, Ayurveda, Homeopathy, Magnetic therapy, Reiki, Therapeutic Touch) 4. Body-Spirit (e.g., faith healing, prayer, First Nations traditions) 	<ol style="list-style-type: none"> 1. Upper right quadrant: exterior-individual (e.g., radiation, chemotherapy, dietary changes, herbal remedies) 2. Upper Left quadrant: interior-individual (e.g., meditation, imagery, support groups) 3. Lower Right quadrant: exterior-collective (e.g., supportive social structures) 4. Lower Left quadrant: interior-collective (e.g., consideration of cultural beliefs) 	<ol style="list-style-type: none"> 1. Era I Medicine: scientific, mechanical medicine: organism is a mindless machine; started in mid-1800s 2. Era II Medicine: Mind-body or psychosomatic medicine: consciousness affects the body but mind is located in the brain; started in 1950s 3. Era III Medicine: Non-local medicine: consciousness is fundamental, not located in brain or body; consciousness can heal.

CAM Use and Responses to its Use

The Increasing Use of Complementary and Alternative Medicine

Although conceptualizations of CAM remain somewhat ambiguous, the trend towards increased use of these therapies is clear (Jonas 2000). However, the exact extent of utilization is proving to be difficult to determine. Different surveys include different techniques and approaches in their definition of CAM; use different methods to collect data; measure use over different time periods; and hence derive different estimates of prevalence.

Studies done in the U.S. showed a 25% increase in the use of complementary and alternative medicine between 1990 and 1997 (Eisenberg et al. 1993; Eisenberg et al. 1998). Almost 32% of respondents in the 1997 survey who were seeing a medical doctor for a principal medical condition (e.g., back problems, arthritis, or allergies) also used an alternative therapy in the previous year. The therapies used most commonly were chiropractic, relaxation therapies, and massage. The greatest increases in use occurred in herbal medicine, massage, megavitamins, self-help groups, folk remedies, energy healing, and homeopathy. For adults aged 35 to 49, one of every two persons used at least one alternative therapy. Utilization was more common among women, those with some college education, those with higher incomes, and people living in the West. The study's authors estimated that Americans spent \$21.2 billion in 1997 on visits to alternative practitioners, a 45% increase since 1990. This amount exceeded the out-of-pocket expenditures for all U.S. hospitalizations (Eisenberg et al. 1998).

The same survey also revealed that a substantial portion of alternative therapy use occurs without input from either a conventional or an alternative practitioner. Among

respondents who had a medical doctor and used one or more alternative therapies, only 38.5% of the therapies were discussed with the respondent's doctor. This finding was unchanged since the 1990 survey. In addition, most use of alternative therapies occurred without the supervision of an alternative practitioner. The exceptions were therapies that require a practitioner's intervention, i.e., massage, chiropractic, hypnosis, biofeedback, and acupuncture (Eisenberg et al. 1998).

Canadians are also showing increasing interest in alternative therapies, although national surveys have yielded inconsistent estimates of utilization. A 1997 CTV/Angus Reid survey found that 42% of all adult Canadians had tried complementary therapies (CTV/Angus Reid 1997). National Population Health Surveys have found that the use of the services of an alternative medicine practitioner among Canadian adults has increased, from 15% in 1994/95, to 16% in 1996/97, to 17% in 1998/99 (Millar 2001). The smaller utilization rate in the second survey may be attributable to the more limited time frame for utilization and to the fact that interactions with a practitioner were measured rather than use of a therapy alone. While the estimates of the extent of utilization differ between the two surveys, the surveys indicate that the proportion of users is higher in western Canada than in other regions and that the rate of use is higher among women and among those with more education (CTV/Angus Reid 1997; Millar 2001). This demographic profile of CAM users is consistent with findings from the U.S. surveys noted above as well as other studies (Balneaves et al. 1999).

It has been estimated that in 1996-97 a total of \$3.8 billion was spent on CAM health care in Canada, with \$1.8 billion being spent on alternative therapies, \$937 million being spent on herbs and vitamins, \$104 million on special diet programs, and more than

\$998 million on books, classes and equipment (York University Centre for Health Studies 1999 cited in de Bruyn 2001).

North America is not the only jurisdiction where biomedicine and CAM are converging. The growth in alternative therapies is also occurring in Australia, the United Kingdom and other parts of Europe (Kelner and Wellman, 1997; Hoey, 1998).

Cancer Patients' Use of CAM

Cancer patients have been using "unconventional" treatments ever since medical orthodoxy coalesced around the ideas and practices of scientific medicine in the early part of the 20th Century (Patterson 1987). Estimates of the proportion of cancer patients who currently use alternative therapies vary widely. One systematic review of studies of the prevalence of complementary and alternative medicine use among cancer patients found the percentage of adult users in thirteen different countries varied from 7% to 64%, with an average rate of 31.4%. The use among pediatric patients in the U.S. varied from 9% to 16% (Ernst and Cassileth 1998). A more recent review of studies of CAM use by cancer patients (Sparber and Wootton 2001) reported a range between 25 and 83%. The highest level of use was reported among patients attending outpatient clinics at a comprehensive cancer treatment centre. In this sample, the most popular therapies were spiritual practices (used by 81%), vitamins and herbs (used by 63%), and movement and physical therapies (59%) (Richardson et al. 2000). Similarly high rates of CAM use were reported among U.S. cancer patients by Bernstein and Grasso (2001). However, a survey of a random sample of early stage breast cancer patients found a lower rate of CAM use of 38.7% (Burstein et al. 1999).

In Canada, a survey of parents of pediatric patients diagnosed with cancer in British Columbia between 1969 and 1995 found that 42% of the patients had used alternative and complementary therapies (Fernandez et al. 1998). A recent survey of a random sample of breast cancer survivors in Ontario found that 67% of women used CAM. Thirty-nine percent of respondents in this survey visited a CAM practitioner (e.g., chiropractors, herbalists, acupuncturists, TCM practitioners and/or naturopaths), while 62% reported using CAM products such as vitamin/mineral supplements, herbs, green tea, special foods or Essiac (Boon et al. 2000). A different survey of a convenience sample of Canadian women with breast cancer also found a rate of CAM use of 67%, with meditation/relaxation therapies, vitamins/tonics, and spiritual/faith healing being the most frequently-used therapies (Balneaves et al. 1999).

Patients' Reasons for Using CAM

Previous studies have identified a variety of motives underlying CAM use. Some people who use CAM are simply making pragmatic decisions to try whatever treatment might work, but others are adopting ways of thinking about health and healing that are contrary to conventional biomedical conceptions (O'Connor 1994; Furnham and Beard 1995; Furnham 1996; Gray et al. 1997; Kelner and Wellman 1997; Astin 1998).

Some studies of cancer patients have suggested that CAM use is associated with a desire to exercise control, including playing an active role in making decisions about treatment (Yates et al. 1993; Montbriand 1995b; Ashbury et al. 1997; Balneaves et al. 1999; Truant and Bottorff 1999; Boon et al. 2000). Other authors have found that cancer patients use alternative therapies because they believe that their cancer could have been

prevented and therefore can be reversed (e.g., through diet), because they are dissatisfied with conventional practitioners and health care systems, or they want to use non-toxic treatment regimes (Cassileth et al. 1984). Encouragement from others has also been associated with use of alternative therapies by cancer patients (Yates et al. 1993).

Some Canadian research provides additional insight into cancer patients' experiences with the use of alternative therapies. Gray et al. (1997) interviewed 32 cancer patients who had purchased "A Guide to Unconventional Cancer Therapies" published by the Ontario Breast Cancer Information Exchange Project (1994). Most respondents had used at least one alternative therapy with an average of four therapies per respondent. The therapies used most commonly were vitamins and minerals, meditation, visualization or psychotherapy, support groups, and specific substances such as Essiac, shark cartilage, echinacea, green tea, or 714-X. Many respondents had been interested in alternative therapies before their diagnosis and their interest typically peaked as their conventional treatment was ending and they were struggling with questions about how to live after treatment. The researchers' definition of unconventional therapy as any activity falling outside the mainstream was not compatible with some respondents' perspectives. Rather than perceiving their efforts to promote their own health as "using an unconventional therapy," some respondents saw these efforts as being just good common sense.

Gray et al. (1997) refute Cassileth and Chapman's (1996) claim that patients' interest in alternative therapies is fuelled by a societal trend away from science and reason and that such interest is indicative of magical thinking which falls into the same category as belief in angels and UFOs.

We saw little evidence of such woolly-headedness during our interviews. What we did see was a willingness to draw on personal and shared

experiences as legitimate sources of knowledge. Although many respondents decried the lack of solid scientific evidence about unconventional therapies, this did not stop them from considering other forms of evidence. (Respondents) were perplexed and disturbed because health care professionals seemed to be interested only in the results of randomized clinical trials (1997:168).

The Biomedical Response: Reluctance to Engage with CAM

Several studies have found that the majority of patients do not discuss their use of CAM with their conventional physicians (Eisenberg et al. 1998; Richardson et al. 2000; Boon et al. 2000). A review of studies of the practices and beliefs of conventional physicians with regard to five prominent CAM therapies (acupuncture, chiropractic, homeopathy, herbal medicine and massage) identified a wide range of physician response to CAM, with the regional popularity of CAM being the primary indicator of physicians' incorporation of CAM (Astin et al. 1998). While some studies indicate that physicians express interest in learning about CAM (e.g., Verhoef and Sutherland 1995; Gray and Fitch et al. 1997), others suggest that conventional practitioners, especially those who treat cancer, are reluctant to discuss CAM use with patients (Cassileth and Chapman 1996; Ashbury et al. 1997; Gray et al. 1997; Fitch et al. 1999; Gray et al. 1998).

The cancer patients interviewed by Gray et al. (1997) confirmed the view that physicians are reluctant to discuss CAM. These patients believed that physicians, especially oncologists, do not have much interest in alternative therapies. Some patients offered stories of seemingly remarkable recoveries from cancer and other conditions that their physicians had been unwilling to acknowledge as related to the use of alternative therapies. This finding is curious in light of the results of interviews with physicians done by the same research team that found stories to be powerful sources of knowledge for

physicians. The Canadian physicians interviewed by Gray and Fitch et al. (1997) said they wanted to avoid engaging patients in conversations about alternative therapies because of their concerns about the limited time available for patient contact, their sense that this topic was outside their expertise, and their belief that alternative therapies are not credible enough to warrant serious consideration: Gray and Fitch et al. observed that a substantial proportion of their physician respondents told stories of patients who experienced catastrophic consequences after using alternative therapies. These stories seemed to have a profound impact, often affecting the physicians' perceptions of the entire field of alternative medicine. The authors of the study raise an interesting point.

We cannot help but wonder about the power of the "anecdotal", not just for patients pursuing the unconventional, but for physicians opposed to it. When research evidence shows that a minority of patients use unconventional therapies in isolation from conventional therapies and that most of the popular therapies are relatively non-toxic, it raises the possibility that anecdotal evidence has influenced physician perceptions of danger beyond what is realistic (Gray and Fitch et al. 1997:20).

Several authors have pointed out the ethical dilemmas posed by patients' use of CAM given the need for conventional practitioners to help patients make informed choices regarding treatment and avoid harmful treatments (Chez and Jonas 1997; Eisenberg 1997; Sugarman and Burk 1998; Verhoef et al. 1999). The dilemmas are challenging. For example, on the one hand, conventional practitioners may be held liable for poor treatment outcomes if they have supported patients' use of CAM therapies (Verhoef et al. 1999). On the other hand, Cohen (2000) raises the spectre that conventional physicians may one day be sued for *failing* to provide patients with comprehensive information about CAM treatment options if CAM becomes integrated into the health care system. These ethical concerns as well as concerns about the quality

of the doctor–patient relationship have led to numerous calls for physicians and other conventional health care practitioners to discuss CAM use with patients in an open, non-judgmental way (e.g., Eisenberg 1997; Gray et al. 1998; Verhoef et al. 1999; Truant and McKenzie 1999; Burstein 2000; Tasaki et al. 2002).

The Biomedical Response: The Call for Evidence

The use of CAM and the issues it raises for the biomedical mainstream have also resulted in calls for research to determine the safety and efficacy of CAM treatments (e.g., Fontanera and Lundberg 1998; Verhoef et al. 1999). Critics of CAM demand that these therapies meet the standards of evidence purportedly used in biomedicine (e.g., Beyerstein 1997; Tannock and Warr 1998). Such critics also want the mechanisms of action underlying CAM to be comprehensible according to conventional scientific reasoning (Beyerstein 1997).

These calls for CAM's legitimacy to be assessed by scientific research come at the same time as conventional medicine is being challenged to make its practices more evidence-based (Willis 1999; Tatarzyn and Verhoef 2001). The fact that the majority of biomedical treatments have not been evaluated using the putative gold standard of science, the randomized controlled trial (RCT) (Gordon 1996; Vincent and Furnham 1997; Bower 1998; Tatarzyn and Verhoef 2001) coupled with the poor quality of much conventional medical science (Vincent and Furnham 1997) has prompted some to point out that a double standard is being applied. Dr. Iain Chalmers, the Director of the U.K. Cochrane Centre⁴ has stated,

⁴ The Cochrane Collaboration is an international effort to produce, maintain, and disseminate systematic reviews on all topics in health care. Two major products are a database of systematic reviews and a registry

These double standards might be acceptable if orthodox medicine was based solely on practices which had been shown to do more good than harm, and if the mechanisms through which their beneficial elements had their effects were understood, but neither of these conditions apply (Bower 1998).

There are methodological difficulties that present obstacles to the evolution of evidence-based medicine, whether conventional or alternative (Tataryn and Verhoef 2001). For example, some alternative treatments (e.g., acupuncture or massage) and some conventional treatments (e.g., surgery) are not amenable to being tested under blinded conditions (Kelner and Wellman 2000). In addition, the choice of appropriate control conditions can be problematic. For example, the choice of an inactive control condition is difficult when the mechanism of action of the test therapy is not well understood (Margolin et al. 1998). For CAM treatments whose mechanisms of action do not fit within conventional ways of thinking (e.g., homeopathy or the various forms of “energy medicine”), this aspect of designing randomized controlled trials is especially difficult (Vincent and Furnham 1997). The situation is even more complicated for CAM treatments where the diagnosis and treatment are highly specific to each patient (e.g., TCM and Ayurveda) and where treatments consist of combinations of different substances or techniques (e.g., TCM herbal prescriptions usually contain 5–10 ingredients) (Kelner and Wellman 2000). Some authors argue that RCTs do not provide an adequate test of approaches like TCM because attempts to standardize treatments or isolate active ingredients violate the principles of the medical system and hence do not test the system as it is practiced (Eskinaze 1998; Eastman 1998). These difficulties have prompted recommendations to develop innovative ways to adapt conventional research designs so they do justice to the assumptions and characteristics of CAM (Hilsden and

of controlled trials. To meet increasing demands for evidence-based complementary medicine, the

Verhoef 1999) and to use qualitative research methods to explore important issues besides efficacy (e.g., the meaning patients give to treatments and the outcomes patients consider important) (Hilsden et al. 2002).

The methodological challenges in CAM research, in combination with the small amount of funding available for CAM research (Ernst 2000) and the marginal status of CAM research (Vincent and Furnham 1997), have limited the development of a body of knowledge regarding CAM treatments. Nevertheless, as of 1998, the Cochrane Collaboration had identified more than 3500 RCTs related to alternative medicine (Ezzo et al. 1998). Despite this body of research, a recent review of the evidence base for CAM concluded that except for the proven benefit of several herbal remedies, the “jury is still out” on CAM (Ernst 2000). Similarly, Furnham and Vincent conclude that there is “very little or no good evidence . . . available for the therapeutic success of CAM” (2000:61). Further, a recent survey of studies focusing specifically on CAM therapies for breast cancer found a lack of evidence for the efficacy of CAM therapies (Jacobson et al. 2000).

The methodological difficulties inherent in CAM research and the apparent lack of demonstrated efficacy reinforce the view that CAM’s scientific legitimacy has yet to be proven. In this time of abundant rhetoric about evidence-based medicine, this might suggest that CAM’s position is tenuous. However, there are some who are questioning the push to evidence-based medicine, whether it applies to CAM or conventional medicine. For example, there is evidence that conventional physicians do not practice according to the findings of science even when these are available (D Gordon 1988a; Tatarzyn and Verhoef 2001). Further, there are those within biomedicine who question the epistemological foundations of the RCT as well as pointing out the ethical and practical

Cochrane Collaboration established a complementary medicine field in 1996 (Ezzo et al. 1998).

flaws inherent in this “gold standard” of research (e.g., Herman 1995). In addition, as different RCTs produce ambiguous or even contradictory results, the question has been raised as to whether evidence-based medicine simply replaces the judgments of skilled clinicians with those of expert epidemiologists (Goodman 2002).

In this atmosphere of controversy about evidence-based medicine, instead of CAM's position being weak, the field is gaining momentum. CAM textbooks aimed at physicians are being published (e.g., Jonas and Levin 1999; Kirkaldy-Willis and Swartz 2001), as are handbooks describing how to integrate CAM into biomedical health care settings (e.g., Faass 2001) and advice for physicians about the legal and ethical implications of integrative health care (Cohen 2000). At least for some in the biomedical mainstream, pragmatism seems to be overtaking concerns about evidence. As one oncologist wrote in a recent editorial comment,

Today the academic medical world in general and the academic field of oncology in particular are in a rather remarkable position where forces in society are demanding that alternative/complementary medicine be investigated and certain interventions be incorporated into standard medical practice. . . . What is increasingly certain is that individuals and groups who claim the benefits of a large number of alternative/complementary interventions in cancer management cannot be ignored (Markman 2001:52).

The CAM Response: The Call for Integration

As noted previously, the use of CAM by the public has prompted calls for CAM to be integrated into conventional medicine. These calls have come from proponents of CAM (e.g., Gordon 1997; Weil 1995) as well as from practitioners and researchers whose allegiances are less obvious (e.g., Advisory Group on Complementary and Alternative Health Care 2001). Discussions of what integration should look like have begun to appear in the literature (e.g., Advisory Group on Complementary and Alternative Health

Care 2001; Tataryn and Verhoef 2001; Faas 2001) as have discussions of some of the pitfalls of integration.

Jonas (1998) provides a historical perspective on previous processes whereby unorthodox therapies have become “integrated.” First, orthodox medicine denounces unorthodox therapies, labeling them unscientific. However, when these therapies persist despite these attacks, orthodox medicine becomes more accepting of these other approaches, identifying their similarities with orthodox practices and incorporating them into the conventional practice of medicine. This process is not always beneficial for those who become integrated. In their attempts to gain legitimacy, practitioners often find their scopes of practice limited, their practice brought under the oversight of medical doctors, and their ideologies medicalized. This kind of co-optation has occurred with acupuncture (Berliner 1984) and with midwifery (Bourgeault and Fynes 1997). The integration of CAM could also mean the loss of some of its philosophical tenets such as the emphasis on self-healing (Jonas 1998).

Despite these potential pitfalls, the “CAM Industry” is gaining ground (Goldstein 1999; Faas 2001). As Weeks (2001) notes, some of the proponents of integration are former biomedical physicians and administrators whose personal interest in CAM has prompted changes in their professional lives. Such leaders are being characterized as “culturally bilingual” or “hybrid” professionals. These leaders are pushing for integration even though initial attempts to integrate CAM have encountered difficulties related to the convergence of disparate paradigms (Weeks 2001). The push for integration, especially in jurisdictions where private health care is a strong economic force, such as the U.S., is

being driven by the economic opportunities arising from the public's interest in CAM (Weeks 2001).

The studies cited in this chapter indicate that public interest in CAM approaches to healing is significant. Some of these approaches are fundamentally different from biomedicine, especially those that originate in non-Western cultures. While patients' use of CAM is growing and CAM proponents are advocating for the integration of these treatments into health care, conventional medicine is responding with caution. The question of whether CAM treatments are legitimate, i.e., whether they are reasonable, whether their use is justified, and whether they conform to accepted standards, has important implications both for individuals and for Canadian society. In order to bring clarity to the issues raised by the convergence of conventional medicine and the variety of healing approaches labeled as CAM, this dissertation focuses on the ways that individuals legitimize different approaches to healing through their engagement with cultural and social forces. In the next chapter I discuss the sociocultural context surrounding questions about CAM's legitimacy and identify the perspectives from the social sciences that have guided my research.

Chapter Two

Social and Cultural Aspects of CAM's Legitimation

Introduction

This chapter describes the social and cultural changes that have been identified as being associated with the presence of Complementary and Alternative Medicine (CAM) in Western society. The perspective on CAM offered by the social sciences illuminates the historical and political aspects of shifts that occur in medical legitimacy. While the current level of public interest in CAM might be new, the authors whose work is cited in this chapter show that the contestation of the legitimacy of different approaches to healing is not. In addition to elucidating the cultural and social dimensions of questions about medical legitimacy, the social sciences also provide useful conceptual lenses through which processes of cultural and social legitimation can be understood. This chapter describes the concepts from anthropology and sociology that have been used as conceptual reference points throughout the dissertation.

Sociocultural Forces Associated with Interest in CAM

It is useful to consider the current academic and public interest in CAM in light of the history of medicine. Starr's (1982) analysis of the evolution of medicine in the U.S. shows that the boundaries between orthodox and unorthodox medicine have shifted significantly at various times. The publication of the Flexner Report in the U.S. in the early part of the 20th Century resulted in a coalescing of medical power and influence around the emerging concepts of scientific medicine. This report brought about changes in medical education as well as creating new connections between medical science and clinical practice. Biomedicine became the norm while competing medical practices such as homeopathy and chiropractic became marginalized. Generally, such shifts in medical power are associated with several factors, including the development of new knowledge, changing attitudes and customs within medical circles, processes of professionalization, larger social and economic changes, and the use of strategies such as political lobbying and legal prosecution aimed at establishing and maintaining the dominance of one school of thought over others (Starr 1982). Saks (1992) describes similar shifts in medical orthodoxy in Britain.

A detailed analysis of the history of medicine in Canada has not been published, but one description of the state of medicine in Ontario in the last half of the 19th Century shows that medical pluralism was as prevalent in Canada during the Victorian period as it was in the U.S. (Connor 1997). However, there were subtle but significant differences between the medical cultures in the two countries. The rivalries among schools, practitioners, and sects did not reach the extremes in Ontario that were reached in the U.S. (Connor 1997). These historical perspectives are important for two reasons: they

point out that competition among different medical approaches for legitimacy is an ongoing phenomenon and that, although the current situation with respect to CAM in Canada may be similar to the situation in the U.S., it would be a mistake to assume that no significant sociocultural or political differences exist.

Even though biomedicine has enjoyed a hegemonic position in North America since the beginning of the last century, some authors contend that, at the present historical moment, Western biomedicine is in crisis. They observe that while biomedicine itself moved from the fringe to the centre in the early part of the 20th Century, its power is now in decline (Bakx 1991; Coburn and Willis 2000).

Criticisms that threaten the hegemony of biomedicine come from several sources. A “medicalization critique” emerged from the liberal humanist and Marxist perspectives of the 1960s and 1970s (Lupton 1997). Early critics of scientific medicine argued that medicine had gradually accrued the power to define and regulate crucial aspects of social life and thus had become an agent of social control (e.g., Friedson 1970; Zola 1972; Foucault 1973). In addition, it was asserted that, rather than contributing to improved health in the population, modern medicine had undermined it by creating iatrogenic illnesses and by disempowering patients (Illich 1976). Further, the credibility of the medical profession was challenged in the 1970s by evidence that very little of the long-term health gains of populations was due to clinical medicine, that many tests and procedures were not necessary or beneficial, and that medical practices varied widely for reasons unrelated to clinical factors (Light 2000).

Biomedicine has also been criticized for focusing on physical disease to the exclusion of important social and cultural factors such as the meaning of the illness

episode to the patient and its effect on social relationships (e.g., Kleinman 1980 and 1995; Good 1994). Some authors argue that the combination of these problems has resulted in a loss of trust in the medical profession (Williams and Calnan 1996; DelVecchio Good and Good 2000).

Other authors note that biomedicine has been weakened by its failure to achieve the advances it has promised. For example, Bakx (1991) states, "Biomedicine has become hoisted on the petard of its own propaganda" (31). The lack of progress in "the war on cancer" after thirty years of effort is especially noteworthy. A report by Bailar and Gornik (1997) on cancer mortality in the U.S. in the period from 1970 through 1994 concluded that, while intense research efforts had brought about some benefits (e.g., improved outlooks for children and young adults with cancer, better treatment for Hodgkin's disease, more effective palliation of some advanced cancers, and a better understanding of cancer which has contributed to improved care for other diseases like HIV), the impact of this research on overall cancer mortality has been disappointing.

Some authors attribute increasing public scepticism about biomedicine to the influence of postmodernism and its criticisms of modernity in general and the institutions of science and medicine in particular (Bakx 1991; Williams and Calnan 1996; Coburn and Willis 2000). It has been noted, however, that despite being disillusioned, the public (somewhat paradoxically) continues to remain hopeful about the next scientific discovery (Crawford 1980; Bakx 1991; Lupton 1994; Fox 2000).

The decline in biomedical hegemony has also been attributed to large-scale social changes, including globalization, corporatization, the rise of neo-conservatism and attacks on the welfare state (Coburn and Willis 2000). This social context provides fertile

ground for competing medical approaches: knowledge about medical systems from other cultures is now widely distributed; big corporations have begun promoting alternative health products; and discourses around individual responsibility for health and consumer choice are prominent (Goldstein 1999).

The public interest in complementary and alternative medicine is seen by some as a social movement (Salmon 1984; Lowenberg 1989; Johnston et al. 1994; Crellin et al. 1997; Willis 1999). The CAM movement has been linked with other social movements of the last four decades, including the counterculture of the sixties, feminism, the peace movement and the environmental movement (Salmon 1984; Lowenberg 1989; MacCormack 1991; Johnston et al. 1994; Scheirov and Geczik 1996). The strength of alternative medicine has also been seen as associated with trends towards consumer empowerment (Lowenberg 1989), which have been partly fuelled by the increased availability of specialized, scientific information through media such as the Internet (Cassileth and Chapman 1996; Williams and Calnan 1996).

Lessons from Previous Ethnographic Inquiries into CAM

It is clear that the relationship between biomedicine and CAM is complex and influenced by many cultural, social, and political factors. It is curious, therefore, that most research into CAM focuses on the medical aspects of these approaches to healing and neglects the social context. There has been relatively little empirical social science research aimed at developing an in-depth understanding of the issues that arise at the interface between biomedicine and CAM. The small number of published ethnographies of settings where alternative therapies are being used illustrate the complexity of the issues that warrant

further investigation and show how ethnographies can contribute to an understanding of these issues.

CAM Users Want More than Biomedicine Offers

McGuire (1988) did an exploratory investigation of the use of non-biomedical approaches to healing by groups of middle class people in suburban New Jersey. Her research team conducted 313 open-ended interviews with members of nontraditional healing groups and did participant observation in 31 different groups that were categorized into five belief-system types: Christian healing; Eastern meditation and human potential groups; traditional metaphysical groups; psychic/occult groups; and manipulation/technique practitioners (e.g., chiropractic, acupuncture, shiatsu, rolfing and reflexology). Groups were selected from the more than 130 healing groups identified in the study catchment area for their representativeness of a type of healing group, their geographical accessibility, and their willingness to participate in the study.

After doing participant-observation for a year, McGuire and her team conducted personal interviews with more than 300 individuals who were members of a healing group and who were perceived to have special healing abilities, who had experiences of healing, or who had varying levels of commitment to the group. McGuire found that less than one percent of respondents involved in alternative healing rejected medical treatment altogether. Her respondents showed considerable respect for the medical profession, although they tended to see biomedicine as one among many potential avenues of healing and saw themselves as active participants in the healing process, not passive recipients of care. McGuire concluded that alternative healing emphasized a

transformation of the self, one that runs counter to biomedical practices. By treating illness as connected to spiritual concerns, those involved in alternative healing delegitimized the dominance of the medical profession.

McGuire speculates that proponents of alternative therapies, being well-educated and articulate, may provoke cultural and social change. But she questions whether the interest in alternative therapies will substantially change the social and economic order or whether, instead, alternative philosophies will be co-opted by more dominant forces such as consumerism. McGuire's work is insightful and thorough. The issues she identifies as crucial are still relevant today.

CAM Expands the Moral Dimensions of Illness

Lowenberg (1989) did participant-observation in a small number of holistic health centres in California. She also conducted personal interviews with practitioners and patients in these settings. Lowenberg's primary research site was a holistic family practice clinic staffed by physicians, nurses, and psychologists. These practitioners were traditionally trained, but had developed a holistic, preventive orientation that they saw as significantly different from conventional medical practice. In the discussion of her findings, Lowenberg focuses on moral and social issues related to the ways in which responsibility for illness is attributed. She argues that, to some extent, the trend in conventional medicine has been to absolve patients from responsibility for illness. The medicalization of mental illness and alcoholism provide examples: whereas both were seen at one time as deviance arising from moral weakness, they now are viewed as illnesses which require medical, not punitive, treatment. Moral questions surrounding

illness can, however, still be seen in the discourse of conventional medicine: the current emphasis on lifestyle choices demonstrates the continuing influence of the notion that illness is a reflection of “badness.”

According to Lowenberg, the ideology of the holistic health movement significantly expands the moral dimensions of illness. Building on the presumed interconnection between mind and body, the rhetoric asserts that illness is caused by the individual’s mental or emotional state. Patients are thus responsible for their illness. The more extreme versions claim that individuals choose their illness, including its form and severity. For example, the Simonton approach to cancer treatment recommends that patients contemplate the reasons why they need their cancer (Simonton et al. 1978). This kind of approach has come under considerable criticism because it “blames the victim” (Lowenberg 1987).

Lowenberg’s empirical work showed that there were considerable differences between the rhetoric of the holistic health movement and the behaviour of its adherents. She found that holistic physicians tried to absolve patients from responsibility using strategies comparable to those used by conventional physicians. For example, practitioners used several theoretical “outs” to avoid attribution of blame, including the beliefs that illness is affected by unconscious or learned processes, and that health-related behaviours are affected by social and cultural factors (Lowenberg 1987).

Lowenberg’s interviews with patients showed that some patients did express guilt and self-condemnation because of their ill health, but that patients nevertheless believed in the holistic rhetoric because it gave them some sense of control over their illness. Lowenberg concludes that holistic health does medicalize new domains of life, but that it

also reduces medical control by encouraging egalitarian patient-practitioner relationships and patient responsibility. However, it achieves this latter benefit at the cost of increasing punitive moral sanctions against individuals who become ill (Lowenberg 1987).

Lowenberg's study provides useful insights into the ways in which patients and professionals integrate the rhetoric about individuals being responsible for their illnesses into their own beliefs and behaviours. Her research highlights some of the issues raised by this particular belief, but it elucidates only one aspect of holistic or alternative health beliefs as they are expressed in one kind of setting. There are many more issues to be explored.

Biomedical Biases Limit the Utility of Research into CAM

Some of these issues have been explored by Montbriand in her ethnographic studies of the use of alternative therapies by Canadian cancer patients. Montbriand has published articles on how patients make decisions about alternative therapy use (Montbriand 1995b), whether the use of alternative therapies represents an attempt to assert control over one's health (Montbriand 1995a), and what themes are expressed in the stories of patients who choose to use alternative therapies instead of conventional ones (Montbriand 1998). Unfortunately, these studies are of only limited value. While Montbriand claims that her analysis "does not endorse either side of the controversy surrounding alternative health practices" (1995a:646), her biomedical bias is both pervasive and obvious. For example, Montbriand asserts that it is important to understand why patients use alternative therapies for many reasons: "some being the possible dangerous side-effects of alternates or the delay of biomedical treatments, (but) probably

the most important is the alternate system's tendency to exploit patient decision strategies for marketing purposes" (1995b:104). In her 1998 article, Montbriand argues that the reason why it is important to understand why patients "abandon" biomedicine is so that health professionals can "facilitate a return of these patients to biomedicine" (1998:36).

Experience Counts in Decision Making

Another ethnography (O'Connor 1994) takes a more neutral approach. The author applies the same investigative stance to both conventional medicine and alternative medicine—what she calls "vernacular" health belief systems. O'Connor considers both vernacular approaches to health and conventional scientific approaches as having their foundations in a belief system. O'Connor (1994) argues that previous considerations of alternative medicine have tended to ignore the diversity of epistemological underpinnings on which different health beliefs rest. Further, she asserts that researchers too often assume first, that biomedical epistemologies and practices are the norm against which other systems should be evaluated and second, that users of alternative therapies must be either ignorant of conventional medicine's benefits or blocked in some way from accessing them (O'Connor 1994).

O'Connor's cross-cultural research and her research with HIV/AIDS patients in an urban area in the northeastern U.S. show that patients make pragmatic decisions about health care based on a wider range of knowledge than that usually encompassed by the conventional health system. Patients rely on the authority of their own knowledge and experience, the experiences and assertions of other legitimized authorities such as friends, family members, or alternative healers, as well as on the basis of scientific

evidence. When different belief systems produce different choices about health care, these differences result more from a reliance on different assumptions, different criteria for the admission of evidence, and different interpretations of observations than from fundamentally different ways of reasoning. O'Connor notes that many of the people she interviewed indicated that, "They (referring to scientists and health professionals) may not know that this (system or treatment) is effective, but *I* do." (1994:163). The lack of scientific evidence seldom was a deterrent to the use of alternative therapies because patients were aware that little such research had been undertaken. Patients perceived science to be one possible source of information, but not the only one. Their own personal experiences were also considered to constitute trustworthy empirical evidence. O'Connor concludes that,

If a disagreement arises between (the patient) and another (say, a health professional or an academic) who considers the system to be ineffective or its mechanism of action impossible on grounds of theory, personal experience will always hold the evidential and epistemological high ground for the experienter (1994:163).

O'Connor's scrutiny of both conventional and alternative medicine through the same analytic lens is refreshing in a field that tends to assume that conventional medicine is the norm against which other approaches should be judged. In addition, her observation that the use of alternative medicine by HIV/AIDS patients has elements of being a social movement is another valuable contribution to the examination of CAM.

CAM as a Social Movement

Another ethnography focuses almost entirely on the social movement dimensions of alternative therapy use. Schneirov and Geczik explored alternative health networks in a

northeastern U.S. city (1996 and 1998) using participant-observation and semi-structured interviews with 38 alternative practitioners, patients, and activists. Their research found that the alternative health movement includes diverse communities, from conservative Christian fundamentalists to left-leaning liberals (1996). The authors found that, while the various elements of the movement differed with respect to some of their values and the way they talked, dressed, and interacted with each other, they shared common allegiances and perspectives. Alternative health adherents from across the spectrum criticized conventional medicine for its reliance on invasive, unnatural treatments and its neglect of dimensions of life beyond the physical. In addition, adherents advocated personal freedom of choice in health care and rejected the excesses and lack of meaning in modern, consumer-oriented society (Schneirov and Geczik 1996).

According to Schneirov and Geczik (1996), participation in the alternative health movement is a way of adopting new identities and meanings as well as a form of resistance to the "colonization of the lifeworld"¹ by state institutions. Drawing on the work of Foucault, Schneirov and Geczik (1998) further argue that the ideologically-driven focus of alternative health regimes on the production of a healthy, vibrant body is an aesthetic project which removes the adherent from the supervision of conventional medicine. They see this aesthetic project as not only stimulating the transformation of everyday life but also as providing an impetus to participate in social action designed to provoke significant changes in economic and political structures, particularly structures that contribute to environmental degradation. They conclude,

¹ This term was coined by Jurgen Habermas.

The alternative health movement's significance may be in its reconstruction of the meaning of illness beyond a narrow medical category. . . . Illness becomes both a representation of the increasing risks of modern societies and the source of bodily and self-transformation that points to other possible worlds. The body both means something and allows us to do something (Schneirov and Gezcik 1998:449).

Schneirov and Gezcik's articles (1996 and 1998) provide an important perspective on alternative therapy use. By examining the social and cultural aspects of alternative therapy use, it provides a counter-point to the biomedically-oriented literature that tends to focus on the individual patient. However, both articles are highly interpretive, using post-structural, postmodern theoretical frameworks to organize the discussion of the data. It is difficult to assess the appropriateness of the authors' interpretations without having access to more of the ethnographic data.

This dissertation research aims to build on the understandings provided by these ethnographies. It provides an in-depth look at the lived experiences of those who are participating in the convergence of biomedicine and CAM. Many authors have noted that such research is long overdue (e.g., Lowenberg 1989; O'Connor 1994; Cant and Sharma 1996). There is a significant need for inquiries into the relationship between the experiences of individuals and changing sociocultural discourses related to health and illness (Lupton 2000; Kleinman and Seeman 2000). It is crucial to consider the growth in CAM within the context of culture (Adler 2002). Not only is culture a critical mediating influence in health care systems (Kleinman 1995) but ethnographic approaches that situate CAM use within social and cultural contexts have the potential to clarify some of the conceptual issues related to the field. This need for increased conceptual clarity has been identified as a priority for Canadian health policy research (www.cihir-irsc.gc.ca; accessed July 2002).

Legitimation as the Focus of Inquiry

This dissertation focuses on the ways in which the legitimacy of CAM is socially and culturally constructed. Whether explicitly stated or not, the question of whether CAM is “legitimate” is central to the current academic interest in CAM, as well as to the questions individuals face about whether and how CAM should be integrated into their treatment regimes.

The concept of legitimacy and the processes whereby values, beliefs, and practices become legitimized have been discussed by sociologists for decades. Talcott Parsons conceived of processes of legitimation as “the primary link between values as an internalised component of the personality of the individual, and the institutionalised patterns which define the structure of social relationships” (Parsons 1960:173). According to Parsons, the perceived legitimacy of a belief or action depends on the content of the belief or the nature of the possible act, the nature and strength of its cognitive justification, the actor’s motivation, and the nature of the social context (Parsons 1960). The determination of legitimacy then, is a function of the interplay between an individual’s values, beliefs, and interests and those of social groups, including formal institutions that are intended to safeguard collective interests.

Parsons asserts that subcultures or social movements that deviate from the norm but seek legitimation within the dominant sociocultural context must convince themselves and others of the validity of their own interpretations of cultural value systems and ideologies. Traditional institutions must then be delegitimized with reference to those shared cultural beliefs and values. Tension is inherent in this process. The

process tends to be characterized by oversimplification and the exaggeration of black and white oppositions (Parsons 1963).

The role and legitimacy of alternative medicine, defined generically, has been a subject for public debate since the 1960s (Cant and Sharma 2000). Since the time of the Flexner Report, biomedicine's legitimacy has arisen primarily from its links to scientific inquiry and experimentation (Starr 1982). The primary claim of CAM's critics is that non-biomedical approaches lack a scientific base (Cant and Sharma 2000). However, some so-called "alternative" approaches have been incorporated, at least to some extent, into biomedicine (e.g., osteopathy, chiropractic, and acupuncture) (Berliner 1984; Jonas 1998). This has occurred despite the lack of a strong scientific base for these approaches. The incorporation of these approaches in different jurisdictions has shown that biomedicine has changed its stance on specific CAM approaches depending on whether the modality is seen as a threat to biomedical dominance and whether it can be incorporated without a major redefinition of biomedicine's legitimacy and its role as the arbiter of medical legitimacy (Cant and Sharma 2000).

There are some signs that the public popularity of CAM may prompt governments to bestow some of the elements of legitimacy (e.g., professional status) to CAM approaches despite a lack of scientific evidence and despite biomedical scepticism (Cant and Sharma 2000). For example, in 1998, the British Columbia provincial government created a self-regulating professional College of Traditional Chinese Medicine practitioners, despite questions raised by biomedical organizations (e.g., the College of Physicians and Surgeons and the College of Dental Surgeons) about the epistemological basis for TCM practices. The government decided that the unique theory and

philosophical base of TCM coupled with its roots in clinical experience substantiated by extensive textual sources satisfied the criteria for a profession to be grounded in a credible body of knowledge. Further, in a bold policy move given the controversies surrounding CAM, the Health Professions Council stated that it did not deem it appropriate or necessary to reconcile the theories of TCM with the ontology and epistemology of Western medicine (Chisolm et al. 1998).

The increasing professionalization of CAM therapies and increasing similarities in the training received by biomedical and CAM practitioners is contributing to the legitimacy of CAM (Cant and Sharma 2000). Saks (2000) notes that while professionalization implies the creation of boundaries and that it was the professionalization of biomedicine that created CAM as an entity external to biomedicine, these boundaries are shifting. As noted earlier, not only are CAM approaches increasingly seen as having legitimacy, but biomedicine's legitimacy is being questioned. As Williams and Calnan note, "A critical re-configuration of professional power and dominance is beginning to take place" (1996:1618).

Investigating the Social Construction of Legitimacy

As noted above, processes of legitimation link individual values and collective social practices and institutions. In postmodern academia it has become commonplace to characterize concepts, values, belief systems and institutions as socially constructed. But how can the social construction of legitimation processes be understood? There are authors who speak of a legitimation crisis within academia itself: this refers to the postmodern undermining of the authority of positivist claims to knowledge (e.g., Gergen

1999; Denzin 1997). The relative, situated, context-dependent nature of knowledge and meaning is being emphasized in much social science discourse. These discourses demand investigative approaches and conceptual frameworks that focus on the contextualized particular, on processes of personal and cultural change, and on the making of meaning. In order to understand the ways in which the legitimacy of CAM is socially constructed, this dissertation uses the concepts of cultural models and situated meanings to guide the inquiry.

The notion of cultural models is widespread in anthropology. Cultural models are both public, in that they represent the shared common-sense understandings of a people and the embodiments of their language, and cognitive, in that they function as paradigms for constructing the world. Cultural models are not presented in everyday speech and action. Rather they are “represented in fragmentary, surface facets. We must infer the more coherent, if unarticulated, models that lie beneath (as we infer native actors must, in learning them)” (Keesing 1987:373–374).

In their efforts to understand the links between culture and experiences of health and illness, medical anthropologists such as Arthur Kleinman and Byron Good use the concept of “explanatory model” first, to point to the cultural forces underlying definitions of disease and second, as a point of entry into the experience of illness. Explanatory models concern the ways in which an illness episode is interpreted and understood. They show how illness is constituted by cultural beliefs and practices. These models provide meaning to experience and hence, they are inherently moral formulations. Explanatory models reflect and are changed by interactions among the person who is ill, his/her caregivers, and others in the three health care arenas identified earlier: the popular, the

professional and the folk sectors. Such models are thus intersubjective and reflective of medical and social power relations (Kleinman and Seeman 2000; Good 1994).

Anthropologists and other social scientists have struggled to explain how cultural models are learned and how such models change. For example, D'Andrade theorizes that cultural models are made up of cognitive schemas² used "to represent something, to reason with or to calculate from by mentally manipulating the parts of the model to solve some problem" (1995:180). D'Andrade points out that cultural knowledge is both shared and distributed, i.e., there are aspects of cultural knowledge that enjoy a high degree of consensus and other knowledge systems that are contested. He also points out the important link between cultural models and individual psychological processes, e.g., the effect of motivational differences on the adoption or rejection of a cultural model. He notes that,

much of the current work on *power and discourse* in anthropology is concerned with problems related to the psychological force of cultural models—debates over what is natural and right. In modern pluralistic societies the cultural heritage contains many alternative and even conflicting cultural models about how things are and how one should act. . . . Cultural models become part of social conflict and social processes by which laws are constructed, norms are established, and deviance is controlled—or fails to be controlled (D'Andrade 1995:242).

Sperber (1996) also emphasizes the role of psychological factors such as motivation in the distribution of cultural models. In addition, he points out the importance of what he calls ecological factors, e.g., the recurrence of situations in which the cultural model or representation leads to appropriate action, the availability of external memory cues (especially written texts), and the existence of institutions that transmit particular models. Sperber maintains that culture is made up of "contagious"

² A schema is an organized framework that can be filled in by the concrete details of experience.

ideas and that the human mind is susceptible to cultural models in the same way the body is susceptible to disease. He advocates for an “epidemiology of representations” that would explain culture by explaining why and how some ideas happen to be contagious.

These ideas about cultural models and their role in sociocultural change obviously have relevance to the question of how unconventional approaches to healing come to be seen as legitimate. They provide a conceptual reference point for this dissertation. The next chapter outlines the rationale for using an ethnographic approach to the research and describes the specific research methods used.

Chapter Three

The Ethnographic Approach to the Research

Introduction

This chapter describes the research methods used in the dissertation. An ethnographic approach was used for several reasons: because of the complexity of the issues that were explored; because of the critical role that social and cultural factors play in the construction of legitimacy and the paucity of previous empirical research that considers the issues within their social and cultural context; and because of the lack of conceptual clarity about the research issues. This chapter begins with a description of my approach to the ethnography. I then outline my own particular position with respect to the research issues. These sections are followed by a statement of the dissertation's objectives, a description of the fieldwork setting, descriptions of the methods of data collection and analysis, and a discussion of ethical considerations. The chapter closes with a discussion of the strengths and limitations of the research.

My Approach to the Ethnography

The Critical-Interpretive Approach

Ethnography can be characterized as a form of research that includes several key features: a strong emphasis on exploring the nature of particular social phenomena; a tendency to work primarily with data that have not been collected in relation to a pre-determined set of analytic categories; the investigation of a small number of cases; an analytic process that involves explicit interpretation of the meanings and functions of human action; and the creation of an end result that is primarily descriptive and explanatory (Atkinson and Hammersley 1994). According to James Clifford,

Ethnography is actively situated *between* powerful systems of meaning. It poses its questions at the boundaries of civilizations, cultures, classes, races, and genders. Ethnography decodes and recodes, telling the grounds of collective order and diversity, inclusion and exclusion. It describes processes of innovation and structuration, and is itself part of these processes. (Clifford 1986:2-3).

The goal of the ethnographer is to link local knowledges, i.e., the emic, contextualized understandings of research participants, with more abstract, etic interpretations which reveal what is generic to the conceptual structure underlying those understandings (Geertz 1973 and 1983). While ethnography has traditionally been associated with the discipline of anthropology, it is increasingly being used in interdisciplinary research where "culture" has become problematized as an object of description and critique (Clifford 1986; Marcus 1998). Ethnographic data are traditionally obtained primarily through participant-observation and interviews (Emerson et al. 1995); some ethnographers also use social texts (e.g., popular literature or cinema) as sources of data (Denzin 1994).

In my dissertation research I have attempted to draw on the traditional strengths of the ethnographic approach while incorporating insights developed through debates among social scientists about the need for social science to be critical, reflective, and mindful of the power dynamics inherent in social and cultural systems (Clifford 1986; Marcus and Fisher 1986; Lather 1991; Denzin and Lincoln 1994; Behar and Gordon 1995; Singer and Baer 1995; Denzin 1997; Marcus 1998). Such critical reflexivity is especially important in investigations of medical settings or health care systems (Good 1994). My research has been undertaken from the perspective of a critical-interpretive approach in medical anthropology that builds on the model of health care as a cultural system outlined in chapter 1. This perspective has been described in detail by Byron Good (1994). Good agrees with Kleinman (1987) that culture is not only a means of representing disease but is essential to its constitution as a lived experience. The biological reality of disease interacts with social practices and cultural meanings to shape the illness experience. This shaping occurs in local settings where power is being contested. As Keesing noted in his discussion of cultural models,

Cultures do not simply constitute webs of significance, systems of meaning that orient humans to one another and their world. They constitute ideologies, disguising human political and economic realities Cultures are webs of mystification as well as significance (Keesing 1987:161).

Given this tendency for culture to both reveal and obscure, Good argues that critical medical anthropology must examine instances when illness representations may actually be misrepresentations that serve the interests of those in power. Such a critical analysis investigates the ways in which the experience of illness is produced, medical knowledge is generated and power relations reinforced. Good advocates that research using this approach should focus on the formative processes through which illness is shaped as

personal and social reality. This approach should heighten our understanding of illness experiences and the ways in which actors make sense of those experiences while critically analyzing the social and historical processes of which actors may be only dimly aware. But attending to issues of power is not enough. We must also open up social science discourse to existential issues and to the consideration of human values, including being aware of the centrality of suffering in human culture (Good 1994).

With this critical–interpretive approach providing a set of orienting principles, my ethnographic fieldwork followed a model for ethnographic research discussed by George Marcus (1998). Unlike traditional ethnographies that focus on one geographically–bounded community or culture, this model focuses on specific topics or problems. The ethnographer follows the problem to whichever sites or locations provide fertile ground for study. This multi–sited model uses the traditional methods of ethnography but allows for a different “research imaginary”—a different way of formulating research ideas and conceiving of fieldwork (Marcus 1998:10).

My dissertation research, with its focus on controversial issues and its location within contested domains of knowledge and power, has required the kind of critical–interpretive approach advocated by both Marcus and Good. Marcus (1998) points out that, while traditional ethnographies studied subjects foreign to the researcher (the “Other”), newer forms prompted by critical hermeneutics are often motivated by the personal interests of the researcher. While emphasizing the need for the researcher to develop distance between the personal and the social, i.e., to project the personal problematic to a more objectively defined subject, Marcus argues that “the extended exploration of existing affinities between the ethnographer and the subject of study is

indeed one of the most powerful and interesting ways to motivate a research design” (Marcus 1998:15).

In keeping with the growing practice for ethnographers to make explicit their positions, values and biases with respect to the issues they are investigating, the next section describes my motivations for undertaking this research, beginning with a narrative outlining my own experiences as a site of convergence between biomedicine and CAM.

My Interest in the Research Issues

My grandfather was a doctor who became British Columbia’s first coroner. I was raised on heroic stories about my grandfather in his horse and buggy with his black bag at his side, traveling through the Fraser Valley to deliver babies, tend the sick and care for the dying. The cultural model that was instilled through these stories was that medicine was a sacred calling, that doctors were worthy of the highest respect, even reverence. In early adulthood, through my undergraduate and graduate studies in Psychology, positivist ways of thinking and representing the world became deeply ingrained. As a result of these influences, some aspects of my thinking about science and medicine became strongly aligned with conventional Western perspectives. At the same time, during my undergraduate studies in the late 1960s, I was introduced to Eastern religions and became strongly attracted to Taoist and Buddhist worldviews and practices. I also became involved in the feminist movement.

When I was in my mid-twenties I was told I might have cancer. Because of my newfound feminist perspectives on patriarchal institutions, my sympathy for Eastern

views on illness being a sign of disharmony in one's life, and my adoption of what were then counter-cultural views on the superiority of "natural" ways of living, I went looking for alternatives to the conventional options I was facing. Eventually, diagnostic tests showed that I had a thyroid dysfunction not cancer. I took the recommended conventional drugs for a while but I also began practising yoga and meditation and eating a vegetarian diet. In addition, I made radical changes in my lifestyle.¹

Several years later, I worked within the conventional cancer care system as the administrator of the Vancouver Breast Screening Centre, part of the National Breast Screening Study (NBSS), a national randomized controlled trial of the efficacy of mammography screening. During my time in that position (three and a half years) I became a biomedical insider to some extent. I saw people working in the system who displayed enormous caring and commitment towards patients and families. I also saw professionals make potentially life-threatening mistakes, sometimes through no fault of their own, sometimes through incompetence that was kept hidden by their peers. I saw a strong allegiance to science and a profound respect for the value of clinical experience, including, in some quarters (especially among nurses) a willingness to rely on intuition as a basis for decision making. I became aware that clinical decision making is fraught with ambiguity.

After I had left the cancer clinic and the NBSS had finished, I saw a response to the results of the study that surprised me. Before beginning the public speaking I did to recruit participants for the study, I had been coached to describe the NBSS as being the only way to definitively answer questions about whether to offer mammography

¹ I left my husband, quit my job, packed up my Volkswagen van and headed to the Maritimes to go "back to the land."

screening and at what age such screening should begin. The rhetoric claimed that doing the science and measuring the death rate was the only way to know whether population screening was a worthwhile health policy strategy. However, when the results of the study were in and no demonstrable benefit for women under age 50 was found, some of the same physicians who had been saying the research was crucial now began saying the research was flawed and its results suspect (for a recent up-date on the results of the study and the controversy surrounding it, see Miller et al. 2002; Goodman 2002; Sox 2002). A province-wide mammography screening program was instituted in British Columbia for women aged 40 and over, despite the NBSS's failure to show a benefit for women between 40 and 49 and despite the study's suggestion that screening in that age group might even be harmful. This seemed to be a clear example of the legitimacy of the science being questioned (even by those who were directly involved in its implementation) because it contradicted strong beliefs about the value of mammography and threatened the interests of particular groups (e.g., radiologists). These experiences in the world of biomedical research made me both appreciative and sceptical of conventional medicine.

Since the 1970s I have continued to practice what many would call complementary and alternative medicine. I meditate and do Tai Chi regularly, eat a vegetarian, mainly organic diet, and have used acupuncture and various forms of bodywork as healing and health promotion strategies. In the late 1980s I co-owned and managed a "holistic health centre" that offered a variety of services, including "floating" (time spent in sensory deprivation tanks), different forms of bodywork, Tai Chi classes, rebirthing, and "New Age" workshops. During the two years I spent in this environment

and another year spent as a Tai Chi teacher, I personally experienced the therapeutic power of some alternative healing approaches and met other people who were helped by such approaches. I also saw practitioners setting up shop with little education or training and little apparent expertise. Some seemed motivated by a desire to capture their share of a growing market rather than any "call" to be a healing professional. I developed the same kind of ambivalence about "CAM" that I had about biomedicine.

After my stint as a "New Age businessperson" I returned to my career as a researcher. Over the next ten years I engaged in a variety of research and evaluation projects and became increasingly convinced of the value of participatory, constructivist, and qualitative approaches to issues related to health policy and practice. Thus, at the time I began my PhD program, I described myself as a "Taoist/Buddhist Critical Feminist Constructivist who is a recovering Positivist."² I saw myself as ideally situated to investigate the interface between conventional medicine and complementary and alternative medicine because of my insider's knowledge of different epistemologies and healing systems and my having learned to live with a multiplicity of sometimes conflicting voices. I was especially motivated to examine the issues related to the legitimation of CAM after watching some close friends struggle to combine CAM with conventional medicine when their young daughter was diagnosed with leukemia.

² To clarify briefly, I am not a "strong" constructivist, i.e., I do not believe that reality is completely socially constructed or that everything is text. I believe that there is a "real" world "out there" but that much of my perception of and relationship to the real world is a function of social/cultural constructions.

Objectives of the Research

The specific objectives of the research were: to describe how cancer patients and health care practitioners come to see different approaches to healing as legitimate; to analyze people's experiences and perspectives in relation to cultural factors; to situate the personal and the cultural in the broader social context; and to discuss the implications of the dissertation results for health care practice, policy, and research.

The Fieldwork Setting

The Vancouver region is a large, urban area with a diverse and multi-cultural population. The area is home to a large, tertiary conventional cancer clinic as well as a myriad of CAM practitioners and services. Conventional cancer treatment tends to be centralized at the British Columbia Cancer Agency (BCCA), although some cancer patients never become BCCA patients. This largely government-funded, provincial body oversees a range of treatment and research services, including four regional cancer care centres, links with nineteen chemotherapy clinics across the province, a Cancer Research Centre which will soon be expanding into a new \$95 million facility, and screening programs for cervical cancer and breast cancer. Patient care services include some modalities that are considered complementary, including therapeutic touch, relaxation therapy, support groups, and art and music therapy. The annual budget for the fiscal year ending in March 2001 was \$223 million (<http://www.bccancer.bc.ca>; accessed July 2002).

There are several non-profit organizations in Vancouver that specialize in providing CAM services to cancer patients. The Centre for Integrated Healing is the first

and only “integrated complementary cancer care centre” in Canada. It opened in 1999. It is staffed by conventionally trained physicians and a variety of CAM practitioners: a TCM practitioner, a homeopath, a naturopath, a body worker, massage therapist, nutritionist, and yoga teacher. It provides alternative treatments such as the MRV vaccine, 714X, and Essiac as well as counseling patients with respect to diet, exercise, and other lifestyle factors. The physicians’ salaries are funded through a special arrangement with the provincial Medical Services Plan. The centre also receives funding from private donations and fees for service.³

The Tzu Chi Institute was a non-profit organization that was operating during the time I conducted my fieldwork. The Tzu Chi Institute opened in 1998 in the midst of a great deal of fanfare. It was founded by a Buddhist charitable organization to conduct research into the safety and efficacy of CAM. The Tzu Chi Institute also attempted to develop a model for the provision of integrated care that drew on the best of both CAM and biomedical worlds. About 30% of the patients who received care at the Institute were cancer patients. The Institute offered group programs such as mind-body programs as well as individual consultations and care provided by an inter-disciplinary team consisting of conventionally-trained physicians and CAM practitioners such as a chiropractor, TCM practitioner, massage therapist, and nutritionist. Initially, core funding from the Tzu Chi Foundation was supplemented by funding from the provincial health ministry and a number of mainstream health care organizations, including the B.C. Cancer Agency, Vancouver Hospital (where the Institute was housed), and the local Health Board. In the spring of 2002, government cut-backs resulted in the complete withdrawal of provincial funding. Infrastructure support from conventional medical

³ For more information, refer to <http://www.healing.bc.ca>

partners ceased at the same time, although research funding tied to specific ongoing studies was maintained. By the spring of 2003, it was clear that the Institute would not be able to secure sufficient funding from private donors to continue operating, so the Institute closed in March 2003.⁴

Hope House is a non-profit organization of professionals and cancer survivors that focuses on providing social support and counseling for cancer patients and their families. It is careful to maintain its financial independence from mainstream institutions and is supported through private donations and voluntary effort.⁵

The Callanish Society is another non-profit organization that provides support to cancer patients and their loved ones. Callanish offers week-long residential retreats for cancer survivors six times a year. It began offering retreats in 1995. Callanish recently began offering similar retreats for health care professionals. The organization also sponsors social events and regular opportunities for retreat participants to come together for ongoing support.⁶

In addition to these non-profit organizations, there is a multitude of individual practitioners in the Vancouver area who provide CAM treatments. Some of these (e.g., naturopaths, chiropractors, massage therapists, and TCM practitioners) are linked to institutionalized professional colleges. Others would be considered part of the "folk" arena, i.e., healing specialists who are not members of government-sanctioned professions. As noted in chapter 1, there are more users of CAM in the West than in other parts of Canada. As evidence of the popularity of CAM therapies in Vancouver, medical students at the University of British Columbia have formed the "Alternative and

⁴ For more information, refer to <http://www.tzu-chi.bc.ca>

⁵ For more information, refer to <http://www.hopecancer.bc.ca>

Integrative Medicine Society” which produces an annual directory of CAM services, training institutions, and products (<http://www.aims.ubc.ca>; accessed May 2003). Thirty thousand copies of the first edition of this directory were printed in 2000–2001. Twice as many copies of the next year’s 80 page directory were printed and distributed. This directory lists the full gamut of professional and folk CAM practices and services, including Therapeutic Touch, Reiki, Rolfing, aromatherapy, Pilates, yoga, meditation, Qi Gong, Tai Chi, iridology and shamanism.

The “popular sector” of the health care system in the Vancouver area also demonstrates the prevalence of CAM practices and beliefs. In some quarters, Vancouver is known as the California of Canada: it is seen as providing fertile ground for various subcultures such as environmentalism, holistic health and the “New Age.” This setting provides numerous examples of the kinds of activity that are associated with CAM. For thirty years, Banyen Books has been a mainstay of the alternative scene in Vancouver. This bookstore has a stock of 26,000 books, CDs, tapes, and videos related to topics such as transpersonal psychology, Eastern spirituality, ecology and community, metaphysics and philosophy as well as a variety of paraphernalia related to “New Age” and spiritual practices such as yoga and meditation. Banyen also holds regular workshops and lectures (<http://www.banyenbooks.com>; accessed May 2003). Two major alternative magazines are based in Vancouver: Common Ground and Shared Vision. Both these free monthly magazines contain directories of CAM practitioners and services. Common Ground claims that each issue reaches 250,000 readers (<http://www.commonground.ca>; accessed May 2003), while Shared Vision reaches 175,000 (<http://www.shared-vision.ca>; accessed May 2003). The Vancouver area also comprises a variety of CAM-related associations

⁶ For more information, refer to <http://www.callanish.org>

such as the Alternative Health Network, an advocacy organization, as well as educational institutions that train practitioners, including several private colleges that teach TCM and a training program in Holistic Health Studies at a local public community college.

Fieldwork Methods

In doing the fieldwork, I relied primarily on three methods of data collection: individual interviews with cancer patients and with conventional and CAM practitioners, participant-observation in relevant settings, and review of textual material. I began doing interviews in the fall of 1999 and did my last one in the spring of 2003. In total, 45 individual interviews were done. The perspectives of a total of 24 cancer patients were included in the research (17 patients were interviewed individually and seven took part in a group interview). The research incorporates the perspectives of nine conventional health care practitioners and eleven people involved in CAM: ten practitioners and one administrator. Eight people participated in more than one interview. I began the fieldwork by focusing on the experiences of patients, since I wanted my interviews with practitioners to be informed by an understanding of patients' perspectives.

Interviews with Cancer Patients

I did individual interviews with 17 cancer patients, all of whom had used some kind of complementary/alternative approach as part of their cancer treatment regime. Ten of these patients were interviewed once; seven were interviewed twice. A total of 24 personal interviews with individual cancer patients were conducted. Ten of the patients were women; seven were men. The age range of the women was from 34 to 69, with a

mean age of 52. The age range of the men was from 48 to 69, with a mean of 58. Two of the participants were Chinese; one was Indo-Canadian; the rest were white. All of the participants had completed high school, with four having some post-secondary education, six having undergraduate degrees, and three having graduate degrees. Eight of the participants were married, and nine were single, divorced, or separated.

The patients had been diagnosed with a variety of cancers and were at various stages of the cancer trajectory, from a few months to more than twenty years post-diagnosis. When interviewed, nine participants believed they were in remission, six were in active treatment, and two were receiving palliative care. As of this writing, six of the patients I interviewed have died. Participants had been diagnosed with the following types of cancer: breast (6); prostate (4); gynecological (2); melanoma (1 male and 1 female); lymphoma (1 female); esophageal/stomach (1 male); and colon (1 male). Four of the patients refused conventional treatment beyond that required to confirm the diagnosis. Thus, this group has a higher proportion of people (24%) who have refused conventional treatment than is typically found in survey samples of cancer patients (usually less than 10%). Most patients used several CAM treatments, typically combining activities such as participation in a support group and meditation with the ingestion of substances such as high-dose supplements, herbal remedies such as Essiac, and/or other treatments such as Iscadore or shark cartilage. Table 2 presents a summary of each patient's situation. For further information, see chapter 4, where the stories and perspectives of six patients are profiled in detail and Appendix A, where brief profiles of each patient are provided.

Table 2: Characteristics of Cancer Patients Interviewed Individually

ID No.	Demographics	Diagnosis Date and Type of Cancer	Recruited Through	Conventional Treatments Used	CAM Treatments Used	Status at Interview
1	<ul style="list-style-type: none"> Male, white, 55. Married with children Retired teacher & social activist. BA and teacher's degree. 	Stomach-esophageal cancer, Oct '97	Family physician	<ul style="list-style-type: none"> Surgery Chemo 	<ul style="list-style-type: none"> Anti-cancer vaccine Essiac Supplements Exercise 	Assumes remission
2	<ul style="list-style-type: none"> Female, Chinese, 50. Single Medical social worker University degree 	Breast, '85; recurrence in bone '93	Counsellor (friend of author)	<ul style="list-style-type: none"> Surgery Radiation Chemo 	<ul style="list-style-type: none"> TCM: herbs Diet change Exercise Naturopathy Support group 	Palliative at time of interview. (Died Fall '00)
3	<ul style="list-style-type: none"> Male, white, 48 Married with children Manager. MSW. 	Prostate, Oct '99	Family physician	<ul style="list-style-type: none"> Hormonal therapy Surgery 	<ul style="list-style-type: none"> Meditation Visualization Yoga Diet change Naturopathy: herbal remedies Acupuncture 	Active treatment; considering radiation
4	<ul style="list-style-type: none"> Female, white, 69 Writer Divorced, grown children. Some university, no degree. 	Breast, Jan '99	Hope House	<ul style="list-style-type: none"> Surgery (biopsy only) 	<ul style="list-style-type: none"> MRV vaccine Essiac Vitamins, herbs, and other supplements Visualization, affirmations Meditation Support Yoga Diet 	Assumes remission
5	<ul style="list-style-type: none"> Female, white, 54 Separated with grown children Retired teacher University degree 	Breast, '92; recurrence in ovary & intestine, '98; new breast primary, summer '00	Hope House	<ul style="list-style-type: none"> Surgery Chemo Hormones 	<ul style="list-style-type: none"> TCM: herbs, acupuncture Diet Meditation Support group Various Mind-body 	Assumed remission at time of interviews. (Died July '02)
6	<ul style="list-style-type: none"> Female, white, 50 Single Counselor Grade 12 	Melanoma, stage IV '77; Recurrence '80; second recurrence few months later	Hope House	<ul style="list-style-type: none"> Surgery Chemo 	<ul style="list-style-type: none"> Iscadore Diet change Meditation Psycho-therapy Yoga Vitamins Homeopathy 	Long-term remission

ID No.	Demographics	Date and Type of Diagnosis	Recruited Through	Conventional Treatments Used	CAM Treatments Used	Status at Interview
7	<ul style="list-style-type: none"> Male, 66, white Divorced, grown children, Retired teacher and administrator M.A. 	Melanoma, diagnosed Feb '99; recurrence Oct '99	Family physician	<ul style="list-style-type: none"> Surgery 	<ul style="list-style-type: none"> diet change Healing touch Meditation Tai Chi, Qi Gong 	Actively pursuing CAM treatment (Died Aug '00)
8	<ul style="list-style-type: none"> Female, white, 62 Divorced, grown children School administrator M.Ed. 	Breast, '97	Family physician	<ul style="list-style-type: none"> Chemo Radiation Surgery 	<ul style="list-style-type: none"> Mind-body Visualization Music Relaxation group 	Assumed remission at time of interviews. (Recurrence Spring '02)
9	<ul style="list-style-type: none"> Female, white, 50 Single Self-employed. 3 years univ., technical courses 	Breast, diagnosed '99; Recurrence several months later	Hope House	<ul style="list-style-type: none"> Surgery Refused chemo & radiation 	<ul style="list-style-type: none"> Vitamins: high dose Supplements Massage enzymes 	Active CAM treatment at interview. (Died '02)
10	<ul style="list-style-type: none"> Male, white, 61 Married Businessman BSc. 	Prostate; Jan '98	CIH	<ul style="list-style-type: none"> Refused hormonal treatment and radiation 	<ul style="list-style-type: none"> TCM: Herbs, acupuncture PC SPES Group support Meditation 	Active CAM treatment
11	<ul style="list-style-type: none"> Female, white, 55 Married Activist (volunteer) BA, some grad school 	Cervical, diagnosed '98; vaginal, diagnosed '99	Hope House	<ul style="list-style-type: none"> Surgery 	<ul style="list-style-type: none"> Naturopathy IV vitamin C acupuncture MRV vaccine Essiac Vit A, other supplements Group Support 	Refused radiation and further surgery; active CAM treatment
12	<ul style="list-style-type: none"> Female, white, 34 Married, young child, Secretary. Grade 12 	Lymphoma Diagnosed '97	Counselor (friend of author)	<ul style="list-style-type: none"> Surgical biopsy Chemo 	<ul style="list-style-type: none"> Naturopathy Essiac Vitamins Group support 	Just finished active treatment at interview. (Later recurrence)
13	<ul style="list-style-type: none"> Male, white, 64 married, grown children, Retired builder. High school 	Colon with metastasis to liver '99	CIH	<ul style="list-style-type: none"> Surgery 	<ul style="list-style-type: none"> Shark cartilage MGN3 (immune enhancer) Vitamins Visualization Group Support. 	Active CAM treatment. (Died Sept '00)
14	<ul style="list-style-type: none"> Female, Chinese, 40 Single, Office administrator. Grade 12 and some college 	Breast, Jan '99	Heard about research through friend	<ul style="list-style-type: none"> Surgery Chemo Radiation 	<ul style="list-style-type: none"> Acupuncture, herbs Group support Reflexology Yoga Diet change Art therapy 	Assumed remission

ID No.	Demographics	Date and Type of Diagnosis	Recruited Through	Conventional Treatments Used	CAM Treatments Used	Status at Interview
15	<ul style="list-style-type: none"> Male, white, 68 Widowed Retired manager Grade 12 	Prostate, fall '99	BCCA	<ul style="list-style-type: none"> Refused conventional treatment 	<ul style="list-style-type: none"> Saw palmetto PC SPES Chinese herbs Diet changes 	Assumes remission
16	<ul style="list-style-type: none"> Male, white, 48 Single Fire fighter Some university 	Prostate, diagnosed '98	BCCA	<ul style="list-style-type: none"> Hormone treatment Radiation 	<ul style="list-style-type: none"> Unconventional radiotherapy in U.S. Cesium chloride 	Assumes remission
17	<ul style="list-style-type: none"> Female, Indo-Canadian, 60 Married, grown children Retired teacher University degree 	Ovarian, stage III diagnosed '97	BCCA	<ul style="list-style-type: none"> Surgery Chemo 	<ul style="list-style-type: none"> Hydrazine sulfate Thymus extract Supplements MGN3 Support group, relaxation group Meditation 	Palliative at time of interview

The patients were recruited for the research through a variety of means. Five were interviewed after they contacted me after seeing a poster about my research (see Appendix B) at Hope House, a non-profit organization that offers counseling and support to cancer patients and their loved ones. Four contacted me after hearing about my research through their family physician (three physicians who are part of my personal network referred patients to me). Three patients were referred to me by their oncologist at the B.C. Cancer Agency after I asked some of the oncologists I had interviewed to help me recruit participants.⁷ Three others contacted me after hearing about my research through mutual friends or acquaintances. Two patients volunteered to be interviewed after hearing about my research when I participated in a patient support group at the Centre for Integrated Healing (CIH), a facility staffed by conventionally trained physicians and alternative practitioners such as naturopaths, and TCM practitioners.

Most interviews were 1.5 hours long. Interviews were tape-recorded and most were subsequently transcribed verbatim. A small number of interviews conducted in the later stages of the fieldwork were not transcribed in their entirety. Most interviews were conducted in the participant's home. Three participants were interviewed in a private room at their place of work.

Interviews were relatively unstructured, the objective being to let the participant's concerns and perspectives contribute to the shaping of the conversation. Generally, I began the first interview by asking participants to tell me the story of their diagnosis and treatment. I asked them to talk especially about how they made decisions about what

⁷ At the beginning of my fieldwork, I intended to post a notice at the BCCA's Vancouver centre inviting patients to participate in the study but later decided not to do this. By the time I received approval from BCCA to post a notice, I was aware of how much patients wanted to talk about the research issues and was

treatments to undergo. Using the information provided in the person's narrative as the starting point, we then explored the ways he or she thought through the decisions to be made, e.g., what sources of information were considered credible, what factors were taken into consideration and why, how trade-offs were made, what role other people played in their decision making, how beliefs about health and illness influenced the decisions, and how the assessment of a treatment's value changed as a result of experience with the treatment or the practitioner. Depending on the time it took to cover this territory, I either asked for the person's perspective on some of the health policy issues in the closing stages of the interview or, if it seemed that there was still more ground to cover, or if I needed time to reflect on what had been said, I requested a second, follow-up interview. Prior to the follow-up interviews with the seven people I interviewed twice, I reviewed the tape or the transcript of the first interview and made notes of specific issues I wanted to explore in more depth or points I wanted to clarify. Generally, after pursuing these topics in the second interview, I asked for the participant's perspective on the policy issues to close the interview.

I also facilitated a group interview at Hope House in March 2000 with seven cancer patients and the spouse of one patient. When I initially solicited research participants at Hope House, the response was so enthusiastic that I decided to do the group interview in order to hear the perspectives of the people who wanted to provide input to the study without weighting the sample (i.e., the group of people who volunteered to take part in the study) too heavily with patients recruited from a single source. The group interview participants were Hope House members who had

concerned that I would be inundated with potential participants when I only needed a small number of patients to complete my sample.

volunteered to be interviewed in response to my original poster or who responded to a subsequent poster inviting participation in the group. In addition to briefly telling their own stories of diagnosis and treatment, the participants in this group talked about how they defined complementary and alternative medicine, what sources of information about treatment options they considered trustworthy and why, and what role their own personal experience played in their thinking about the value of different treatments and what importance they gave to scientific evidence. This group interview was tape-recorded and transcribed verbatim in its entirety.

Interviews with Conventional Practitioners

I interviewed six oncologists who work at the Vancouver centre of the British Columbia Cancer Agency (BCCA). Three of these are radiation oncologists; three are medical oncologists. Four are male; two are female. Most had more than ten years experience in oncology. I also interviewed three BCCA nurses, two of whom work at the Vancouver centre, one of whom works at the Fraser Valley centre. All the nurses are female. One is a nurse engaged directly in patient care; two act as consulting specialists to other nurses.

Two interviews were conducted by telephone because this was the most convenient arrangement for the participant, given the constraints on his or her time. The remaining seven interviews were conducted in person at the Vancouver Cancer Centre. The interviews lasted about an hour. All interviews were tape-recorded and most were transcribed verbatim in their entirety. The recording quality of two interviews was so poor that they were not transcribed.

The conventional practitioners were recruited for the study by means of an e-mail invitation that was sent in June 2001 to all BCCA oncologists and nurses through the office of the secretary of the CEO of the BCCA. I interviewed all those who responded to this invitation during the summer of 2001.

In general, I began my interviews with conventional practitioners by asking them to talk about the issues they are facing related to the use of CAM by cancer patients. Depending on their responses, the interviews continued with considerations of questions such as the following: How have your experiences influenced your thinking about why patients use CAM? How does CAM use affect relationships between conventional practitioners and patients? What are the fundamental differences between conventional medicine and CAM? What sources of information about the safety and efficacy of different treatments should practitioners and patients use in making decisions about treatments? What ethical issues does CAM use raise for you? And what are your views on the concept of integrative medicine?

Interviews with Complementary and Alternative Practitioners

I interviewed one administrator of a CAM treatment centre and ten CAM practitioners who practice a variety of healing approaches, including healing touch, traditional Chinese medicine (TCM), naturopathy, chiropractic, massage, and counseling that encompasses spiritual as well as psychological concerns. Two of the practitioners are conventionally trained physicians who now rely on techniques that fall into the category of CAM (e.g., the use of unconventional substances such as anti-cancer vaccines, herbal remedies, or dietary regimes, and meditation). Four of this group of informants was affiliated with the

Tzu Chi Institute, a facility whose objectives were to offer integrated biomedical and CAM treatments and to conduct research regarding these treatments. One practitioner was affiliated with the Centre for Integrated Healing. One was affiliated with Hope House. Six of these CAM practitioners specialize in cancer care. Two are themselves former cancer patients. Most would be considered members of the professional health care sector, rather than the folk sector. The exceptions might be the healing touch practitioner and the counselors, although these practitioners had undergone specialized training and received remuneration for their work.

The CAM practitioners were recruited for the study through a variety of means. In some cases I requested an interview after meeting the individual through my fieldwork and learning that the individual or the organization with which he or she was affiliated played a key role in CAM cancer care in Vancouver. In some cases I had not met the individual but requested an interview after hearing about the practitioner from patients or other practitioners. In the case of the Tzu Chi practitioners, I attempted to organize a group interview with the Institute's practitioners, but scheduling difficulties made this impossible. Instead, I interviewed the three practitioners who were most interested in participating in the study individually, by telephone. The other seven interviews were conducted in person in the participant's home or place of work. One individual was interviewed twice, the rest were interviewed once. There was only one CAM practitioner that I approached who did not take part in the study. This naturopath initially agreed to be interviewed but repeated attempts to arrange an interview were unsuccessful.

Generally, the interviews lasted 1.5 hours. All interviews were tape-recorded. Three interviews were transcribed verbatim in their entirety. In the case of the other

interviews, notes on the interviews were done while listening to the tapes. Only selected passages were transcribed, primarily those destined for inclusion in the dissertation.

The interviews with CAM practitioners generally began with them providing a brief explanation of their approach to healing, if I was not already aware of their work. I then covered the same issues covered in my interviews with conventional practitioners: What issues are you facing as complementary and alternative medicine and conventional medicine converge? Why are patients using CAM? What are the fundamental differences between conventional medicine and CAM? What sources of information about safety and efficacy do you consider credible and trustworthy? What are your views on integrative medicine?

Participant–Observation

I did participant–observation in several settings. From December 1999 to October 2000, I was a member of a committee consisting of representatives from the BCCA and the Centre for Integrated Healing (CIH) that was created to consider whether and how to achieve the integration of conventional and CAM facilities and practitioners. After several meetings, this committee evolved into a larger committee (two patients and another researcher joined the committee) with a specific mandate: to develop recommendations regarding the integration of conventional and complementary/alternative health care as part of a national effort to form a comprehensive strategy for cancer prevention, screening, diagnosis, and treatment. This committee met every two weeks while it was discussing these issues and formulating its recommendations (which were submitted in June 2000). The other committee members

gave informed consent to allow me to include my experiences in the committee in my research. In the early stages of my involvement with this committee, my role was predominantly that of observer. Since I was taking notes anyway, I became the group recorder. Once the committee took on the responsibility to develop a set of policy recommendations and the group expanded, I became a more active participant, offering my perspective on the issues when I thought this would help the committee achieve its objectives. Participating in this committee gave me a strong appreciation for the questions and concerns of people on both ends of the biomedical–CAM spectrum as well as giving me a direct experience of struggling with the thorny policy and practice issues presented by the convergence of CAM and conventional medicine.

I also participated in a group for cancer patients at the CIH. This group met weekly for five weeks with the goal of teaching patients about various mind–body approaches to healing (e.g., meditation and visualization). The group members gave their consent for me to participate in the group; they were eager to contribute to the study because of their perception that the topic was important. I attended all but one of the group sessions and participated in all of the group activities, including the occasional sharing of personal stories and experiences. It is important to note this group did not reach the level of intimacy that patient groups sometimes do, since the emphasis in this particular group was more on providing instruction in mind–body techniques than on providing emotional support.

I attended a number of conferences relevant to the research issues: a conference on CAM for physicians sponsored by the Tzu Chi Institute and the B.C. Medical Association in September 1998; a conference for practitioners and patients called “Living

Well with Cancer” spearheaded by the BCCA in March 2000; and the annual “Comprehensive Cancer Care” conference in Washington D.C. sponsored by the Center for Mind–Body Medicine, the National Cancer Institute, and the National Institutes of Health (I attended in June 2000). In addition, I attended an August 2000 public consultation on the regulation of natural health products organized by Health Canada, a symposium on Aboriginal healing approaches used in several countries held at the University of British Columbia, a First Nations medicine wheel ceremony, and a variety of public lectures and presentations by well-known CAM proponents (e.g., Carl Simonton, Deepak Chopra, and Marion Woodman) and local experts on the issues (e.g., Steven Aung and Allan Best). Attending these public events gave me a feel for the social context surrounding the research issues and gave me first-hand exposure to the perspectives of some of the major players in the debate about the legitimacy of CAM.

Collection and Review of Texts and Discourses

In September 1999 I began collecting relevant stories from the local print media and from national publications such as *Saturday Night* and the *National Post*. These stories included items about new cancer treatment approaches, both conventional and complementary or alternative, human interest stories about individual patients, debates about the legitimacy of CAM, articles about the role of science in society, and articles about health policy and CAM. I also reviewed transcripts from a series of programs aired on CBC Radio’s *Ideas* program in the spring of 2000. This series, entitled “Rethinking Medicine,” dealt directly with many of the issues that are central to the dissertation.

Relevant passages from these texts were highlighted and observations about public discourses were included in the analytic memos I wrote as the fieldwork progressed.

After interviewing patients and realizing the important role the Internet plays in patients' decision making, I "surfed" the Internet to find out what kinds of information patients are encountering. At first, I approached the Internet as if I were a cancer patient looking for information about CAM treatments. I quickly became aware of the profusion of information and perspectives relevant to the dissertation issues that can be found on the Internet and so continued exploring, looking for examples that would illustrate some of the key features of the public discourse surrounding the legitimacy of CAM. Some relevant examples from these discourses are presented in chapter 7.

Ethical Considerations

The plans for the research were evaluated and approved by the ethics committees of the University of British Columbia and the British Columbia Cancer Agency before any data collection was undertaken. Other settings where fieldwork was undertaken (e.g., complementary and alternative facilities) did not require separate ethical approvals. The research complied with the guidelines for privacy, confidentiality, inclusion, informed consent, and other ethical concerns presented in the Tri-Council Policy Statement regarding Ethical Conduct for Research Involving Humans (Social Science and Humanities Research Council 1999). (For copies of the consent forms, see Appendix C.)

There were no unusually difficult ethical dilemmas that needed to be resolved in the course of the fieldwork. I had no difficulty "entering the field" and was warmly welcomed in all the settings in which I collected data. I had no difficulty recruiting

people to take part in interviews or obtaining informed consent. I had to be careful about confidentiality, given the relatively small world of CAM cancer care in Vancouver. I had to be sensitive to the hopes and fears of those whom I interviewed. I had to be mindful of the danger of leading respondents in particular directions given the unstructured nature of the interviews. But, given people's eagerness to talk about the issues and my lack of formal affiliation with any organization or healing approach, I did not feel that coercion was a significant danger. While there were a few occasions when patients became angry or upset about their situation during an interview, they recovered their composure as they continued telling their stories and I sensed no risk of lasting harm. On only one occasion did a patient ask me directly for information about alternative treatments she might use and, since I knew nothing about specific treatments for the kind of cancer she was inquiring about, I simply said that. Other than this one occasion, patients seemed to understand clearly that my role was not to provide information or advice about different cancer treatments.

Since the dissertation presents detailed descriptions of individuals' situations and perspectives, there is some risk that research participants could be identified thus nullifying the assurance of anonymity they were given. Where there was significant risk that a description or quote might enable others to identify a participant, I gave the relevant sections to the participant before finalizing the dissertation (e.g., the patients profiled in chapter 4 reviewed their profiles). I asked the participant specifically to consider whether their anonymity was at risk. None of these participants expressed concern about the material in the dissertation. Some said that they might be identifiable but that this was acceptable to them since there was nothing reported in the dissertation

that they had not either already said in public or would be willing to say in public. In addition, the question of whether to identify the B.C. Cancer Agency as the site of my interviews with conventional practitioners was discussed by my supervisory committee, which included the CEO of the BCCA. Given the likelihood that readers would easily identify the agency because of the central role it plays in cancer care in Vancouver, it was decided that it was acceptable to name the setting where these interviews took place.

Analysis and Interpretation of Data

The tapes of almost all of the interviews were transcribed verbatim into Word files. The tapes and transcripts were reviewed many times during the course of the fieldwork. Particularly cogent, insightful, eloquent, or relevant passages were highlighted as potential quotes for inclusion in the dissertation. In the case of a small number of interviews done later in the fieldwork, summary notes were word processed while listening to the tapes and then verbatim transcripts of selected passages to be used in the dissertation were done.

In the early stages of the fieldwork, the transcripts were analyzed according to the constant comparative method described by Emerson et al. (1995). This method involves iterative rounds of coding, starting with "open codes" based on the ideas, themes, and issues expressed by research participants, and progressing to more abstract "focused codes" and categories of codes. Analytic and reflective memos were written in conjunction with the coding process as a way of extending the process of inquiry by making connections between categories of codes. For example, one category of focused codes or primary themes was "medical systems." This category included open codes such

as “CAM outcomes,” “limits to conventional medicine,” and “patient–doctor communication.” Another category was “social–cultural context.” This category included the following open codes: “cancer culture,” “vested interests,” and “forces behind CAM use.” A third category, “Epistemology” included codes such as “knowing through the body,” “mind–body link,” and “trial and error.”

In the later stages of the fieldwork, when the predominant themes and categories of themes were clear, the coding process focused on identifying interview passages that confirmed or added new dimensions to those primary themes. Passages from different interviews were cut and pasted and compiled according to theme.

Since participants rarely spoke about legitimacy per se, I also reviewed the interviews and asked the question, “How is this person determining the legitimacy of the different approaches to healing that we talked about?” The analytic memos that resulted from this review of the tapes and transcripts also made comparisons between participants, including comparisons between the legitimization strategies of patients vs. those of biomedical or CAM practitioners.

The field notes describing participant–observation sessions were not analyzed in as standardized or systematic a way as the interview data, since the settings were very different and the degree of my engagement as a participant varied. My reflections on what I experienced in the settings where I did participant observation were incorporated in the various analytic memos I wrote. Thus, the data from my participant–observation sessions provided contextual information that helped move the inquiry and the analysis forward. Excerpts from the notes from some of these sessions are included in the description of CAM settings in chapter 6.

In order to integrate the preliminary analyses I had done and create a conceptual synthesis of the fieldwork data (i.e., the interview data, the lessons from my participant observation, and the textual material I had collected), I relied on a framework for discourse analysis described by Gee (2000). This analytical framework is congruent with the interdisciplinary and critical–interpretive, constructivist approach I have taken in the research. The framework encourages critical inquiry into exactly the kinds of sociocultural legitimation processes that are the focus of the dissertation.

Gee’s framework uses a number of analytic tools or thinking devices. Two of those conceptual analytic tools were particularly relevant to my dissertation: situated meanings and cultural models. Gee defines situated meanings as mid–level patterns or generalizations that are not too specific, but neither are they too general. They are flexible, transformable patterns that come out of experience and in turn, construct experience as meaningful in certain ways and not others. Situated meanings are a product of the bottom–up action and reflection with which one engages the world and the top–down guidance of cultural models (Gee 2000).

Cultural models mediate between the micro level of social interactions and the macro level of social institutions. They serve to establish what counts as a central, typical case and what counts as marginal or non–typical. Cultural models are images or storylines or descriptions of simplified worlds in which prototypical events unfold. Cultural models can coalesce into “master models” that incorporate more discrete models and provide generalized, encompassing perspectives. For example, the master model around cancer being a “dread disease” (Patterson 1987) includes other cultural models such as “cancer should not be talked about openly” or “donating money to research will

bring about the cure.” Cultural models are rooted in the practices of socioculturally defined groups of people. More will be said about this connection between cultural models and social practices later in the dissertation. Gee’s conception of cultural models is congruent with the way this concept is used by other authors (Gee 2000).⁸

Gee (2000) describes “little d” discourses—the way language is used—as being melded with non-language “stuff” such as clothes, gestures, symbols, tools, values, attitudes and beliefs to create “big D” Discourses that enact specific identities and activities. For example, using the language of Gee’s framework, there is a Discourse of biomedicine that includes discourses about the legitimacy of different approaches to healing. In the ensuing discussion of my fieldwork, when I want to invoke this larger conception of Discourse—as a force that both carries and bestows social and cultural power—I will capitalize Biomedicine or CAM or the word Discourse.

Gee’s (2000) analytic framework allowed me to use the concepts of situated meanings, cultural models, and Discourses to examine the fieldwork data in light of several questions that Gee identifies as crucial to applied discourse analysis (i.e., discourse analysis that is intended to further the understanding of important issues and serve as the basis for effective action). These questions include: What cultural models seem to be at play in connecting situated meanings to each other? What Discourses and/or institutions are being (re)produced in this situation and how are they being stabilized or transformed? What relationships and identities with their concomitant personal, social, and cultural knowledge, beliefs, values, and feelings seem to be relevant to the situation? What social goods (e.g., status, power, legitimacy) are relevant (and

⁸ See the concluding section of chapter 2 for a discussion of the relevance of cultural models to the dissertation.

irrelevant) and how are these social goods connected to cultural models and Discourses? How do situated meanings, cultural models, and Discourses interact to create coherence for the actors in the situation? (Gee 2000)

Using Gee's (2000) framework as a guide, I reviewed the tapes and transcripts of the interviews with patients again, asking the above questions. On the basis of the resulting analytic memos, I prepared the patient profiles presented in chapter 4. I then reviewed the tapes and transcripts of the practitioner interviews asking the same questions, wrote analytic memos, and selected passages that illustrated relevant perspectives or dynamics. The results of these analytic processes are presented in chapters 5 and 6.

The results of this discourse analysis dovetailed with the results of the earlier coding and categorizing of the interview data, i.e., the three key areas that are being unsettled and contested in the debate about CAM's legitimacy are: the relationship between patients and practitioners, the nature of the links between the mind and the body and the nature of health and healing, and the value of different ways of knowing. The chapters that describe the perspectives of those within the Discourse of Biomedicine and the Discourse of CAM and the chapter that presents relevant examples from public discourses focus on these key issues.

After writing the patient profiles presented in the next chapter, I also drew schematics that attempted to portray the dynamic processes whereby patients use cultural models and discourses as a basis for making treatment decisions (see Appendix D). The process of drawing these schematics contributed to the "ripening" of the theoretical

analysis of the data from patients and laid the foundation for the discussion of legitimization processes contained in chapter 8.

This description of the analysis of the fieldwork data has followed the academic convention of focusing on what is done with the data after they are collected. Without downplaying the role of these after-the-fact analytic processes, I want to mention the important role that doing the fieldwork played in the process of "analysis and interpretation." I had countless large and small "aha!" experiences during interviews and events where I was doing participant observation. The unstructured nature of the interviews allowed for a mutual exploration of the research issues, sometimes with the result that both the participant and I discovered new territory. For me, the experience of doing the interview, being with the participant and seeing his or her facial and bodily expressions, hearing the story, and feeling the emotions, contributed useful insights and helped move the inquiry forward. It is also important to note that the analytic and interpretive process continued as the dissertation was being written.

Trustworthiness of Analysis and Interpretation

Constructivist social science research attempts to use new ways of establishing the validity or verisimilitude of social science research. Various alternatives to positivist conceptions of validity and reliability have been proposed, including constructivist criteria of trustworthiness (e.g., credibility and confirmability) and authenticity (e.g., fairness and capacity to enhance understanding) (Guba and Lincoln 1994) and feminist notions of catalytic validity (the degree to which the research process provides an impetus for transformative action) (Lather 1991) and voluptuous validity (the degree to

which research includes and reflects women's experiences) (Lather 1993). As an ethnography, this dissertation is inherently interpretive. It cannot be judged against any objective standards of truth. Ultimately, its readers will be the arbiters of its trustworthiness, authenticity, and utility.

I have endeavoured to provide a partial assessment of the trustworthiness of my representations of the fieldwork data by having people I interviewed review specific chapters of the dissertation. Four of the six patients whose stories and perspectives are described in chapter 4 have reviewed their own profiles. Unfortunately, two of the patients who are profiled passed away before the drafts were written. The four patients who reviewed their profiles all verified the validity and relevance of my description and interpretations. Virtually no changes to my drafts were requested. Two patients made a point of expressing their appreciation that I "got it." Similarly, I asked two of the six oncologists and one of the three nurses I interviewed to review the chapter that describes the perspectives of biomedical practitioners. In the case of this chapter as well, no substantive changes were seen as needed. The biomedical practitioners, too, perceived that I had accurately represented the situation as they saw it. For example, one said that things resonated with her and that her reaction to the chapter was, "Of course." The reactions of the conventional practitioners who reviewed this chapter also suggest the thesis may have catalytic validity. One oncologist thanked me for giving him the opportunity to read the chapter since it had prompted him to think differently about some of the issues. The chapter describing CAM was reviewed by four of the eleven CAM-associated people I interviewed. Their feedback was similar to the conventional practitioners: my description and analysis reflected the situation as they saw it. Thus,

these "member checks" by people from the various groups whose perspectives are presented in the thesis testify to the trustworthiness and relevance of my analysis and interpretation.

The strength of my analysis is also affirmed by its internal consistency, i.e., the results derived through the constant comparative method converged with the later discourse analysis. In addition, the three key themes that emerged from the analysis of the data from patients are the same issues that two other authors have highlighted as central to the questions under investigation. I was unaware of these other statements of the key issues until after my analysis was complete, so my identification of these same issues arose independently. This congruence further reinforces the claim for the trustworthiness of my analysis. In discussing the changes that have been occurring in the social and cultural context surrounding medical care, Lupton (1994) points out that patients are demanding to be better informed, to be included in decision-making processes, to be treated as more than just physical "bodies" and to have their own knowledge about their health valued. The second author whose interpretations coincide with mine weaves the story of her own treatment for cancer into a social and cultural analysis of cancer, biomedicine, and CAM. She notes that, "The patterns of the conceptualization of illness, disease, the body, the doctor and the patient have become 'second nature' to our contemporary Western culture, and are integral to its fundamental discourses of rationality, objectivity, and positivism" (Stacey 1997:52). Stacey (1997) sees these assumptions being unsettled by discourses associated with the prevalence of CAM.

Strengths and Limitations of the Methods

Despite the above assertions that the analyses and interpretations reported here are trustworthy, there is no question that what is written here is a construction that very much reflects who I am and what I believe. This is both a strength and a limitation. Given my knowledge of and experiences with both the worlds of biomedicine and of CAM, I had little difficulty gaining access to the settings and the people who were the subject of inquiry. As something of an insider to both worlds, I was able to understand the perspectives and speak the languages of most people I met during the fieldwork. This facility with the Discourses of both Biomedicine and CAM opened doors that might have been closed to other investigators. I often felt, during an interview, that the ease with which the participant and I found common ground contributed enormously to the depth and richness of the conversation. In this respect, my being an insider was a strength.

On the other hand, my experiences with both biomedicine and CAM meant that I did not approach the research with what in the world of Zen practice is called “beginner’s mind” (Suzuki 1973). I came to the fieldwork feeling more aligned with CAM than with biomedicine. This bias, no doubt, meant that I did not pursue some questions with participants that I thought I already knew the answers to, or believed were not interesting. As a result of my experiences during the course of the fieldwork, my perspective changed. For example, I became more appreciative of conventional oncology practitioners because I got a glimpse of the courage it takes to continue practicing in the midst of the ambiguity, frustration, and suffering they encounter every day. I also became more sceptical about some aspects of complementary and alternative medicine as I

explored the role of cultural models in creating meaning and saw the influence of belief systems in my own thinking about health and illness.

Each reader must make her or his own judgment about the dissertation's trustworthiness. As the writer, I make no claims to truth in the positivist sense. If the dissertation deepens understanding and clarifies the issues (which themselves concern the question of how legitimacy is determined), then I hope it will be considered as one example of the value of ethnographic approaches to complex issues.

My representation of the perspectives of those I met during the fieldwork may be seen as problematic, given the current concern about representation in ethnography. The material from the interviews presented in chapters 4, 5, and 6 portrays only one side of the conversation. That is, the words of the participant are quoted, but my questions and comments are not. I have also selected some passages for inclusion and omitted others. These are both limitations imposed by space constraints. I chose not to use the dissertation as an opportunity to show how the conversations were co-created because I believed that while this is an important consideration, it is neither central to the dissertation's themes nor crucial to the kind of analysis that was performed. As the analyst, I assumed the right and the responsibility to select what was important. This focus on selected parts of the participants' input, their extraction from the dialogical context, and the focus on the content rather than the form of our conversations seemed to me to be appropriate given the relatively broad scope of the dissertation and the need to limit its length. However, it is important to acknowledge that a different type and level of discourse analysis could have been undertaken and the issue of representation could have been engaged more explicitly.

Another aspect of representation that is important to consider relates to the size and composition of the groups of people who were interviewed. The strength of the patient sample is that those who volunteered to be interviewed were thoughtful, articulate people who believed in the importance of the research and who were able to directly address the research issues. However, this group is only a small portion of the number of people in the local region who have cancer and who are exploring a wide range of treatment options. In addition to this group being small, I think it may under-represent patients who have little allegiance to cultural models associated with CAM. Given the nature of the inquiry, I think this is not a major weakness, but it means that the reader should be careful about assuming anything about the predominance of different cultural models in the general population.

The group of biomedical practitioners that took part in the research is also small and self-selected. Some of the practitioners had a strong interest in CAM and one or two may even consider themselves “hybrid” practitioners. None of the biomedical practitioners who volunteered to be interviewed were openly hostile to CAM, so that perspective is not seen in the interview data, although it is presented in the context of the discussion of public discourses in chapter 7. The inclusion of the anti-CAM side of the debate in that chapter and the high degree of consensus among the conventional practitioners I met regarding the issues reassures me that the dissertation manages to adequately consider the range of biomedical perspectives on the legitimacy of CAM.

It is the sample of CAM practitioners that I believe is the weakest. The CAM practitioners I interviewed represent only a small minority of a large, heterogeneous population. CAM includes a wide variety of different practices, some of which are rooted

in different worldviews and paradigms. In addition, my understanding of the challenges faced by those who are attempting to integrate biomedicine and CAM is based on interviews with practitioners, not direct participation in settings that are striving to implement integrated health care models. While the fieldwork generated enough material to answer the research questions to some extent, I believe that additional exploration of the perspectives of CAM practitioners and focused participant-observation in integrated settings would elucidate the issues further.

This ethnography aimed to follow the research problem to relevant sites of inquiry. While I did manage to engage with many of the key environments and players, I do not feel I reached the point of “saturation” that is often the goal of qualitative research. Because of the broad scope of the inquiry, I “left the field” feeling there were still people to meet, perspectives to learn more about, and relevant settings to observe. For example, to reinforce the point made in the preceding paragraph, I think it would have been fruitful to explore settings where integrated care was being attempted and to pursue some of the specific approaches to healing that are subsumed under the CAM label in more depth, especially those such as traditional Chinese Medicine whose systems include substantially different cultural models. However, I believe that the dissertation has revealed new and useful insights and understandings that can and should be used as a foundation for the resolution of some of the contentiousness evident in the interface between conventional medicine and CAM.

To close this section, I offer some brief reflections on the interdisciplinary nature of the inquiry since I believe this aspect of the dissertation is both a strength and a limitation. The strength of the interdisciplinary approach to the research is that it has

required me to draw on relevant research and thought from the social sciences, medicine, and health policy. This has been essential to the attempt to look at the research issues from a comprehensive perspective that embraces all of the important aspects of the issues rather than isolating and focusing on only a small piece of the puzzle. I believe this has been the right approach to take given the limitations of previous research in this area, particularly medically-oriented research that is not informed by the critical perspectives offered by the social sciences. The issues cross disciplines, thus it makes sense for the research to cross disciplines as well.

However, the interdisciplinary nature of the work has limitations. First, given that the research has been done by one person rather than a team of scholars each grounded in his or her own discipline, there is a risk that the research has not been sufficiently rooted in the depth of knowledge of any one particular discipline. Further, my being a traveler in several disciplines and a resident in none has meant that I have not been a member of a cohesive academic community and so have not had the benefit of frequent dialogue about the research among peers. Another aspect of this lack of connection to a particular academic community has been the somewhat idiosyncratic way in which I have woven together threads from different disciplines. This may mean that the readers of the dissertation will not share the same discursive space, either with me or with each other. Academic work is intended to be read and judged by a community of scholars, but the challenge of interdisciplinary work is that it does not necessarily have a logical home community to receive it. This dissertation, like most ethnographies, presents only a portion of what was learned through the research. Much of the work is subterranean, underpinning what is visible but not itself directly seen. In work done within a single

discipline, where much of the subterranean knowledge is shared, the writer can invoke that knowledge without having to explain it. In the case of interdisciplinary work, a shared knowledge base cannot be assumed. These factors have made the writing of the dissertation challenging.

The other challenge related to my attempts to cross disciplinary boundaries has arisen from the strength of the intellectual socialization I received in my undergraduate and graduate training in Psychology. Doing this research has made me acutely aware that scholars in different disciplines not only use different languages and different methodologies but their thinking processes are different. There have been countless times during the analysis and writing where I have had to re-orient my thinking away from the search for linear variables and relationships that can be controlled and towards the task of making sense of the maelstrom of life outside the laboratory. Even as I write this, the logical positivist in me is still looking for *the* answer that will bring closure to the research question.

Chapter Four

Conversations with Patients

Introduction

This chapter presents the stories and thoughts of six people who have been treated for cancer and have used complementary and alternative approaches¹, usually in combination with conventional treatments. These six patients were selected as exemplars because each person's situation portrays important aspects of patients' experiences at the interface between conventional medicine and CAM. In addition, considered together, the six cases encompass the range of situations and perspectives I encountered. The conversation extracts included in this chapter show how patients use cultural models and discourses to create meaning and coherence out of profound uncertainty. The names given are not the real names of the people interviewed. Some characteristics of each individual have been described: I have endeavoured to provide descriptions that embody each individual's language without revealing the person's identity.

The verbatim quotes from the interview transcripts have been edited to some extent. For example, hesitations, pauses, and some sentences that represent false starts,

¹ The patients I interviewed usually did not speak of "Complementary and Alternative Medicine" as a singular entity, although they knew what was meant by this term. Patients generally spoke of particular CAM therapies, approaches or products rather than speaking of CAM as a whole.

have been deleted. Where sections of speech have been omitted in the interests of brevity, I have inserted an ellipsis. The aim of the editing was to achieve coherence and cogency while preserving the content and flavour of each speaker's contribution to our conversation.

The conversations described in this chapter clearly reveal the predicament that cancer patients face. There is a plethora of information available about cancer and its treatment and much of it is contradictory. Unfortunately, conventional medicine can provide few guarantees. As one participant in the group interview I conducted said, "I don't think it's being disloyal in choosing to try an alternative treatment. We're just trying to save our lives. If the conventional treatments were working, we wouldn't even be having this discussion."

The conversation with Joel:
"If it's not going to harm me, I might as well try it."

Joel is a 55 year old retired teacher and social activist. He volunteered to be interviewed after hearing about my research from his family physician. I interviewed him twice in his home: a large old house, located in a neighbourhood of similar houses, most of which have been subdivided to accommodate a mix of students and middle class families. Joel is married with adolescent daughters. He has a wiry build, and longish hair. His short beard, like his hair, is salt and pepper gray. The interviews took place in a small den, which had floor to ceiling bookcases filled to overflowing with books, magazines, and stacks of paper. Several oil paintings filled up any otherwise empty wall space. Small oriental rugs dotted the wood floor. The house felt like a house that is used for living, not for show.

Joel was treated for stomach and esophageal cancer two years before our interviews. He had surgery and chemotherapy soon after his diagnosis. He described himself as "a poster boy for health" since he does not drink coffee or alcohol, nor does he smoke or eat meat. He is also a strong believer in the health-promoting power of exercise.

I was given an oncologist at the hospital. And what she basically said was, "What we'll do next is let you recuperate for another five or six weeks and then we'll start giving you chemo." And basically that was it. They didn't give me any advice. Just go home, rest, and get ready for your chemo. I mean, this was the first of my disillusionment with the traditional oncologists. I mean, without needing to have anyone else tell me, I just thought, "This is crazy." I decided I am going to treat this chemo like anything else I've learned in life. It's a major battle and I've got to prepare for it, so I'll go out and exercise. I decided that I would just do a heavy regime of walking.

Actually, when I was in the hospital, from the day after surgery, even when I was still on morphine, I started walking. I'd go five minutes at a time. And I'd do it ten to twelve times a day. And I did it every single day. And I made them take me off the morphine. Because that's another thing I didn't mention earlier, is I never take drugs. I don't even take aspirins, you know. I basically stay away from all chemicals. I mention this because I think that's all part of an alternative approach, too. I don't like taking drugs unless you have to.

Before his diagnosis, Joel knew very little about cancer. He credited conventional medicine with saving his life. But he already had a long-standing commitment to exercise and healthy eating and living a happy life, so he believed that his recovery had to include a focus on what he called holistic health.

I believe that, you know, I'm not going to reject traditional medicine. We've come too far. I think it saved my life. Without that operation, I'd be dead now. No doubt about it. But I don't trust traditional medicine because they are so narrow.

Like the oncologist that I had. At one point I said to her, "You know, I'd like to discuss some of the alternative things I'm doing. Like, I'm doing a lot of exercise." And her response was, "Well, it's never been proven that exercise has ever helped anybody with cancer." And I said, "Well, I believe in healthy eating." "Well, you can eat healthy if you want, but there is no proof. There is no direct correlation between healthy eating and cancer being

beaten.” And we went down the line of everything that I was doing. So actually at that point I just rejected her and I went out and found another oncologist.

Joel was critical of his first oncologist’s stand on alternative approaches, and also her approach to him as a person.

She is a scientist and she is using me as a research guinea pig. She is doing chemo on me. She is keeping nice stats. And then somewhere along the line she’ll say, you know, “Fifteen percent were supposed to have survived, but 30% survived, so chemo works,” or “Whoops, only 10% survived. I’d better change the dosage.” And it’s like I’m a guinea pig. And if I do the other alternative things, I almost got the impression that would harm her statistics because it would confuse the data.

So she doesn’t care about me as a person. She cares about me as a statistic. That’s the impression I got. And that doesn’t make her a bad person. She’s a nice human being. But she’s a scientist and her brain forgets about the human person that’s in there. And I think that’s the Number One thing if I had to talk about mixing alternative and complementary and traditional medicine, is the first thing is, that you treat the patient as a human being and as a person that matters, not as an object.

Joel believed he needed to do everything he could to make himself holistically healthy since the surgeon told him that his chances of survival were 15%. So he decided to use both conventional medicine and complementary/alternative medicine. In addition to his focus on exercise and healthy eating, Joel took supplements and Essiac tea, and got injections of anti-cancer vaccines from a physician he saw who is conventionally trained but prescribes complementary and alternative treatments.

He’s a little bit fanatical—his shtick is healthy eating and he’s also got something that I don’t agree with. He believes that the body is born healthy and that only the environment can cause it harm. Somehow, that’s the same as the theory that people are born perfect and only the world corrupts us. It would be nice if it was that way. And our bodies aren’t born healthy sometimes. Our genes are imperfect and they’ve got problems and they are just programmed to break down or the environment acts upon it, of course, and causes all sorts of problems. So, whereas, you get people like the oncologist who are taking the position that, “Forget the environment. It has no effect on you. This is just some cancer you’ve got now. We’ve got to give you radiation and chemo and operate and then pray for the best.” And then

(the complementary doctor) takes the opposite—that it's all the environment. It's somewhere in between, is my take on the truth.

But basically I really enjoyed going to this doctor because it was nice to be with someone who encouraged healthy eating, and I learned a bit from him about some things that I didn't know. But I don't feel that he emphasized enough things like exercise, you know. He just had this one thing in his mind—healthy eating. That was his obsession. Which happens to be an obsession of mine, so we matched. But I am smart enough to know that's not enough.

Joel described a time near the end of his chemotherapy treatment when he felt this physician's advice was dangerous.

I was like somebody from Auschwitz. I was just like a skeleton, you know. And so, I go to see (the complementary physician) either near the end of my chemo or at the end of it. And he says, "You know what you need to do right now? We've got to purify your body. I'd like you to go on a three day fast." And luckily I had enough brains to say, "Give me a break. If I do that, you'll kill me. My body has just lost thirty pounds. My body can't take it. I've got to be fortifying myself right now." So I just ignored him. But the fact that he would do that, is just (pause) and I still go to him. I know peoples' warts and their strengths and their weaknesses, but it's dangerous, that kind of thing.

Joel obviously had a clear set of beliefs about how to promote health and healing and was willing to make his own independent judgments. Once he had time to reflect on the treatments he had received, he became deeply ambivalent about chemotherapy.

It probably has some use. It's better than nothing and you might as well do it, but it's so primitive. It's so barbaric and it's so stupid. . . . And I still don't know what the long term effects of it are. Two years later, I am still extremely tired. I sleep ten to eleven hours every night. I had a nap yesterday for an hour and a half. In between that I can still go for an hour and half run. You know, I have strength, but I am just so tired. And I think it's because of the heavy-duty chemo I had. And it's not true of everybody. Because I have other friends who had chemo and they are back to normal now. But I think it must have killed something in me. Or did something to me. But I am alive, so what the hell.

During the interview I felt there was a contradiction in what Joel was saying about his decisions to avoid drugs, alcohol, and meat and his decision to undergo chemotherapy. So I asked him about this.

Why did I take chemo? Okay, well, what it is, the reason is simple. First, I didn't have the advantage of knowing about cancer. It was like foreign. It was like going to Mars. I knew nothing about cancer. I knew nothing about chemo. And so when I got it, it was like out of the blue. I mean, I knew nothing about it. I didn't even know what chemo was, hardly. And so, I had two sources of information. I had my oncologist who is just, "It's God's gift to the world—chemo." You know, "Take it and you'll be better." You know, bullshit, you know.

And then I had (the complementary physician). So I went to him and asked him what he thought and his approach was, "Well, you might as well take it because, we don't know." He wasn't prepared to say, "Don't take it." But, so both sides of the coin were telling me to take it and I didn't know enough about it. And I still don't know enough about it today. Even today, I don't know. Even knowing what I have gone through, if it comes back, I'm probably prepared to take it again. Even though I know it's such a barbaric, stupid, idiotic thing and that it's probably hurt me more than it's helped me. I often think back, if I hadn't taken it, I wonder if I'd be better off today. I am just so tired of sleeping ten, eleven hours a day. Just wasting my life.

As I struggled to understand Joel's perspective, I asked him to clarify something he had said earlier about mistrusting conventional medicine.

I'm not sure I said there's a lack of trust of conventional medicine. I think what I was saying is there is a lack of trust with traditional practitioners because they tend to be too focused on a few techniques and how far they've taken us, but I think that they are too narrow. That they are not open to other things and they are also not open to the greatest hubris of all, which is that what's acceptable in medicine today might very well be considered a crock twenty years from now. That what they might be doing is quite dangerous. And that's just the nature of science. Almost everything in science is soon discovered to be wrong. I mean, even all the great theories that Einstein came up with, they are all superceded. That's just the nature of science. Science is made to be overthrown.

In order to ensure that I understood how Joel had made treatment decisions, I said that it seemed that he had a balanced perspective on science and its limitations as well as a willingness to go with his own gut feeling or his own experience. He laughed and said,

Yeah, I'm willing to gamble and try things that aren't scientific as long as they go along with my personality. Like for example, I don't like meditation because it doesn't fit my personality. Meditation stresses me out more than it relaxes me. That's why if you give something that's a "one-size-fits-all" it doesn't work.

To confirm my understanding of how Joel made decisions about treatment, I asked if it was true that if something was not likely to do any harm, he would try it.

Precisely. That's it exactly. That's my bottom line. If it's not going to harm me, then I might as well try it because if there is a 5% chance that it's going to help me, that's 5% better than nothing.

Reflections

Joel's description of his experience with cancer treatment shows how he has "jerry-rigged situated meanings in integral interaction with context." (Gee 2000) His creation of personal meaning draws on dominant cultural models related to cancer (it is a battle; it is caused by a combination of factors including genetics and environmental influences) and to biomedicine (its treatments are life-saving). He also expresses cultural models that are critical of biomedicine: medical research is exploitive; conventional practitioners treat diseases not persons; conventional medicine is too limited in its scope; and conventional cancer treatments are harsh and primitive.

In making sense of his situation Joel also expresses his acceptance of cultural models about holistic health that pre-date his diagnosis: exercise and diet contribute to good health; and drugs and other toxic substances should be avoided. While he accepts some of the beliefs associated with alternative or holistic models, he rejects the view that if environmental toxins are removed, healing will inevitably follow.

In his explanation of his perspective, Joel both affirms the legitimacy of conventional medicine and its scientific underpinnings and decries the hubris of conventional practitioners. Similarly, Joel both affirms the legitimacy of holistic health or alternative medicine and criticizes some of the beliefs and practices of the particular

complementary practitioner from whom he receives treatment. While he sees the oppositions in the Discourse related to Biomedicine and the Discourse related to Complementary and Alternative Medicine (e.g., with respect to the question of whether genetics or environmental factors cause cancer) he seemingly has no difficulty positioning himself somewhere in the ground between these Discourses. While Joel holds definite opinions, he does not seem to find it necessary to align himself with a position that is either black or white. Nor does he seem to find it necessary to make his beliefs and actions completely consistent.

Joel has created meaning for himself by connecting contradictory Discourses with his already-established approach to life. He is a doer, a pragmatist, an independent thinker, and even more, he is a fighter and a risk-taker. Thus, Joel's situated meanings are a product of his integration of discourses and cultural models from both Biomedicine and CAM as seen through the filter of his own experience and his commitment to practices such as exercise and healthy eating. The experience of cancer does not seem to have threatened Joel's identity. Rather, he apparently responded to cancer the same way he responds to other challenges, with self-discipline, with a willingness to both accept and be sceptical of authority, and a determination to find his own way.

Joel's strong commitment to practices such as the avoidance of drugs makes his decision to agree to chemotherapy especially curious. Joel's explanation of his initial decision and his indication that he would likely take chemotherapy a second time shed light on the way he makes connections between information from external authorities and his own values, beliefs, and identity. His thoughts also reveal the deep ambiguities that cancer patients face. Joel says the explanation for his decision is simple. He was ignorant

about cancer and about chemotherapy. He was getting the same advice from both his oncologist and his CAM practitioner. Although he does not mention this explicitly during his explanation, he had also been given a poor prognosis. Within the context of this threat to his life, given his lack of knowledge and the congruent advice from practitioners on “both sides of the coin,” the decision made sense.

At the time of the interviews, however, Joel was no longer ignorant about cancer. And he was acutely aware of the damaging side-effects of chemotherapy. He said that the chemotherapy killed something in him, that it had probably hurt more than it had helped and that the resulting fatigue made him feel like he was wasting his life. Even so, he said he would probably take it again if the cancer recurs. His comment that, “I am alive, so what the hell” suggests that, for him, life is lived in degrees. His willingness to do chemotherapy again suggests that he can imagine hanging on to life in degrees.

Joel’s willingness to consider taking chemotherapy again seems to represent a repudiation of his commitment to avoid toxic substances and a denial of the knowledge gained from his own experience of the treatment’s side-effects. But the context is all-important. The link between his values and his identity and the balance between what he knows and what he does not know would shift in the context of recurrence. To say that the situated meanings he has created would be de-stabilized by this serious threat to his life is an understatement. Being a pragmatist and someone who seems to be comfortable with ambiguity, Joel seems to understand that, for him, if the cancer were to recur, all his ideological bets would be off. Chemotherapy may have little legitimacy for Joel in some respects (“it’s barbaric, stupid, idiotic”) but in the context of recurrence, it seems that survival would be a more important consideration.

Joel's situation is not unique. The next patient whose situation is described shows clearly how the decision-making parameters change when the prognosis changes.

The conversation with Brian: "Pulling out all the stops"

Brian is a 48 year old with a background in counseling who works as a manager in a non-profit agency. He has a Master's degree. He is married with two small children. He volunteered to be interviewed after hearing about my research from his family physician. I interviewed him twice in his home: a three-storey, wood frame house in an established East end neighbourhood that has become trendy in recent years. Brian looks fit and healthy. He is clean shaven and neatly dressed in jeans and a sweater. We did the interviews in his front room. The colourful collection of kids' toys and baby paraphernalia that was strewn around seemed incompatible with the subdued elegance of the room's antiques and oriental rugs.

Brian was diagnosed with prostate cancer four months before our first interview. After the diagnosis, he was put on a hormone treatment to shrink the tumour. He was scheduled to have surgery the week after our first interview.

Brian began his story by telling me that he came from a medical family. Both his parents were physicians. He is a descendant of William Osler, a Canadian physician who became well-known in the early part of the 20th Century for being both an inspiring teacher and a highly-skilled clinician. But this family tradition did not prevent him from seeking out alternatives.

I have cringed at the idea of going to alternatives, but I've gone to alternatives because I also have to differentiate from my family. I've never been thoroughly immersed in the orthodoxy, but the influence has been

strong. So, the first thing I did when I got the diagnosis was to go into a similar mode of coping with any challenge which is, learn what I can. Just kind of, partly in shock, but just bat-out-of-hell read, read, read, read, read.

Brian read books about cancer and searched the Internet. He decided to change his diet to some extent, and to start taking nutritional supplements and vitamins. He also began doing visualization and meditation. He had already been doing yoga for many years. He tried to find a way to combine the best of both conventional and alternative medicine.

The medical orthodoxy that I grew up with and the experiences that I had gave me a really positive experience with medicine and I have a lot of faith in medicine. But I also recognize that there is a lot of blind spots in that. And my Dad was probably the stronger influence in some ways. He's much more conservative. He is tied to the scientific method, and that cautiousness of, you know, you do things according to procedures and you follow things, you know, that sort of stuff.

So, I have a lot of faith in medical orthodoxy but I also am a little more adventurous than that scientific method would allow. And as I figured out what is right for me (pause) I know the medical piece is there, as long as you get the good doctors, and I am certainly not blind to the fact that there is a lot of abuse in the system. There's a lot of incompetence in the system. And, the bureaucracy gets in the way, and things like that. So I am certainly not blind to the faults in the system. But I also have a lot of confidence that doctors are well-intentioned, highly educated, skilled, and do the best that they can. So I've got a lot of faith at that level. I guess "faith" is an okay word to use there.

But I also don't want to rule out other possibilities. Because paradigms can blind you to other possibilities. The medical paradigm, the scientific method, the scientific stuff leaves out a whole lot.

And, I think throughout my adult life, I've kind of chafed against being imprisoned by the orthodoxy of that kind of stuff. When I was in my twenties I left a job that I knew I wasn't going to be happy in, and went down to the States and worked in a social change community using Gandhian principles of non-violence for effecting social change. And lived there for several years, doing campaigns around neighbourhood organizing and housing issues, and anti-nuclear power issues, and anti-war stuff. And things like that. So there is a way in which that kind of looking for alternatives and being open to alternatives has always been part of my life.

Brian began receiving acupuncture and other treatments from a well-known local naturopath. He described some of the tests and treatments this naturopath uses as

stretching his credulity. He said, "They are a little beyond the pale, but this naturopath has such a good reputation that I've been kind of swallowing it whole."

When I asked Brian to clarify how he made decisions about what is credible and what is not, he talked about the need to balance his own experiences with what conventional medicine might say, especially given the limitations of the biomedical model. He also spoke about the importance of his prognosis.

A lot of factors come into it. I think it comes down to a felt sense. An intuitive felt sense of what feels right to me. And that has to have components of both the orthodoxy and my experience. I think the limits of the medical orthodoxy are that it does not allow for the spiritual, it does not allow for emotional factors, it doesn't allow for that kind of inner wisdom. It has to be logic.

It's a very, very patriarchal kind of model. And a lot of my experience has been challenging me on patriarchal assumptions and opening up to more intuitive parts of myself.

Probably if I was (pause) I mean, clearly my diagnosis was (pause) they were talking of, "This is prostate cancer, and it's treatable and probably curable." We are talking surgical cure. They are not talking management. I think if I was on my deathbed, I might have been more open to saying, "Okay, I'm going to pull out all the stops and do anything."

Two months later, when Brian and I met for our second interview, we began by talking about his surgery results. The specimen that was removed had positive margins, so the assumption was that the cancer had spread beyond the prostate. Brian was told that the odds of the cancer recurring if he did not get radiation treatment were about 50 to 60% but the chance of recurrence would be much lower if he had radiation. Brian's doctors recommended radiation, but he and his wife were not sure whether to agree to it because of the side-effects that might occur. These potential side-effects include erectile dysfunction and damage to the bladder or bowel. Brian reported hearing about new treatments that might be preferable.

There was an article in the *National Post* this past Saturday on cancer treatment and one of the things that they found is that if they do low doses, low regular doses on a long term basis of some of the same drugs used in chemotherapy—so, drugs that are already approved and would not have to go through an approval process—that they can successfully fight some cancers without attacking the actual cancer itself. What they do is they attack the formation of blood vessels that supply the cancer.

And this is a new discovery and it's making a big, big splash in the newspapers and therefore doctors are being inundated with calls about it. So, I don't know if that has any implications for me. And then previously, in the last month or so, there have been a number of other articles. One about somebody's research here in B.C., about some proteins that if you block the protein then the cancer doesn't multiply and they figure that that approach will be available in about two years for some preliminary trials and that's holding a lot of promise. This thing about the *National Post*, they're talking about possibly having it ready for some worst-case cancer cases by possibly December or January. So, really soon because the drugs are already approved. But they don't know that it works on people yet. They know it works on mice for that one.

So there is other things from conventional medicine that are coming up, that are showing promise, that make me wonder whether to do radiation or not because the potential damage that radiation can do is something I'd like to avoid if I can.

In addition to looking for conventional treatments that might replace radiation,

Brian was continuing to use alternative medicine.

I was chuckling to myself when I was anticipating our interview, because when I saw the naturopath last time, he's in a mode of preparing me for radiation. And from his perspective radiation has a significantly drying effect on the body, and so he wants to do things to both cool me down and keep me moist, whatever that means. So he's got a number of things that he is doing with me, acupuncture being one of them and prescribing meds and kind of evaluating the various things that I am taking. I am on quite a regimen of general immune system boosting stuff as well as a lot of other things that he's given me. But he gave me three new prescriptions. And he's got a dispensary where you can buy them, and these three I don't think I could get anywhere else. Well, the cost of the three prescriptions was four hundred and fifty bucks. And so, the reason I was chuckling was I started thinking, "Okay, now how do you decide when you are going to put your faith in complementary medicine or not?"

Brian started taking the medications he was prescribed but he was sceptical, especially about the homeopathic remedy, which is a substance that has been diluted many times.

It's like this little sachet of sugar. And I think, "What the hell am I doing?" And so, I don't have a lot of faith in it. And one of the things I sometimes think about with alternative treatments is, how much is the placebo effect? Or how much is that, "Well, if I spend the money, then I'll believe in it." Well, I don't really believe in it. And so I don't know if I'm just throwing away the money.

Brian had also searched the Internet again and had changed his diet based on information he found there. He reported eating more soya products and tomato products. He had also been reflecting on his psychological coping style and had decided he needed to be more assertive. This had prompted him to make some changes in the way he dealt with family issues. He also began using more aggressive imagery in his anti-cancer visualizations.

Brian talked about how the pathology report had prompted him to realize that he had to make some choices about many different aspects of his life. He agreed that the changed prognosis was prompting him to lean more towards "pulling out all the stops."

That's one of the things that this has done. It strips away the, you know, those assumptions we don't question about. . . . And the false impression that, "Yeah. We are mortal but that doesn't really apply to me. I don't have to think about it today." Well, guess what? You've got to think about it. You know? Because I'm young for a prostate cancer. It's got a lot of time to grow.

Even though Brian was spending significant amounts of money on alternative treatments at a time when his income was limited by being on medical leave, he expressed ambivalence about whether alternative treatments should be covered by public or private health insurance.

I don't know. I mean, in terms of public policy and funding, I don't see that it's realistic to fund the kinds of choices that I've been making. I am certainly taking my receipts and sending them to my extended healthcare plan. Some of them have been bounced back saying, "Sorry we don't cover this." And that's what I expect to happen with the \$450 prescriptions that I got. I mean there is so many experimental and unproven and hare-brained ideas of treatment out there. That I wouldn't want to see covered. As a taxpayer, I wouldn't want to see them covered. And if people want to try that, that's their choice.

I mean, this is where a lot of the thinking around, "Do I believe in the medical model or not?" comes down to where the rubber hits the road. Am I willing to pay for it with my tax dollars? And do I want it covered for my expenses?

And then it also brings into question the monopoly that the established medical and scientific regime has. How did the doctors get in such a privileged position? We hardly question that, you know. I don't know. I guess my faith in the medical system is stronger than my faith in the complementary. And I wonder how much my participation in complementary medicine . . . when my faith in it is because of what complementary medicine can do or because of the placebo effect. And I guess you can say the same thing of conventional.

Reflections

Brian's experience shows how the prognosis influences the judgments patients make about the legitimacy of different treatments. At the first interview, Brian believed that his cancer would prove to be treatable through surgery alone. He was using CAM approaches to support his mental and physical health generally but was assuming that conventional medicine would be able to cure his cancer. At the time of the second interview Brian was in a very different situation. His changed prognosis unsettled the balance he had initially created. He now had to find a different balance that took into account the probability of recurrence and the possibility of side-effects that would affect his quality of life. He was trying to make decisions rationally but could not ignore the anxiety that his changed prognosis had awakened.

During the first interview, Brian linked his exploration of CAM to his identity: he needed to establish himself as independent from the family medical tradition and he had a history of questioning established cultural paradigms. He seemed comfortable making situated meanings on the basis of a variety of factors: his faith in biomedicine tempered by his awareness of its limitations; his previous use of alternative approaches such as yoga; his naturopath's reputation; his own experience and intuitive wisdom; information from books about cancer; and information from the Internet. Like Joel, Brian responded to the challenge of cancer the same way he had responded to previous challenges. In Brian's case this meant reading as much as he could and integrating this information into a perspective that had strong roots in orthodox medicine but allowed for alternative truths when they were reinforced by personal experience.

During the second interview, Brian's struggle to find coherence and comfort in the face of his changed prognosis was palpable. The changed context had caused him to examine the available options more carefully, but it seemed that the criteria for making judgments had themselves become de-stabilized.

Brian believed the cultural models that assert a link between cancer and emotional states, so he was using interpersonal strategies and visualization techniques that reflected a new commitment to becoming a more assertive person. He also believed in the connection between diet and cancer, so was increasing his intake of foods that supposedly had cancer-fighting properties. The legitimacy of strategies based in these cultural models was not in question because the models fit within Brian's pre-existing worldview and he had little to lose by pursuing them. However, the legitimacy of his other options was more difficult to determine.

Brian was looking to medical science for a new breakthrough that might save his life. His faith in conventional medicine was bolstered by media reports of promising new treatments. But he was also acutely aware of the limitations of medical science since the currently available conventional treatment could not increase his chances for survival without risking life-diminishing side-effects. Further, he was beginning to question the privileged societal position of science and biomedicine.

At the same time, Brian was using alternative treatments that had been prescribed by his naturopath, even though he was sceptical of the theory underlying them and their efficacy. He expressed different degrees of faith in these alternative treatments at different times during the interview, indicating that he continued to be uncertain about their legitimacy. Further, he wondered how much of their apparent efficacy was attributable simply to the placebo effect.

For Brian, the cost of treatment was connected to the question of legitimacy. As an individual patient, he had enough faith in his naturopath to pay for treatments that, as a taxpayer, he did not consider legitimate enough to be covered by insurance. For Brian, the economic considerations were where "the rubber hits the road." Belief in a treatment approach is one thing, paying for one's own choices is another, and supporting the inclusion of a treatment in public health insurance is different again.

In Brian's attempts to create coherence, he relies on the biomedical discourse that is so familiar, as well as some alternative discourses that fit within his identity as an independent thinker, including discourses that are critical of biomedicine. But none of these are sufficient to address the prognosis that has brought his mortality to the

foreground, unsettled his identity and shaken earlier situated meanings.² The turmoil and vulnerability he expressed stand in stark contrast to the confidence of the next patient.

**The conversation with Angela:
“Erasing, rearranging, and creating personal meaning”**

Angela is a 54 year old retired teacher. She is separated from her husband. She has two grown children. She volunteered to be interviewed after seeing a poster about my research at Hope House. I interviewed her twice in her home: a basement suite in East Vancouver. Angela is short, with a matronly build and short, blonde hair. When we met she was dressed comfortably in grey sweat pants and a bulky, red, knitted sweater. Her apartment was small, with low ceilings. But it seemed cozy and filled with light. Both times we talked, we drank herbal tea, ensconced in overstuffed arm chairs.

Angela was diagnosed with breast cancer when she was 46. At that time she had a partial mastectomy, plus radiation and chemotherapy. She also began seeing a traditional Chinese medicine practitioner. Six years later, she had a recurrence in her ovaries, so she had a hysterectomy. A month later, she had another recurrence and had further abdominal surgery. She was told that she did not have much time to live. Chemotherapy was suggested but she chose not to do anything radical, although she agreed to take Tamoxifen. She continued seeing a traditional Chinese medicine practitioner. She has been taking Chinese herbs every day since then. She does many other things that can be categorized as complementary or alternative medicine. She meditates; she attends a group that does movement exercises designed to increase awareness and release emotions; she

² When Brian reviewed this profile, he told me that he had undergone radiation, but that his PSA count was still high. He had stopped seeing the naturopath because he did not perceive any benefit from his

is part of an ongoing support group for cancer patients; and she has attended residential retreats for cancer patients. As she put it, "I am forever constructing and creating something or another to maintain my health and to celebrate it." She has CAT scans on a regular basis and these scans show no signs of cancer. Her latest check-up was a month before our first interview.

Angela described her conventional treatment as "rugged" and "very, very, harsh."

Not only were the treatments harsh, but so was the way she was given the diagnosis.

I was just given (the diagnosis) in the hospital and that was a devastating thing and I didn't know much about cancer at that time, other than what is the common—I call it a myth. Cancer seems to equate to death. So all of those cultural . . . all that stuff came forward. And when I went to see the surgeon, fortunately my daughter was with me, and the surgeon said, "Well, yeah. It's cancer and if you don't do something you'll probably be dead in about six months."

And he rattled on saying some more stuff and my daughter said, "You need to stop for a minute. Excuse me. You know, back about five minutes ago when you told my mom she would have six months to live. I don't think she's heard anything that you've said since that point. I really don't. I think she feels so scared. I don't think she has heard you. So maybe you could just back up and go over that for her again and fill in a little bit."

So he did. Because she was right. I just like, (pause) the emotion took over. And the intellect couldn't follow the language that was being presented to me.

Angela's decision to use traditional Chinese medicine came out of a long-standing interest in the Chinese system of philosophy and living. Prior to her diagnosis, she had been eating macrobiotically, meditating, and living a simple lifestyle in the country. Since the counter-culture wave of the sixties she had been a student of Eastern spirituality, reading authors such as Krishnamurti, the Dalai Lama, and Thich Nhat Hanh, a Vietnamese Zen monk. Facing her own mortality gave her increased incentive to put their teachings about kindness and compassion into practice.

One of the gifts that I've received from being told that I'm going to die soon is that I have had a lot of really deep changes in the way I think and how I relate to the world. Really deep. But, the way of going for alternative or complementary systems of medicine or anything, is not new to me. . . .

The first round of, "You might die," put me into a mode of being committed to sticking to some of the things that I knew and continuing with some of the practices that I was involved in. The second was the ovaries, and then it was like, "Oh, it's here again." And, the last one was just like, "Well, this is for real." It really, really could happen. And it made me (pause). No, it allowed me—it didn't make me at all—it allowed me an opportunity, which I took, to admit that I really wanted to live. That I really did. And so I got really, really, really clear that I wanted to stay alive.

And then I decided that I would play it as if I was going to. And I would honour the process that I was in, even though it was very, very frightening. I would honour and hear the diagnosis and all the information that was given to me. And I'd hear the prognosis, but I wouldn't buy into it. I was willing to say, "I will take the attitude that cancer can be cured." And I know that isn't the common paradigm, or notion around cancer at the moment, but what have I got to lose? Why not embrace it? So I did. And I do. And I consider myself cured. And I don't have cancer any more. And I went about investing my life's activity and energy in practicing and celebrating life. So I continue to keep my choices in that realm of affirming life, and knowing that if I died, I died.

I have chosen to have the spiritual component always there. I don't see that we are only our bodies and I know that I am not my disease. I am not my job. I am not my (pause) or at least I am not only my disease and I am not only my job and I am not only my role as a mother and wife. Like, this is happening but isn't who I am. It isn't who any of us are. And I am more interested in seeing beyond that and actually acknowledging myself and all other people for, you know, being what I call the divine beings, or you know, cherished entities.

So, the fix-it thing is a component. It has to be. I mean if it wasn't for surgery and chemo I would be dead, possibly. There's good service but it's only one component. And it's not the only thing. And I also think that I participate in the disease to some extent in creating and living it and through it. I don't have a direct cause and effect like, if you think bad things and you don't eat well, this is cause and effect. I don't think that is useful to say, "You do this and this is what will happen." But it's along the idea that there is more going on than we can possibly have an idea of, and I don't know whether I genetically was predisposed to cancer. I don't even know if it's a disease. It's something that happens. And I know we believe that cancer is a disease and it's this and it's that, and those are things that we believe but we also used to believe that the earth was (pause) you know? (laughs) And people were *burned* for thinking differently.

When I asked Angela to clarify what she meant by saying that she wasn't sure if cancer was a disease, she expressed a perspective that reflected her years of experience with Eastern spiritual thought and practice.

If I say cancer is a disease I'm taking it out of myself. I am separating it. And I am putting it in the realm of the duality of—it's bad and it's separate and it's something that has befallen me. And that there is a reality which says that cancer is inevitable. That it is bad. And diseases are those things. They're something that's contagious. They're viral. They're bacterial. That one is searching for the cure. That it can be eradicated. It is something out there. The enemy is out there to attack. And, I, of course, lived with that. That's how we are.

And recently, I've been considering and practicing and I'm finding it very useful, not to pursue it in that vein at all. And to allow for the possibility that we don't know what any of this is. We don't even really know what a viral infection is. We don't know what disease is. We are just frightened. We put it out there. We try to eradicate it. And so, it has to do with, this is an occurrence. This is an experience. This is a part of being human. This situation occurred and I was in the hospital. These people did what they do and they're trained to do. And they did their thing and I did my thing. And my family did its thing. And we all did visiting and we all did our participating. Sort of like, you know (pause) living. What's the difference between doing that and going and having a meal?

And another component to that, or another way of making a mental module or construct for myself, is looking at it that I'm living the mystery of life. I am not solving it. I am living it. . . . One time I was sitting there and I thought, you know, I'd like to be able to see everything as sacred. And then I went, "Well, then do it! Go for it." (laughs heartily)

And as I started to go for it, then how can I say, "Cancer is a disease. It's a bad thing." If everything is sacred, then that means I am not allowed to choose. I can't go down that road of thought.

Angela extended these ideas to the debate around whether CAM is as legitimate as medicine that is based in science. She contended that the solution was not to believe in your beliefs.

Science is a belief so that's where (proponents of conventional medicine) are getting tricked. What they don't understand is that they believe that science is something. But it's a belief. And when I'm taking the Tamoxifen I'm taking it and I'm allowing myself to participate in the belief that Tamoxifen, you know, sits in the chair where estrogen would like to sit, and doesn't let it sit down. I'm choosing to accept that. That's a belief. It's not anything better

than when I go to an acupuncturist who is saying, "Okay. It's your kidney meridian that's weak." It's a belief. It's all belief. . . .

But anybody who has gone anywhere along the lines of Einstein, who has traveled a little bit with him, knows that there is no such thing as "fact." And the scientists are just hoodwinking themselves for pure self-aggrandizing and so (pause). It feels good to be important. Why not? (laughs)

Angela was comfortable combining approaches from both Western and Eastern medical systems and respected what each was able to contribute to her healing. But she expressed some criticisms of Western medicine. The Western doctors she saw expressed no interest in her use of CAM, even though she had outlived her prognosis. In addition, her Western doctors had no communication with her CAM practitioners. The TCM doctor she saw, in contrast, supported her use of Western medicine.

The Chinese doctor I go to was very, very much in synch with western medicine and read all my path reports, wanted me to do all the tests and kept saying, "No, no. We have to work together. We have to work together. They are complementary. Both work. Need them both," he would say. "The Chinese medicine will take care of some of your symptoms from the drugs and helps speed the cleansing process. We'll support your emotions. We'll support different things and get you towards a whole well being, including your spirit, your emotions, your body. And we'll do that, but the diagnostic component and some of the interventions like the surgery, some of the medicines, definitely all the diagnostics are really essential. They work together and they need to be going together." So it was easier for me to be with him because he didn't separate out. He used everything and respected everything equally.

Angela also noted another important difference between her conventional practitioners and the TCM practitioners she saw.

The difficulty I have—which is a sadness—and something that concerns me a great deal with the Western medical model and the way that it's practiced, is the form of communication that it takes. And I have talked quite a bit about this with other cancer patients and it's fairly consistent. And the problem is with the process of being positive and supportive. For example, with myself, at no time has any doctor—Western medicine doctor—said to me, "There's hope." What I've been given is statistics, that this is what could happen, you might have this much to live. So it's all fear-invoking and it's dismal. And

you feel very engulfed in a hopeless situation. And you feel that you are dependent on this medical model.

When you are that vulnerable, you are that sick, you are that in need; what you hear is, "If you don't do chemotherapy you are doing to die." That's what you hear. It isn't the exact words and so, you know, you can't go to the oncologist and say, "Why did you tell this woman that she was going to die." And the oncologist would say, "I didn't. I was just giving the statistics." It's a cop-out.

I think that both things can be given. The hope and the reality. Or the diagnosis and possible prognosis. But bring in hopeful scenarios. I mean, I am a case at hand. Honestly, the oncologist who met me last December thought I wasn't going to make it. I am sure that oncologist isn't saying to somebody who comes in, like I did a year ago, "Well, I know a woman, came in with the same MO as you've got, she's still trucking along." Whereas, when I was talking with the Chinese doctors that I've gone to, the thing that they start out with is, "This is really serious and the first most important thing is hope. Believe. Have faith. Be hopeful. That's the first most important thing. Is have that hope."

Well, when somebody says that to you, do you ever listen differently! Do you ever feel different! And that is what has sustained me from the medical people I've been with is that point of view of "We're going to work really, really hard. Have hope. Hang in there. It might not be very pleasant or comfortable but there is hope. There has been success." Neither of the doctors—the Chinese doctors—gave me misinformation or diminished the seriousness of the situation. They addressed it with the same clarity and intensity, but they added the component. "I like you. I'm going to work hard and there is hope."

Angela referred to this failure to understand how vulnerable and suggestible patients are as "the Achilles heel of allopathic medicine." She believed that this separation of doctor and patient was a strategy that medical professionals used to protect themselves.

I think the doctors have learned how to protect themselves and they don't realize what they are missing. And they don't understand that they don't need to protect themselves. I've often wanted to say, "Well, look. It's not going to hurt you any less, when I die, if you hold it all in now, or whether you have a relationship with me—that we communicate. It's still going to hurt the same. The hurt is going to be the same.

Angela also talked about how statistics are used when the diagnosis is given and how these exacerbate the fear and vulnerability that patients feel.

The statistics were not interpreted for me. I didn't ask for interpretation because I think, in part, I've been in education and it's like when you are giving grades. There's all sorts of statistics. So I've had some experience with statistics so I didn't bother asking. If you had no understanding of statistics, and that's what I'm listening to with friends and other (cancer patients). Is that they don't understand what the statistics are, and it's terrifying them. They think it's real. Like they don't understand that it's just a statistic. They don't understand that there's the whole process and they think it means, in reality, this is what's going to happen. Different than, "These are figures that we use to (pause)," you know.

That's where I'm hearing that it's terrifying for them. It was hard enough for me to hear that, and I know what the process of developing statistics is. And I still found it very disturbing and I had to go home and do my own erasing and rearranging and creating my own meaning for this information. But I know how to do that. And I choose to do that. I was able to get through it. I don't think that's common. I think it's very hard for people if they don't know what statistics are.

Angela argued that, in order for the kinds of problems she had experienced to be avoided, patient-practitioner relationships had to be based on a different model than was typical in Western medicine.

That's where there has to be some kind of realization, and I see it growing amongst my friends, of the patient's input. And this process of hierarchical thinking and hierarchical behaviour . . . When I go to see any doctor, I do not go thinking that they are superior to me or have any more information than I do. I see them as a human being equal to myself who has information that I may need and I don't have. And I have information that they may need and don't have. And we are two people sharing. And I won't buy into, "Somebody knows and somebody doesn't." And I think that's what we have to focus on. Is that there isn't somebody who knows and somebody who doesn't. There isn't somebody who has the answer and somebody who *needs* that answer.

And patients have to start seeing themselves as going to this person to share and to share something from themselves so that they are equal. Like their honesty of experience and their questions. It's definitely a two-way thing. And holding that notion, I think, is the trick.

Reflections

When Angela was diagnosed with cancer, she was already aligned more with Eastern ontology and epistemology than conventional Western ideas. She had been living a

counter-cultural lifestyle for decades. Cancer did not threaten her identity or her ideas. Instead it strengthened her resolve to practice and embody her spiritual beliefs (including the resolve to avoid being attached to beliefs). She continued to engage in individual and group pursuits that she saw as contributing to her growth and healing.

The legitimacy of different approaches to healing did not seem to be a crucial issue for Angela. She considered every approach legitimate. Every approach had its place and deserved to be respected. And even though every approach was fundamentally limited by its being a construction, a belief system, this did not make the system illegitimate. It simply made the system more ephemeral than most people realized. For Angela, this was all part of living the mystery of life. She was comfortable taking part in the conventional Biomedical discourse when that was appropriate and necessary and equally comfortable with the TCM discourse and other CAM discourses, which she saw as complementing Western medicine. The coherence she made of her situation was rooted in her commitment to value not-knowing instead of striving for a linear, logical certainty.

In making sense of her situation, Angela rejected many Western cultural models. She chose not to make cancer part of her identity. She chose not to buy into the cultural "myth" that cancer is incurable. She even questioned the dominant cultural models about the nature of disease and the actuality of science. Instead, she drew on Eastern models about non-duality and non-attachment. Her alignment with these alternative models made it easy for her to integrate divergent beliefs and practices and to reframe information and beliefs that she felt did not serve her (e.g., the statistics related to her prognosis).

Angela's emphasis on the way that Western and Eastern practitioners in her experience either withdrew or provided hope is interesting in light of her stance on beliefs. It may seem contradictory to assert on the one hand that beliefs should be transcended, and on the other hand, to criticize conventional doctors for failing to inculcate a belief in the possibility of healing. But Angela's stance may well be a reflection of her awareness of the power of language and the way entire Discourses are invoked through the use of certain words and behaviours. This awareness likely comes from previous experiences of examining beliefs and their origins in social conditioning and attempts to disengage from deeply-held beliefs (e.g., her earlier rejection of the dominant Western worldview and her adoption of an alternative Eastern worldview).

Angela described how conventional physicians use statistical rationales for their treatment recommendations and are careful to maintain a distance from their patients. This stance of scientific objectivity and of statistical certainty is an integral part of the Discourse of Biomedicine. Angela was able to resist this discourse, to erase and rearrange the information to create her own meaning. But even she found her interactions with conventional doctors disturbing. And she believes that most patients invest the information they are given with more predictive power and more veracity than they should. Angela suggests that this invocation of the weight of Biomedicine is especially harmful when it is connected with a diagnosis of cancer because it comes at a time when patients feel dependent, vulnerable, and afraid. And she suggested that this Discourse is being used as a shield against practitioners' own vulnerability and fear.³

³ Several months after our second interview, Angela was diagnosed with a new primary cancer. She underwent further conventional treatments, including chemotherapy. She continued using alternative treatments. She died two years later.

The next patient's situation provides an example of how some people are enacting new roles with respect to health care decisions that run counter to the expectations of the Biomedical Discourse.

**The conversation with Marcia:
"This is my body and I decide."**

Marcia is 50 years old, single, and a lesbian. She is self-employed. She is tall, slender, with very short, graying hair. We met for one interview in her basement apartment. The combination living room, dining room, and kitchen was small and spare. A folded-up massage table leaned against one wall. The space had a Zen-like quality of serenity.

Marcia was diagnosed with breast cancer a year before our interview. When she first received the diagnosis, she did not want to have any conventional treatment. As she put it, "I just didn't, couldn't see the value in any of those things." She immediately got in touch with an alternative practitioner whose approach to cancer she had read about in a local New Age magazine. On the basis of the stories of patients who had been helped and the practitioner's confidence, Marcia decided to begin the treatment. She paid \$25,000 for an immune system-boosting regime that consisted of very high dosages of vitamins (including intravenous Vitamin C), minerals, and other supplements, including protein supplements, and digestive enzymes. She was giving herself an injection and taking 250 pills every day. When I asked her if there was any scientific research regarding the approach she was using, she responded angrily.

What's that going to tell me? Tells me shit-all! It doesn't tell me anything. What's that going to tell me? That people of undescribed situations, undescribed ages, undescribed races, if they took a placebo, this happened and if they took something else, that happened. Placebo alone is worth 30%. Chemotherapy, I was told, had a 12% chance of helping me. Placebo would be better than chemotherapy.

Well, it's the same when I go to a doctor, what can they tell me that is going on in my body? Nothing. What are they testing? What are they noticing? What are they picking up in the bodies? Like I don't get it. Every scientific advance has been made by intuition. And they want to discount intuition. It's like, excuse me, I don't get it.

Marcia rejected her oncologist's recommendations about chemotherapy and radiation but eventually agreed to have a lumpectomy to remove the tumour. She described being "shocked" by the conventional treatment she received at the time of the surgery. She felt she was not given enough information about the surgery or about the post-surgical care she needed.

After six months on the intensive alternative treatment regime, Marcia went on to a lower-dose maintenance program. Within a few months, she was diagnosed with cancer again, this time in an axillary lymph node. She then returned to the intensive alternative regime.

Marcia expressed a strong and long-standing disenchantment with conventional medicine because of its inability to provide her with knowledge about what was happening within her particular body.

I never had anything to do with it in all my adult life. I've done all my healing through bodywork and psychic, intuitive stuff. In most cases, conventional medicine is not sensitive enough. It just can't tell me what's going on in my body. All it can do, all they can do is say, you know, "Based on what I've seen or what I know, I'm going to give you this." "But do you know what's going on in my body?" "No." And they still don't know what's going on in my body. All they can say is that I have a lymph node that is cancerous. They can't tell me how my metabolism is doing. They can't tell me what organs in my body are stressed. They can't tell me where the cancer is in my body. Like, where is this scientific advance? You know, they can't tell me anything. All they can say is, "It's here. We'll cut it out." What is that? I mean, I want to know what's going on in my body.

Marcia also objected to the conventional doctor-patient relationship.

Sometimes it seems like, you know, if I go to them, then it's like they get to decide. And it's like, no, no, no. *I go to you and I get to decide.*

And a lot of doctors don't seem to understand that. Even my surgeon. They don't seem to understand that this is my body and I decide. So there is a lack of trust and a lack of credibility in dealing with people who don't know that this is my body and I decide. So it's partly fear and avoidance. So that's definitely an element of it. It's like this is not safe for me. I'm not being taken care of. I didn't feel taken care of with the surgery. You know, don't feel taken care of. My needs are not being met. You know, it's not supportive. It's not kind. I am not being properly informed and my choices are not being recognized.

She contrasted conventional medicine's inability to reveal what was happening in her particular body with the ability of CAM approaches.

And then on the other side of things, I think part of it would be over the years tuning in to different things that have felt wrong in my body and trying to find out, so what is it? And finding the best source of information is people who have some access to intuitive senses. So whether they use kinesiology, or the muscle testing, or you know, like iridology, or something (pause). Somebody who can read my body and say, "This seems to be going on in your body right now. And this is what I recommend from my practice that would get it organized." And there are many, many different disciplines that can do that. And, you know, they are all different and they all have a different thinking and different kinds of things that they do. But it seems like there's many different ways to do that.

In her description of her perspective about the nature of health and healing, Marcia said that she believed the mind played a central role in the process of achieving harmony or balance. She also talked about what she believed to be the cause of her cancer and the role that emotions played.

I see cancer as being caused by environmental stresses. That's my personal opinion. And that's why there is so much of it. And it's an opportunity to do (pause) for me (pause) it's been an opportunity to do emotional work, primarily physical and emotional work. Like it seems like spiritually, I'm okay. But I've done a lot of physical and emotional work. Because what cancer brings up is death, and one of the things to deal with is will-to-live. So all the places where my will to live is weak have come up and have had to be addressed. So it brings up (pause). Last year I was pretty well traumatized the whole year 'til about December. So when I first had cancer, it was like a physical (pause), you know, recovering from the surgery and surviving the

day, and can I do housework, and what help do I need. And when that started to calm down, willing-to-die came up. And I spent the rest of the year willing-to-die. . . .

I didn't know I was willing to die. I had no idea I was willing to die. . . . It's probably different for everybody. But when I was trying to figure out (pause) okay, is there a meaning or something associated with my lump, when I still had a lump, the issue that came up for me over and over again was loneliness. And I am very independent and self-sufficient. And as coping mechanisms for loneliness they've been very successful. I am not aware of being lonely. People asked me if I was lonely and it was like, "Nah, I'm fine."

But when it came right down to it, you know, from my childhood and whatever, there is a certain sense of isolation. And it's very well protected and organized and you know. It takes a lot to unravel it. And to allow the distress to come to the surface.

When she spoke of the factors she believed contributed to her illness, Marcia mentioned that in the years before her diagnosis both her parents and two other family members had died, so she was experiencing a lot of grief. She related this to the Taoist idea that extended depression causes weakness in the organs. She summarized the emotional cause of her cancer as being a long-standing issue with loneliness or isolation that was exacerbated by the grief arising from her mother's death. She also mentioned that both her parents and her aunt died of cancer, but she seemed not to consider genetics that important. She believed that the emotional factors made her vulnerable to environmental factors that weakened her immune system.

I would say the actual cause of my cancer would be vaccines when I was young. Having been on the birth control pill in the sixties and seventies when it wasn't a very good pill and I was under twenty. Lack of good quality air from having lived in various cities in my life. I would say those would be what entered my body and weakened my immune system. Now, why do *I* get cancer instead of somebody else getting cancer would be the (emotional) factors.

Marcia said that the conventional doctors she had seen were upset that she was not using conventional treatments. She was indignant that they did not give any credence

to what she was doing to promote her healing. She also believed that people like her who reject conventional medicine are in turn rejected.

Well, if you don't do what you are told, you are disappeared from the awareness. Like all the studies are done on good patients. So anyone who is not a good patient or who isn't following the rules, they go into nowhere-land, right? Now you do not exist as a cancer patient. I don't exist as a cancer patient. I am a non-existent cancer person.

Reflections

Marcia is an example of the small minority of cancer patients who reject conventional medicine and use unproven treatments, even when conventional medicine offers some chance for healing. Marcia's rejection of conventional medicine pre-dates her cancer diagnosis. Her criteria for medical legitimacy go beyond the usual concerns about safety and efficacy. She requires that a credible healing approach be able to tell her exactly what is going on within her particular body. It is not enough to have knowledge about "the body" in general or about groups of patients. Medical science is discounted because it is not sensitive or specific enough to shed light on her individual situation. In addition, developments of medical science (i.e., vaccines and the birth control pill) are seen as toxins that cause cancer.

For Marcia, legitimacy seems to depend on there being a connection between a plausible explanatory model and her own experience. Marcia's process of making decisions reflects her allegiance to unconventional cultural authorities, practices, and models. The Biomedical Discourse does not hold as much weight as Marcia's own assessment of a practitioner's personal power, her trust in alternative information sources, and her perception of a treatment's fit with alternative models about the body that she has come to believe.

Marcia objects to the expectations about the patient–practitioner relationship that are embedded in the Biomedical Discourse. She very clearly sees her body as her territory, her domain. She has developed some beliefs about how things work in that domain in the course of working through previous disharmonies and she is not willing to surrender the agency she considers crucial to good decision making. But she is willing to consider knowledge gained by others who have legitimacy in her eyes—those who are intuitively sensitive who can “read” her body’s signs of distress.

In explaining her use of alternative medicine, Marcia draws on cultural models that are not only associated with alternative medicine: e.g., the model that connects cancer with immune system weakness and the model that affirms a patient’s right to choose. She also draws on cultural models about intuitive knowing and the links between psychic factors and illness. These models differ from biomedical models about the body and the causes of illness, and are more radical than mainstream psychosocial models that posit links between emotions and health. The importance she places on her discovery of her willingness to die (as opposed to the will to live) and her attention to the feelings of loneliness and isolation that she connects to the lump in her breast are congruent with models that posit emotional and psychic healing as the foundation for physical healing.

Marcia seemed strongly identified with some parts of the CAM Discourse. So strongly identified in fact, that she was willing to stake her life on her allegiance to that Discourse.⁴ And yet, she wanted her identity and her agency acknowledged by the conventional system. She was distressed that, because she was using a treatment that was not considered legitimate, the legitimacy of her personhood was denied. She had

disappeared into nowhere—land, become non—existent. Her experience is a poignant demonstration of the power of Discourses to both create and erase.

The next patient also experienced this power of erasure, but in a different way.

**The conversation with Linda:
“The terror nobody is addressing.”**

Linda is a 40 year old office administrator. I interviewed her twice in her small basement suite, where she lives alone. She is Chinese, with short dark hair, and a lively manner.

Linda was diagnosed with breast cancer just over a year before our first interview. She had surgery followed by chemotherapy and radiation. When she was on chemotherapy she also did acupuncture and took Chinese herbs to boost her immune system. It was natural for her to use traditional Chinese medicine because it was part of her culture and she believed in it, but she had to stop when she could no longer afford it. She also did yoga and went to a number of different support groups.

Linda had a very hard time deciding whether to do chemotherapy. She was given frightening statistics regarding the probability that the aggressive type of cancer she had would recur. Chemotherapy and radiation were presented as being able to increase her chances for survival, but she was concerned about their side—effects. She did as much research as she could. But in the end she made decisions that she felt were pretty arbitrary.

What happened was I was probably doing the dishes or something like that, and I just, I had all this information in my head, it was all conflicting, it was totally up to me, it was (pause). It's like they take all your power away and then they tell you, “It's your decision.” Do you know what I mean? They

⁴ About a year after our interview, I spoke with Marcia and she said that her conventional doctors believed she was dying, although she believed her alternative treatments were working. About a year after that, when I tried to contact Marcia to have her review this profile I learned that she had passed away.

either don't give you the information truthfully, or they give you misleading information, and they sort of make you feel like, "We're God. You should do what we say." But then they won't take the responsibility for that. And they let you make the decision although you are not an oncologist. You don't know anything about this and you need help with deciding it. They won't (pause), they won't do that. So, (pause), because then you could sue them. Right?

And it was so frustrating because I kept finding more information and I kept thinking, "Okay, this is going to (pause)." I would phone this place, I would phone that place. I would research this, research that. Right? And I would always be feeling like I wasn't doing enough, because I would hear somebody else who had got more. And so it got to the point where I think I just rebelled. Like I don't know what other women would do if they didn't have a rebellious nature. In a way I am glad that I have a rebellious nature, because I just said, "That's it. Fuck it. I can't do this anymore. I am going to do *that*. And I am going to do acupuncture. I am not even going to think about it any more because I can't." It was too hard to try and find an answer, right?

During the course of her treatment, Linda decided she needed emotional and spiritual support. She tried to find what she was looking for in several different groups. Some were in conventional settings; others were in complementary/alternative settings.

The support group, instead of being about what we were going through and how it affected our lives—that kind of stuff, which is what I assumed a support group is for—instead of being about that, it ended up being about exchanging information. So one woman would say, "Oh, well, I'm doing this. I've got this book and I'm doing this." And then another woman would go, "Oh, well, I didn't know about that. So could you tell me about that." And basically though, it never ends. Because there's a zillion cancer books out there. Most of them are useless. And so, it was this competition and it was all to allay this terror that nobody was addressing.

And what it did to some of the women, me included, was we just got totally fed up. We couldn't take it any more. And so we went back to eating hot dogs or whatever it was that we did. We went right back to the way we were before we got cancer. And we ended up just doing what made us happy. Whether that was proper or not. Whatever form that came in.

There was no room for your reality if your reality was not (pause) I guess a conventional reality. Which would be that you are not too poor, you're not too dark, you're not too negative and you talk a lot about appreciating things and keeping positive and stuff like that.

Then you get, you *do* get better health care. You get talked to nicer in the hospital and stuff if you do that. I learned to do that. I mean, I did that after a while. And if you make sure you are grateful to the doctors. Like, at first,

after my surgery and before my chemo, was a really hard time because I was in shock still and then all of sudden I had to deal with being scarred and so I had to deal with this whole body image thing. Which was never addressed. Never, never, never addressed.

I couldn't believe it. You know, and I tried to bring it up. And, nobody would acknowledge it. I just dropped it. But it was hard because I was challenging the oncologist. I was saying, "Well, I want a second opinion. I want this. I want that. What about this? What about that?" Because I was angry and I was terrified.

I saw really quickly that if you aren't that way, you know, appreciative and basically submissive, right? Then they will withdraw. They will withdraw efforts to help you, right? If I was thankful all the time and agreed and kind of, you know, said, "Oh, thank you," you know, whatever, then I would get more information, right?

If I said, "I want a second opinion. I don't understand why this is happening," then I would get less information. They just wouldn't come forward with it. They didn't have to. I mean, nobody knows what to do about cancer but they won't admit it. The medical profession cannot admit that they don't know what to do.

So they put it on to you. So a lot of the damage, I think, happens when you're sort of demonized for having (cancer), right? Then you are told to be positive.

Which means that you can't be depressed, you can't be angry. You can't be scared. You can't be sad. You can't grieve. You can't do anything. So what would happen is that I would be in these support groups and you could feel the terror right underneath the positive thinking. It was like, right there.

I mean, cancer is cancer and people react to it like, "Oh, my God, it's the worst thing in the world." And yet in that venue, there's this denial. Right? There's a denial of what it actually is. Like it basically, what it is, is that you will never have your life back again. You will never know ever again how long you have to live. So your whole way of living has just been destroyed.

And you could talk about that, but you have to end it on an up note. So you'd have to say, you know, "My whole life has changed but I am so grateful for every day that I have now." Like you have to do it *that* way. Right? The amount of denial is the kind that makes me feel like I'm in a cult. It's so pervasive.

I asked Linda if she experienced this phenomenon in complementary and alternative settings or just in conventional ones. She replied, "In some cases with the alternative people, they even wanted it more because the New Age stuff kind of got in there too. So, there was even more of that, 'You are your disease and you can get rid of it.'"

Reflections

Linda's situation shows how different medical Discourses confuse and constrain patients.

With her diagnosis, Linda found herself entering what could be called the culture of cancer. Linda saw this world as being destructive enough to be called a cult. She felt that certain emotions and behaviours were required of cancer patients while others were taboo. Being given the diagnosis brought her under the influence of cultural models about what cancer means: it is "the worst thing in the world;" cancer patients are "demons;" as well as models about how patients are supposed to respond to cancer: e.g., by eating right, and by expressing the right emotional attitude—upbeat, grateful, and positive.

Linda felt that all of her emotional pain—her uncertainty, her anger, her grief over the loss of her breast, and the loss of her taken-for-granted life, her fears about death—was disallowed, not only by the conventional cancer discourse, but the alternative cancer discourse as well. In fact, the alternative cancer discourse may be even more dismissive of patients' suffering because of the alternative models that assert that cancer and its healing are dependent on emotional, psychic, and spiritual states. Linda's comments expose the deep contradictions in the dominant cultural models: cancer is terrible *and* the appropriate response is to be confident and grateful.

Not only are cancer patients supposed to behave in certain ways in order not to make other patients and professionals uncomfortable, but, in Linda's experience, the quality of the care they receive depends on their compliance with the cultural models. According to Linda, if she did not behave according to the cancer models about being hopeful, and the biomedical models about being grateful and submissive, her care providers actually withdrew information and care. She learned how to participate in the

Discourse in order to receive the care she needed, but she continued to rail against what she saw as the pervasive denial of the reality of both patients' pain and professionals' fundamental ignorance about cancer.

In addition to Linda's refusal to align herself with the dominant discourses around cancer, she also rejected the expectations of the biomedical discourse with respect to the patient-practitioner relationship. Like Marcia, Linda objected to conventional medicine's norms about patient behaviour. But while Marcia felt confident about her knowledge base and her ability to make good decisions, Linda was searching for answers in a context where there was too much information and not enough clarity about how to judge its veracity. Linda saw the Biomedical Discourse as putting patients in an impossible situation. Doctors carry an aura of infallibility. They hold the body of necessary knowledge, but they do not share their knowledge completely or accurately. At the same time, they demand that the patient make the final choice about treatment because of their fear of legal liability.

In the end, Linda did not make treatment decisions according to a coherent set of criteria for legitimacy. She made decisions out of exhaustion and in a spirit of rebellious pragmatism. As was the case with many of the patients I interviewed, faced with an uncertain future and contradictory discourses, Linda relied primarily on her own identity, her own values and pre-existing coping strategies to find meaning and coherence.

The next patient also relied on his identity and familiar coping strategies when faced with uncertainty about what treatment to pursue. But for him, the questions provoked by the cancer experience were more political than personal.

The conversation with Jack:

“Hands-on all the way”

Jack is a 48 year old, single, firefighter. He volunteered to be interviewed after being told about my research by the oncologist he sees at the local cancer clinic. I interviewed him at the fire hall where he works. Jack is tall, with a sturdy build. He looks fit and healthy, although a little overweight. At the time of his cancer diagnosis, when he was 45, Jack was doing triathlons and lifting weights. He was found to have prostate cancer after requesting a PSA (prostate specific antigen) blood test as part of a routine check-up. He insisted that he get the test even though the digital rectal exam the doctor did was negative because he had been advised by a friend to demand the test. His PSA level was high so a biopsy was done after antibiotic treatments failed to reduce the PSA reading. The biopsy revealed that his prostate was “loaded” with cancer and showed some signs of invasion beyond the prostate. Jack’s urologist recommended surgery and his oncologist recommended radiation. It was predicted that these conventional treatments would give him a 60% chance of survival but would likely result in impotence and incontinence. Jack was not willing to become “a eunuch wearing diapers.” So he went to the Internet looking for a “plan B.”

Prior to his cancer diagnosis, Jack had very little experience with the health care system because he had always been so healthy. He found himself on a steep learning curve. He spent days on the Internet, on the phone, and at the library, educating himself about prostate cancer and all the available treatments, both conventional and alternative. Jack said he had been good in school so he approached this as “just another scholastic endeavour.” By chance he intercepted an e-mail from a man who was on his way to receive treatment at a private clinic in California. After learning more about this

treatment Jack believed it would offer the same chance for survival as the treatments recommended by his local doctors but without the side-effects.

Jack's plan B consisted of anti-testosterone hormone treatment prior to radiation using a new proton beam technology that is only available at this one clinic in California. This was followed by conventional photon radiation at the cancer clinic in Vancouver. Jack paid \$50,000 out of his own pocket for the treatment he received from the private clinic.⁵ Jack himself ended up making decisions about how much of each type of radiation he should have and for how long. He chose to get a higher dosage than was typical because he believed he was younger and stronger and would be better able to tolerate radiation than most prostate cancer patients. Jack felt comfortable doing this because he felt he had educated himself to the extent that he was the one who had the most knowledge about his particular situation.

I was hands-on all the way. I got kicked out of the doctors' offices and all the rest of the stuff because I said, "Well it's me and I'm handling the show." And even like the guy who handled me at the Cancer Clinic, I said, "You got a problem?" He's a nice guy. I said, "Do you have a problem with me saying, 'Here's what we're doing.'" He said, "No, not at all. It's kind of nice." So he was fairly, kind of proactive, in that situation and that's great. So he didn't have to give me any of the lie lectures or anything because he knew that I knew what everything meant. And not, "Well you'll be fine." It was like, "Well you know what you're going to be, so I won't go there." So he was very good.

Jack took this approach after receiving advice from other prostate cancer patients.

There's so many guys that are so involved who are, well, quite angry with the whole way this is being treated and one guy said, "You have to become the best student of your problem because you can't trust anybody else to treat you." And I thought at first, "What's he talking about? I've got the best urologist in town."

⁵ The Fire Fighters' Benevolent Association later reimbursed Jack for the majority of the cost of his treatment.

Well (later) I sent him a couple of e-mails and phoned him and said, "Were you ever right." I said, "If I left it in their lap and they made all the decisions I shudder to think where I'd be today."

And so it's so true, if you're not a hands-on patient you're getting poorer service from the physician. And this is not a vendetta against the physicians. I mean, we know how busy the medical system is and how antiquated their tools and equipment is. I mean the government won't pay for them to get any more education on top of what they've got. I mean, they are in a pretty ugly spot. So it's not against them, but it boils down to the fact that if you're a patient and you're getting lousy treatment the only way to get around that is to become a bit of a physician yourself. If you're not hands-on, you don't get the best treatment.

Jack also took cesium chloride, which is supposed to affect the oxygen metabolism of cancer cells. He also went to a local clinic that provides complementary and alternative cancer therapies but he did not become a patient there. When I asked Jack how he determined what sources of information were reliable, he made a distinction between "chemical alternatives" and "hocus pocus." He judged chemical alternatives using several criteria: the evidence that was cited and the theory behind the treatment had to make sense to him; claims that the treatment cured everything or everybody were not credible; and price. He dismissed mind-body approaches such as meditation as being potentially helpful to one's mental state, but not effective against the disease itself. Despite having confidence in these guidelines, Jack knew his decisions were fraught with uncertainty.

You've just got to take a lot of stuff with a grain of salt and you should. And you're shooting in the dark. You've got to look in the mirror and go, "Cross my fingers and hope I've picked the right one," or whatever, because you are shooting in the dark. No one knows.

The experiences Jack had with the Canadian health care system made him angry. He compared the free screening mammography program that is available to women over 40 to the practice of men having to pay \$25 for a PSA test unless their doctor finds

clinical signs to justify the test. He pointed out that two physicians failed to detect any problem with his prostate in their physical examinations and he showed no symptoms of cancer. He believed that these different policies regarding two cancers with similar prevalence and mortality rates are discriminatory and reflect men's failure to advocate for more effective screening. He stated that his physicians had told him, off the record, that the medical system could not support the load of diagnostic and treatment procedures that would be required if there were an effective early detection program for prostate cancer. Jack asserted that the U.S. system does a better job of testing for early disease because of the concerns in that jurisdiction about avoiding medical litigation.

Given Jack's concerns about the number of men in their 40s and 50s whose prostate cancer might go undiagnosed until their disease is advanced, Jack began educating other firefighters about the need for early PSA testing. He successfully lobbied the firefighters' benefit association to pay for the cost of PSA tests for their members. He said that he had saved more lives since getting prostate cancer than he had in his 25 years as a fireman.

But for Jack, this was not enough. He asserted that the Canadian health care system is fundamentally flawed.

From what I've seen, and this is just a straight layman, it is so screwed up. It's like a house where you've started with a foundation uneven and then they started to build up and then correct and correct. And you had five different engineers and now you've got just an absolutely huge monstrosity that's been there for so long and so many people have so much interest in it that they don't want to tear it down and yet you have to spend twice as much money just to keep it standing. And it's not working.

Having seen what can be done in a system that includes private clinics, he questioned why Canadians are so committed to the principle of universality.

In a utopia it would be nice if we had nirvana and everybody got the same as everybody, it'd be cool. I'm just curious as to why somebody threw a dart at the board and went—medical—that's where we're going to draw the line. I can't figure out why, somehow, somewhere, they drew the line *there*. I mean you wouldn't have as many sick people if they drew the line with, "We all get the same food, healthy and nutritious, and the same water and the same clothing and housing."

Reflections

Jack is different from the other patients whose situations have been profiled. He did not have any interest in any of the philosophical or ideological aspects of complementary or alternative medicine, either before or after his cancer diagnosis. Jack's exploration of alternative cancer treatments arose from his unwillingness to lose his sexuality and his sense of physical mastery, two very important aspects of his identity. His decision making was heavily influenced by his participation in Internet-mediated networks of cancer patients. The treatments he chose were not based on conceptual models that were substantially different from conventional biomedical models. Rather, from Jack's perspective, these treatments were advances on what was available through the conventional Canadian medical system. They simply had not been around long enough to be legitimized by the usual means.

Jack's experience of cancer did not seem to prompt him to question biomedical models but it did cause him to challenge the way the delivery of medical care is structured in Canada. He became convinced that, because the medical profession lacked up-to-date equipment and education, patients had to become hands-on decision makers. The dominant role he played in his care seemed to be rooted more in a pragmatic concern for his own welfare than in any allegiance to cultural models about patient choice or the moral rightness of more egalitarian doctor-patient relationships.

In Jack's criticism of the Canadian public health care system, he drew on cultural models that are becoming increasingly prevalent in the debate about the future of the health care system: the system is inefficient, fundamentally flawed, distorted by special interests; and people should be allowed to pay for private insurance and private care if they can afford it. He challenged the legitimacy of the Canadian master model around the sanctity of universal health care by pointing out its apparent arbitrariness.

While Jack's experience of cancer did not seem to destabilize his identity or the ways in which he found coherence in his life, it did prompt him to conclude that the Discourse of Canadian health care lacked coherence. The resulting anger prompted him to become what could be called a prostate cancer activist. He began advocating for the reallocation of societal resources and the realignment of political choices.

Jack's situation demonstrates that people who are making decisions about cancer treatment are not only subject to the Discourses of Biomedicine and CAM. They are caught up in larger public discourses as well.

The profiles presented in this chapter show that patients strive to find coherence and meaning in the face of the challenge of cancer; this is not surprising. What is noteworthy is that the coherence they "jerry-rig" is not necessarily all that coherent. The examples in this chapter show that situated meanings can be unstable, contradictory, and linked to competing cultural models and Discourses. They are truly situated, i.e., dependent on circumstances and contexts that are uncertain and changeable. The next chapter presents the perspectives of conventional practitioners. Their experiences demonstrate that being firmly entrenched within the Biomedical Discourse brings other kinds of uncertainties.

Chapter Five

Biomedical Perspectives on CAM's Legitimacy

Introduction

In this chapter I discuss conventional medical practitioners' perspectives on cancer patients' use of Complementary and Alternative Medicine (CAM). The material in this chapter is based on individual interviews I conducted with professional staff from the British Columbia Cancer Agency (BCCA). When I did these interviews I was impressed by the substantial nature of this embodiment of the Biomedical Discourse. If war is being waged on cancer, places like the Vancouver Cancer Centre are the fortresses, the command centres in that war. The entrenched legitimacy of this institution is unmistakable. All the signs and symbols of sociocultural medical power are here: the expensive technological equipment; the doctors in their white lab coats; the nurses in their sensible shoes; the technicians with their clip boards and files; and the support staff bustling about looking harried. One thing that is striking about this setting is the amount of financial and human resources that are invested in it. While this chapter focuses on the language and ideas expressed by people who work within this environment, it is important to remember that these textual elements are embedded in a Discourse that has a

complex material, social, and political infrastructure that has enormous weight and stability.

I interviewed six oncologists (three medical oncologists and three radiation oncologists) and three nurses. Most of the oncologists had more than ten years experience in cancer treatment and research. The nurses had varying lengths of service in specialized cancer care. These practitioners responded to invitations to take part in the research that were sent to BCCA professional staff. The practitioners selected themselves for inclusion based on their interest in the topic and their belief that they had something to contribute to the research. Among the conventional practitioners I interviewed there was a remarkable homogeneity in practitioners' views about the issues they face as CAM and Biomedicine converge. As noted in chapter 3, the practitioners who volunteered to be interviewed did not express extreme, oppositional views about CAM. In fact, a small number likely view themselves as having their feet planted in both worlds.

The material in this chapter is organized according to three topics that were covered in the interviews that are most relevant to the dissertation: the use of CAM by cancer patients; patient-practitioner relationships; and science as a source of legitimacy. The focus in this chapter is primarily on the political and epistemological aspects of the issues that are arising with the convergence of CAM and Biomedicine, since these are what have become most unsettled for biomedical practitioners.

The previous chapter focused on individuals with cancer. It presented cancer patients' personal stories and perspectives. This chapter focuses less on the personal and more on respondents' roles and the implications of their position as insiders within the Biomedical Discourse. The quotes in this chapter come primarily from interviews with

four oncologists. The quotes have been selected for their cogency and salience. While the the nurses I interviewed are not often quoted directly in these pages, nurses' experiences and perspectives provided important richness to my understanding of the biomedical context.

The people whose thoughts and opinions are presented in this chapter are not living with cancer in the way patients are. Professionals in the oncology field live in a different relationship to cancer. Within the dominant cultural model that portrays an encounter with cancer as a battle, they are "the troops."¹ They make their living in opposition to a disease with which they become intimately familiar. It is also their mandate to care for people who are ill with cancer. It is often difficult to combine these two activities: fighting the disease and caring for the person who is ill. But, in contrast to the patients profiled in the previous chapter, the practitioners whose views are presented in this chapter are not struggling to create meaning or coherence by drawing on a variety of cultural models and conflicting Discourses. Their professional identities and allegiances are clear. They are living within the Biomedical Discourse, a Discourse that enjoys a hegemonic sociocultural position. The primary question related to CAM for these practitioners centres on how their work is affected by the CAM Discourse.

As CAM and Biomedicine converge, conventional oncology practitioners are in a difficult predicament: they are already experiencing stress and overwork because of the demands of providing cancer care in a health care system that is hampered by financial cutbacks and staff shortages; they are meeting patients who expect them to be knowledgeable about a multitude of different CAM therapies and their potential

¹ During the time I worked at the BCCA I often heard staff refer to professionals who worked in the oncology field as "the troops."

interactions with conventional treatments but they have little time to spend educating themselves and few sources of knowledge they consider credible; they are interacting with patients who expect them to adopt new models of patient–professional relationships; their professional motivation and commitments are questioned by critics of “the cancer establishment;” and while they are aligned with biomedicine and appreciative of its accomplishments, they are all too aware of its limitations, as only insiders can be.

Cancer Patients’ Use of Complementary and Alternative Medicine

The practitioners I interviewed noted that there has always been a segment of the cancer patient population that has used unconventional treatments. Nevertheless, practitioners reported that there has been a shift in the pattern of CAM use in the last ten or fifteen years: a higher proportion of patients are using CAM and those patients are using an increased number of different substances or approaches concomitantly, e.g., rather than taking one or two alternative anti–cancer treatments, many patients now use a comprehensive regimen of CAM that combines such approaches as meditation, psychosocial support, nutritional supplements, and dietary changes as well as specific alternative anti–cancer treatments. One oncologist, named Charles,² described the situation this way:

I’ll tell you a little story about how my eyes were opened to how much this is happening. For me, the gold standard of the person who’s really got their feet on the ground, as sensible, is the (prairie) farmer. . . . And when my retired farmers, when they were all coming in with alternative therapies, I thought, “Hey this is main street!” (laughs) The Asian population I can understand, my Aboriginal population, sure, that’s their culture. But my goodness, this has really hit the mainstream. (laughs)

² The names given to the practitioners who are quoted are pseudonyms.

Another oncologist estimated that, 15 years ago, probably 70% of her patients were using CAM therapies while about 85% are using CAM now. This oncologist did not see this increase as particularly significant. What was significant in her opinion was the increased openness about CAM (i.e., both patients and practitioners are more willing to talk about it) and the widespread availability of different therapies and products. Most practitioners mentioned the Internet as a factor in the increased public awareness of complementary and alternative treatments. Some practitioners commented that it was not uncommon now for patients to come to their clinic appointments with stacks of print-outs from websites that they wanted help deciphering or used as reference material in their demands for better information or different treatments.

The conventional practitioners also mentioned the increased number of CAM practitioners such as naturopaths that were promoting particular approaches as well as the increased availability of products such as herbal remedies and nutritional supplements in mainstream retail outlets. For example, one oncologist named Patricia described the change as follows:

There was always a significant minority using alternative therapies and now I think it's a significant majority. So it's grown and it's partly grown, I think, because of access to information but you can also see it's grown because of availability. There's a naturopathic store on every corner, you know, and there clearly is an appetite for it or all the stores wouldn't be functioning and making an income from their products. I think the easy availability of knowledge through the media and through the Internet has facilitated that. I think people's ability to travel, their high level of education, wish for some autonomy or less dependence on perhaps traditional medical advice, more wish to try and look after themselves—which is all very good, you know—those are all healthy things. That has led to a steady growth.

Conventional practitioners believe that not only has the level of use of CAM by patients increased but the sociocultural presence of the CAM Discourse has grown: it has

become mainstream. As the preceding interview excerpt shows, conventional practitioners see the use of CAM as being linked to other cultural shifts, including changing values related to patients taking more responsibility for their health and exercising more autonomy in relation to biomedicine. These are the kinds of cultural models that CAM proponents are promoting, as chapter 7 will illustrate.

In their comments about the changing role of CAM in cancer, two oncologists offered other observations about larger cultural forces. Patricia spoke about the tendency for patients to not only want complementary and alternative treatments, but to demand the best of conventional medicine as well.

I also see the other side of the coin and that is patients generally are *desperate* for the cutting edge of medical care. They want *anything* that can be done, done. And most people are clamouring for conventional therapy and often very confused about what they read on the Internet about some research taking place somewhere which they think is an established treatment and why can't they have it tomorrow.

There are very few people at that fringe end who repudiate conventional treatment and *only* go for the alternative. There are a few. I saw one last week, it was absolutely shocking. This young woman has thrown away her life. Because she wouldn't accept treatment for a cancer that's now going to kill her. And that's rare. The vast majority want the best of *everything*. *The best*. They're clamouring for the best of conventional treatment and in the area that I'm in, it happens to be cancer drugs and I just get *bombarded* by phone calls from patients, trying to access drugs that are not approved in Canada or the United States. They are only in research or being tested on mice and people don't understand that they can't get it, you know.

And patients think they're being denied something. The thing that does drive me completely crazy, it really does, is there's this pervasive sense in the public and patients that they're being denied all kinds of things because it's too expensive and the Canadian health care system won't pay for it. And in fact there's hardly anything they're being denied. At all. Nothing I can think of.

That's not the issue. It's just that these drugs are still in early research and either haven't been tested on humans or proven to be any use yet and they've read about something in the newspaper or on the Internet and they're *very* upset they can't get it. And I spend a lot of time explaining to people, "You have no idea this stuff is any use and it will probably be several years before we do." And you know, they want it now. And so, again, it takes a lot

of time and people are very hurt, angry and upset because they think that somehow the health care system is letting them down. But in fact we don't have miracles for many cancers and I remember one health care person in the States that I went to a lecture in Harvard, saying, you know, "One of the issues with the North American society, there's a section who truly believe death is optional." They can't believe there isn't a solution and sometimes there aren't.

Patricia was not the only oncologist who linked CAM use with society's denial of death. A second oncologist, named Joan, also made this connection. The following remarks were prefaced by Joan's observation that a lot of what was happening in medicine is related to the widespread materialism in our society and people's unrealistic expectations of life.

(What) I see complementary medicine mainly as, is a reflection of these woes of our society and of people's lack of centeredness . . . I think a huge amount of it is the people's fear—death is not supposed to happen, disease is not supposed to happen. I've got to control it.

This focus on control and the triumph over death can be seen in some of the CAM Discourse (e.g., see the excerpt from Deepak Chopra's book given in chapter 6) but a denial of death has also been described as an unhealthy aspect of the Biomedical Discourse (Weil 1995; Gordon 1997; Robbins 1998). It is interesting that the oncologists did not connect this cultural attitude with biomedicine, but saw it as something "out there" in society. This may be an example of a cultural model (i.e., a belief that death represents a failure of control, or that death is a mistake) that is reinforced by several Discourses in a positive form (e.g., discourses around the quest for perfect health or the perfect body) but that no Discourse wants to overtly claim in its negative form.

When I asked the biomedical practitioners what issues the use of CAM raised for them, the oncologists spoke about the dilemma they face with respect to advising patients

about what treatments can be taken in combination with conventional treatments.

Patricia's response was typical.

People have a high expectation of physicians having knowledge of a variety of interventions and high expectations of having time to talk, especially when they are dealing with a serious illness like cancer. So the biggest challenge for me is answering people's questions in an even-handed, non-judgmental way that supports them in some of their very reasonable decisions, then also balances the advice I must give them about any medical risks of anything they choose to do, seasoned with a dash of concern if I have people heading off to take treatments that I know are very expensive and offered by charlatans. Those are the bad end of the spectrum. Most complementary interventions I think are healthy and helpful in that I think they support the patient's need for doing something to help themselves, it gives them a sense of purpose, a sense of control and all the things we are very familiar with.

So I think the knottiest problem for me is when the patients come in on about ten or fifteen things they are taking by mouth—so this isn't the massage therapy or the psycho-social support end of it which I think . . . are terrific. . . . But when people are taking a bunch of *stuff*, the difficulty is that a lot of these different herbs and chemicals do contain some active ingredients but you often don't know what. So it does leave me in a dilemma. Because generally adverse reactions almost never happen, but a few do. And they may not be the adverse reactions when patients get sick. There are some natural foods that can inhibit the metabolism of certain drugs or accelerate the metabolism of certain drugs, such as chemotherapy drugs. And nobody actually knows if it makes a difference because there's not a lot of information. You know, you're not having droves of people signing up for studies to try and evaluate the interactions between various compounds or even to evaluate efficacy.

So the difficulty for me is what to say to the patient when they come in and show me this endless list of things they're taking and ask me, "Is it alright?" Because on the one hand I tend to say, "Sure it's alright, many of my patients take these, no problem." But on the other hand I sometimes wonder because I actually don't know what's in these things and each one of them has a long list of sub-ingredients. . . .

I sometimes will ask the pharmacist to scrutinize everything and give some advice, and they do frequently then advise the patient not to take some of these things during the course of the chemotherapy and other things they say, "That's fine."

So I think that's my biggest concern. I don't want to do any harm to the patient by giving them something that may cause an adverse reaction with some of the other things they are on, but in my twenty-something years of practicing oncology I can probably only think of two occasions when that's happened. So it's very, very infrequent. So I'm not particularly neurotic about it. But I am concerned that I am not giving the patient the right advice. And

yet at the same time I want to support the patient in feeling that they don't have to be defensive or feel criticized if I say, "You know, I'm not sure this is something I'm happy with you taking," because then it tends to generate a sort of "us and them" sort of sense. They're torn between wanting to trust their conventional physicians . . . but also wanting to believe whatever they've been advised by, perhaps a naturopath or even health food store. . . .

I strongly encourage people to do certain things that I think are very meritorious, you know, support groups, psychological counselling—very helpful. I recommend it for a number of people, a number of soothing interventions whether it's crystal therapy or any of these. Whatever it does, it can't do any harm. (laughs)

As long as whatever information you are being provided with is not erroneous. I think where practitioners like me actually get positively upset is when patients are given profoundly erroneous advice—guarantee of life-saving treatment or whatever—nearly always linked to a high price tag. Or being force-fed the concept that there's a conspiracy amongst the general conventional doctors to deny you curative treatment.

Patricia makes a distinction between psychosocial interventions that provide benefit or at least do no harm and expensive treatments offered by "charlatans" who offer unrealistic guarantees. The ethical issues related to this aspect of CAM use are of great concern to conventional practitioners, as the next section demonstrates.

Patient–Practitioner Relationships

Many health discourses advocate for a new kind of relationship between health care professionals and patients. The patients' comments in the previous chapter provide some examples of the kinds of relationships patients are coming to expect. The model that is being promoted is one where patients and practitioners engage in a healing partnership where the knowledge, needs, and interests of patients are given more weight than they traditionally have held in conventional medical settings. Although "patient-centred care" has been a buzzword in the Biomedical Discourse for several years, the reality is that

many health care providers have not changed their way of relating to patients. One nurse

I interviewed gave the following perspective on the situation.

You know, we always talk about here, that we should have person-centred care. We do talk about that a lot (here). But I think we're not walking our talk, at all. I think we're so enmeshed in a system that's constrained by funds, by worldviews, by history and myths—you know myth is involved in there too—"Because we've always done it that way." People aren't willing to step outside the box and look at this thing differently.

However, Charles reported that the dynamics of patient-practitioner relationships are changing.

More and more, and quite appropriately . . . it's a much more collaborative decision-making process than it used to be, for sure. And so I will see a patient and I will recommend, "These are your options, you know, this is the best chemotherapy for you. On the other hand you may, if you don't want chemotherapy, you could do this or you could do that."

So you always try and give people options so they can make a final decision with as much information as they can. And that's what a lot of people want. Now there are some of the older people they're not used to that model, so they'll just say, "Oh doctor, please tell me what I should do." Alright. But this is really changing and it's a very different market place out there.

While some of the practitioners agreed that patients should have more control in the process of making decisions around treatment, Bernard, an oncologist, pointed out a major difficulty posed by this more egalitarian model.

You never impose a treatment on a patient. You can't do that. You can say, "Look I really think this is going to save your life and it's effective and if you don't have it you may die in a few days." But if that patient says, "Thanks very much but no thanks," then that's it. Our only commitment there is to say, "Can't I go over this again." . . . And there are people with very different beliefs to me and if that's their belief, that's their choice. We can't chain them down and do that. So they have always had choices to that degree. But if they want real choice they've got to go through medical school and do that, because reading the books tends to generate confusion and more questions.

For biomedical practitioners, questions about how to structure patient-practitioner relationships and how to manage the process of making treatment decisions are strongly

linked to ethical considerations regarding informed consent. These ethical considerations are connected to the role of CAM practitioners in patient care and to the concerns raised by patients about conventional medicine "robbing hope" in the process of giving a diagnosis and prognosis.

Joan said that the situation is affected by our sociocultural tendency to want facts and figures. She illustrated her point by talking about all the media stories that report statistics and surveys. She argued that patients are making paradoxical demands on physicians as a result of this discourse around quantitative facts.

People want these (facts and figures) but they don't really want it in medicine. But they *do* want it in medicine. They want the doctor to say, "I have a 72% chance of curing you with this treatment." So they ask for that average . . . but they don't want to hear it. They ask for that. Medicine has responded. Medicine has also responded to this ethical thing. Medicine has dealt with the legal issues and the liability issues by increasing the ethical denominator and by increasing how we define our ethics.

I don't think that's bad. I think we have to be ethical, but in defining ethics, you know, one of the major things is veracity. With veracity you tend to be sometimes more blunt and less benevolent than you are without veracity. Whereas the old doctor used to say paternalistically, "Leave it to me. I'll look after you, my dear." . . . What the patients are demanding is saying, "I want the facts. I saw on the Internet this, this, this. Tell me the facts."

So a patient comes in and says, "I read about my breast cancer—stage II breast cancer—I read that I have a 60% chance of being cured at ten years or a 40% chance of dying." What do you say? You either say, "You're reading the wrong things," or you say "You're reading the right things." But if you say, "You're reading the wrong things," you have to give a new figure.

So patients come in demanding veracity, as much as you can give, and demanding figures, but they don't really want to hear it. What they want to hear is the paternalistic, "I can cure you." So medicine has been pushed by society and by its reluctance, I think, to really look broadly at being more holistic. They've been pushed to this ethical defensible corner of providing facts and yet what the patient wants is hope. Hope and reassurance and paternalistic autocrat. The patient wants the doctor to be the autocrat. The patient wants you, in a sense, to say, "I can do this, I can heal you." And that's what they're getting from the alternative view.

There's a few issues around that. . . . One of the issues is that if you give less than facts then patients often feel like they are getting a less good deal

and they want facts, they want books, they want articles, they want reading material. They want you to talk to not just them, but their partner and their ex-partner and their next partner and their daughter and their son and they want everybody involved. Everybody who becomes involved comes with their own set of facts and expectations, and their own opinions. So therefore it becomes even more prudent for the oncologist or the physician to give as hard facts as they can. And yet at the end of the day all the person wants is 100 or zero. Is this disease going to come back or not? So everybody wants hard facts, but they really don't. They want this hundred or zero.

There's an issue too about how we give facts, and how people hear facts and when facts are given, because I think that facts can be given to people in a way that is a cup half-full rather than a cup half-empty. Facts can be given people at the right timing. Some people want to hear all the facts at the beginning, some people don't.

And very rarely do patients come alone any more, which is good, it's good to have another set of ears. Having said that, it's good if they come with another set of ears and not with their own agenda. But their own agenda being there often changes the normal rhythms of the patient. So what does the patient do? The patient gets freaked by what they think they want or what their support people want. And what do they want? They want to know hope, they want to know cure, they want to know they're fine. And they then go to an alternative healing (approach) which has not backed itself into this ethical corner, which has no responsibility to give facts, which has no liability about facts, which has no facts, is the reality. And they get a lack of facts, they get hope, they get reassurance.

Patricia also spoke about the different ethical standards that biomedical and CAM practitioners must uphold and the way that these differences affect patients.

I think in some ways what naturopathic medicine can do and other complementary methods, is it gives the patient a major comfort factor and sometimes the promise that if they do certain things, something good will happen. They will feel better or stronger or be helping to fight things off. And I think my job's harder. It's much easier to peddle hope than to deal in reality. . . If I'm trying to get a patient to choose between two or three quite tough options, they *need to know* what the risk of severe or life-threatening side effects are. I can't just say, "Oh take this stuff. It's great for you. It'll do the trick. Yeah, chances are you'll be fine, don't worry about anything else." Because that would be malpractice. I have to spell out the choices, have to empower the patient to decide, and I can't overstate the benefits.

So I'm bound by my professional, not only professional standards that I have personally, but professional standards supplied by the College of Physicians. That licence you to practice that you have to be forthright and honest in disclosing to the patient all of the circumstances. Sometimes you have to disclose so much it's overwhelming.

I've heard the expression ("robbing hope") and we in conventional medicine shouldn't be robbing people of hope in that you shouldn't say, "Oh darn, you've got really bad cancer, you'll be dead in six months and there's not much I can do about it." I mean that would be robbing somebody of hope. That would be appallingly bad style to communicate with a patient.

However if I have a woman for example, who's brand new, who's come to me with something terribly bad, she's got a liver full of cancer and I have a treatment that will maybe prolong her life by three months if she's in the one in three who respond. And if she's in the two out of three who won't respond, all it will do is perhaps make her sick and make her hair fall out. So it's very important she understand the limited merit of that treatment and feels able to make the decision. I mean if she says, "I'm not feeling too bad right now and my son's graduation or wedding or something is in four weeks and I'd rather not be sick, I want to enjoy that, and I don't think I want your treatment or I'd like to put it off for a bit," I'd like her to feel she has the choice. Not, "You've got to take the treatment now, you're going to get much worse, you have to get on to it quick, like next week."

So it's very difficult to fulfill your obligations to provide reasonable disclosure in a way that's understandable for that patient's level of emotional stress that day, the language, education. And it's more than one visit, it's an iterative cycle of trying to explain things to people and nurture them along to what they think's the right decision.

So you are constrained. You can't just *peddle* hope, you have to deal in facts. But you can present it in a supportive way and when you get to that final discussion where you're saying, "I don't have any further active treatment to control your cancer," then it should be done in a way that ensures the patient feels that you're putting in place the supports they need. Putting in place the family doctor's support, the homecare nursing support, you're giving them an opportunity to ask about death and dying, what it's like. You're giving them an opportunity to be reassured that their pain can be controlled. All of the things that are *terrifying* for human beings you want to be able to assure them that you're doing *something* to help, that's not the same as, "Take your vitamins and all will be well." You know, it's a different role that we're fulfilling. And I think that for patients it's often hard to understand that.

Some of the practitioners told stories of patients who had been led to believe that their complementary or alternative treatments would cure their cancer and, in their final months, became angry that they had been misled. Joan related a conversation she had while providing palliative care to a patient who had been told by a complementary physician and a naturopath that her breast cancer could be cured.

"How dare they treat me that way," the patient said. "When I met you (Joan)," she said, "I hated you 'cause you told me you couldn't cure me. And I turned around and I went to see them and they both told me they could cure me and they could make me fine." She said, "So who do you think I would have believed? But why didn't they tell me the truth?"

Patricia described similar situations and emphasized the difficulty physicians have responding to patients' questions about their prognosis.

I've occasionally had patients come and say to me that they were very angry with some other doctor whom they've usually just fired because they *didn't* forewarn them that their life was going to be short. And these patients felt robbed of an opportunity to use those last few months constructively. And they were usually at this point dying and they said, "You know, if I'd known it was this serious, I would have done this, I would have done that, I would have spent time." Usually with family and friends doing certain special things, or sometimes it was sell their house or stop fussing about money, whatever—things that were important for that person at the end of their lives. And the difficult thing is that, as the doctor, you don't know what space that patient's in when you first meet them and you're trying to judge it. You don't know what their pressing needs are. . . .

It's up to the discretion of the individual physician (whether to give a time frame) and you've got to be *terribly* careful about time frames because you *often* (pause) *get* (pause) *it* (pause) *wrong* (pause).

And it's quite acceptable to give a range but even that can be misunderstood by the patients. Because if a patient asks you, you know, you don't usually ram it down their throats, you don't usually say, "Well by the look of you you're going to be dead in six months." But you introduce the idea that perhaps you're not going to cure them and you introduce the fact that you may have run out of options for active treatment, but you still have lots to do for symptom control. And you give them an opportunity to express whether they're interested in knowing more, but if so, you should respond honestly but not dogmatically.

You don't know. Somebody you think is going to last three months might be dead next week and somebody that you think is going to be six weeks at the most is still chugging along nine months later, so that people and their diseases are unpredictable. So I generally say, "Well it looks to me as if you're probably into the last few months of your life and I'm not sure that you're likely to make it through another year." And in reality it's often a lot shorter than that but you can't be too precise because if you are, again, patients feel angry. . . . People are so uptight when they ask that question they don't (pause), they're not taking it in.

These interview excerpts demonstrate crucial differences in the roles that conventional practitioners play compared to CAM practitioners. Being within the Biomedical Discourse with its professional ethical standards and vulnerability to legal action means being constrained in your relationships with patients. This is one of the prices of legitimacy. Being part of the legitimate professional community bestows the privilege to practice within a government-regulated system that grants certain benefits and freedoms. But it also imposes limits that do not affect practitioners who are outside this legitimized circle.

The conventional practitioners saw their role as being much more difficult than that of CAM practitioners. One nurse speculated that part of the reason why patients view conventional practitioners as being less humane and supportive than CAM practitioners is that it is conventional practitioners who give the cancer diagnosis. Since they convey the bad news they become associated with that traumatic experience.

The biomedical practitioners I interviewed generally agreed with some aspects of the cultural models about patient-practitioner relationships that seem to be gaining ground in both CAM and Biomedical discourses. There was a consensus that patients need complete and accurate information about their disease and their treatment options. There was agreement that patients ultimately have the right and the responsibility to make treatment decisions and that patients' thinking and decision making must be respected. But there was also a strong awareness that the situation is not as straightforward as it might appear to patients or others outside Biomedicine. Professional regulations and policies determine what information can be given and limit the ways in which it can be given. Patients "want the facts but don't want the truth." Practitioners

may not know a patient well enough to be sensitive to what he or she needs at a particular time. The growing tendency for patients to come to appointments with one or more support persons introduces additional needs and agendas into the situation. Patients do not have the depth of technical knowledge and experience that highly-trained professionals do. And, perhaps most troubling of all, even for those with professional expertise, it is very difficult to predict the course of cancer in an individual case.

I sensed a certain amount of frustration on the part of conventional practitioners that they were being seen as failing to provide hope and reassurance. They felt it was unfair that they were being judged in comparison to CAM practitioners who do not labour under the same professional and legal constraints. I also sensed some frustration related to the fact that it is usually the conventional system that cares for patients in the final stages of their lives. There seemed to be an underlying resentment that CAM practitioners had the freedom to promise benefits without being held accountable, either legally or practically, for these promises regarding treatment outcomes.

Another aspect of the patient-practitioner relationship needs to be mentioned and that is the question of whether "caring" has been lost from biomedical health care. Some of the patients quoted in the preceding chapters expressed dissatisfaction with this aspect of their interactions within conventional health care settings. Some public discourses, including some parts of the CAM Discourse, present a stereotype of biomedical practitioners as unfeeling technicians who fail to engage with their patients as people. But, the practitioners I interviewed did not fit this stereotype. Sometimes during our conversations I thought I detected hints of the apparent callousness that people inside difficult situations adopt as self-protection. But, for the most part, the practitioners I

interviewed seemed deeply concerned about their patients' well-being. It may be that this is one way that this self-selected group is biased. One of the nurses I interviewed noted that some doctors are better than others at conveying the diagnosis and prognosis. But it seemed the oncologists and nurses I met were committed to providing care that was not only technically of high quality but also sensitive and respectful.

During one interview I was particularly struck by a moment that clearly revealed the human engagement that professionals feel. The oncologist, Bernard, and I had been talking about the idea that people cause their cancers and can therefore heal themselves. He expressed adamant opposition to this tendency to blame the patient.

I think if you see the number of patients that have cancer and the number of patients that we can't fix, even the patients we fix, the stuff they go through to get fixed, and on no evidence whatsoever that I can see, you put out that it's their fault, I think that is sinful.

I then asked him if he saw patients in treatment that were approaching cancer as a wake-up call that prompts transformative changes in their lives. He said that he had heard of that, but that because of the specialized role he had with patients he didn't really get to know a lot of them well enough to be aware of those kinds of dynamics. He explained the specialization of the treatment system and the large caseload each specialist carries.

I see them, I'm looking—is the cancer back—no. If it is back, what symptoms do you have, how can I help that best, do you need radiotherapy, do you need chemotherapy or do you need your doctor to look after that with painkillers. Do you need someone to get you a walking stick, and a chair, which is other stuff that other people have to do. Because I've got another five hundred patients that need just this particular thing (that I do). So we're blinkered, and I think that's an unfortunate area of it. I think it's unfortunate for the patient, that some of the treatment is split up like that.

I think it's led to a level of expertise in some of the technical steps that are then done extremely well and overall give beneficial effects for the patient, though it is a bit bouncing back and forth to different people, and it would be nice to have a balance between that, so that with expertise, you had some sort of integration.

After saying this, he shifted in his chair and paused slightly before saying that he was sure this specialized separation of roles was a defence for some of his colleagues, a way to "fix the fixable" and allow them to limit their engagement with patients. Then he paused almost imperceptibly again and his voice lost the confident authority it had carried up until that moment, and he said, "To be with them until death through all of the bits is hard. It's really hard."

In that brief moment I felt the shield provided by the Discourse of biomedicine—the white lab coat, the expert opinion, the scientific objectivity—drop away. Then Bernard looked at me and said, "So I've lost what the question was. Sorry."

Science as a Source of Legitimacy

Chapter 1 showed how some biomedically-oriented authors look to science to definitively answer questions about the legitimacy of complementary and alternative approaches to healing. It was during my conversations with biomedical professionals about this topic that discrepancies between the public and private biomedical discourses became strikingly obvious. The conventional practitioners I interviewed were acutely aware of the limitations of science and were forthright in pointing these out. For example, Patricia had this to say.

Well, science is not absolute, science is an art too. It's just like they say, "There's lies, damn lies and then there's statistics." You can also say, "There's little lies, big lies and then there's how you interpret the science." (laughs)

Because science is not like it's a black and white thing. And I think that's the difficulty. I think the profound difficulty for members of the public and patients is how to sort the information. . . . Science is only relative and it gives you a relative body of information from which to make reasoned judgments. So the patient's trying to make reasoned judgments and the

doctor's trying to make reasoned judgments, but we're playing from different decks of cards.

And I swear some of my patients know far more about alternative and complementary medicine than I do. They've probably read a great deal more. Whereas I know a great deal more about the reality of their disease—how it's going to behave, in the most part—and because patients and diseases vary too. And how it's likely to respond to treatment and what the likelihood of failure or success is. But they're likelihoods, they're not absolutes.

So science is never clear-cut in the health care situation unless you've got something as simple as, "Does aspirin relieve pain?" "Sure." "Does penicillin kill certain bacteria?" "Yes it does." "Does taking your appendix out stop you getting appendicitis again?" "Yes it does."

But does taking multi-vites or tamoxifen or chemotherapy guarantee you something? *No it doesn't.* Does it even increase your chances in certain circumstances? It does. But that's the difficulty and I think for the majority of members of the public it would be nice if there was a set of simple answers and there aren't.

Bernard also talked about the uncertainties of science. At the same time, he emphasized the importance of using science as the primary source of medical legitimacy, despite its limitations. His comments will be cited in some detail since they provide an instructive example of how insiders think about this issue. Bernard began our conversation by saying that he had a very sincere question about the problem I was investigating. He stated that he "did not see alternative medicine or complementary medicine as a real event, in any way." He clarified this by saying that CAM is real inasmuch as it is the subject of conferences and is talked about in the media. But, in his view, it made no sense to posit the existence of separate medicines. He was concerned that the increasing public discourse around CAM was giving it a legitimacy it did not deserve and allowing the use of totally untested substances.

Bernard asserted that what is necessary is to generate testable questions or hypotheses on the basis of empirical observations, to do studies testing for safety and efficacy and then to adopt the treatment if it is both safe and more effective than standard

treatments. He gave the example of acupuncture, which he believed has potential that has been overlooked.

I understood that the art of acupuncture looks at some lines and associations and connections that we don't recognize anatomically, if you like, at the moment in biology, but it's ever been so. When we come to the edge of what we know, what we don't know is what we don't know.

It may be, for instance, that the old idea of those various connecting lines may be totally wrong as the reason why it worked, but that doesn't stop it necessarily working.

But at the other end of the scale, and for cancer treatment we use periwinkle plants, we use a red fungus-type bacteria and we use the bark of the yew tree, as state-of-the-art treatments for cancer. We take out the active ingredients so we know exactly how much we've got so you can give someone an accurate dose, so you can predict something about the side-effects and benefits. So I don't see anything as being a different, a separate medicine.

From Bernard's perspective, no matter what the technique or how it might affect what happens in different parts of the body, "the only criteria is that it makes things better.

And if we make a person better, that is the practice of medicine."

Bernard expressed strong views about the "conspiracy theories" in the public discourse that assert that the "cancer establishment" is suppressing effective alternative treatments.

I say to some patients, I say, "I treat cancer. I trained a long time to do this. I try very hard to do the best I can. If there was a treatment out there that really cured this, do you think I would avoid it?" And they say, "Oh, I hadn't thought of it that way."

And . . . a lot of complementary (medicine) is sold on the basis that there's really a conspiracy here to keep them out. I think some of the frustration with my colleagues (pause), I'll admit some of the immediate frustrations that I have—and I try very hard never to pass on to the individual (patient) because it's not their problem—is that if I started using a drug like that, I would be struck off the register immediately and potentially held criminally negligent because it would be an untested treatment. And there are only very special situations where you can do that. You have to get a license for the drug from the FDA. You have to get ethics, signed consents, and this is for phase I (trials) just to see what the toxicity is.

So there may be a frustration that my colleagues feel. There are certainly several things out there that are still being used that have been tested, like Essiac was tested, I haven't looked at the details of that study, but really did not show any effect. There are things like Vitamin C and several of those things, that have also been tested. So some of my colleagues (pause) our frustration at times would be it's almost not fair. I can't, I'm not allowed to do that, or that's inappropriate. Because the medical (profession), in our wisdom, try to protect the public by doing things as cautiously and testing them as rigorously as we can.

Bernard did not portray biomedicine as having all the answers. And he acknowledged that the public is aware of the uncertainties surrounding conventional cancer treatment.

We have a situation where, just the cancers I treat, we are far from 100% success. There's a huge wanting. And when I approach a patient, there are lots of situations where I say, "I can't do this," to a greater or lesser extent. I mean there are always things one can help with, one can support, one can aim treatment to palliate, but even in that our treatment is incomplete. It's uncertain when I start on a course of treatment, even to palliate pain from a metastasis to bone, it's a very simple treatment, quite a high chance of reducing the pain but not entirely . . . and the public know we don't have all the answers.

In the course of talking about the kind of uncertainties he faced, Bernard told a story that demonstrates the difficulties he perceived in trying to resolve those uncertainties through science. He described a very hard-working colleague who had done some laboratory experiments. His friend wrote up the results of his studies and found they acquired increased legitimacy at each step along the way. Bernard quoted his friend as saying, "Then I wrote it out, and it looked as though there might be something there. Then I got my secretary to type it and it looked terrific. And then it got published and it was God's truth."

Bernard went on to explicitly undermine the credibility of scientific medical journals.

A colleague of mine, he said, "Things that appear in the orthopaedic journals I automatically do not believe. They are lies, until somebody really proves otherwise." Because the motivation to get them there and the science that they are commonly associated with in his experience was terrible, and the fact that they were in print meant nothing at all.

While this oncologist was obviously sceptical about some of the science being conducted and reported, he also expressed strong appreciation for the strength of the scientific method. Bernard told another story of colleagues who thought they had observed a particular phenomenon related to the treatment of lung cancer. But when his colleagues did a study to examine the situation systematically they discovered that what was occurring was exactly the opposite of their hypothesis. Bernard said that this example showed that one's clinical experience can be misleading. He said that he, like others in medicine, is not immune to having blind spots and that it is necessary to "go back to the basic science to make me honest."

The following excerpt from our conversation summarizes Bernard's perspective on the predicament faced by people doing biomedical research and treatment.

The system is far from perfect, but it is like anything else. Safety is a relative term and it is an honest attempt in any of those settings to do the best one can.

... What is more recent . . . is so-called evidence-based medicine. I was almost affronted when this first came out, because in oncology . . . they did the first randomized controlled trials in the world long before they were done in any other subject. And if you look through any of the oncology texts, the staging of disease measures the extent of the problem, and somebody reports their results and says that the portion of patients alive at five years with *this* disease, *this* stage, is so many with *this* treatment. And if you want a new treatment you get this disease, this stage and you see if you can get a better five-year survival rate. And that's pretty objective. Alive and dead is not a grey area. . . .

However, there are lots of situations even in oncology where it's clear, that even in palliating (patients), that we have a wide range of possibilities out there. Which means that the truth is not obvious. Nobody knows exactly how to do this. And things are done with the best intention of improving a condition and it's a situation where somebody comes to you with an illness

and you've got a machine, you say, "Well, I must try and treat this." Again with the best intention in the world, but at some point you may be just doing the do-able. Do you put a plaster of Paris on the leg or do you radiate their chest? It might make the same difference in terms of—this one seems to be addressing the right problem—but there are situations where we've shown now where we don't have any impact on the quality of life or survival. And some of the evidence-based medicine can now look at all these things.

And it's interesting in Britain because the NHS³ is sort of omnipotent or very ubiquitous in Britain. They've got a whole unit, a big unit that's looking at treatments that the NHS funds. And it's looking at the evidence and then finding that this treatment has no effect—tomorrow it's stopped. . . . I mean, people feel a bit outraged that we used to do this and stopped. They realize that you actually tie your heart to this flag when you've been doing it for so long. And for somebody to tell you that this doesn't work, you feel a bit affronted that you've misled yourself.

I mean for the longest time now since that's come up I have to tell myself, "This is, at the moment, what we think might be best or what I think is best for this patient in this situation given the best I know. But I know I could be wrong." And you have to keep saying that, because you could be wrong. I don't really know this.

Hearing this oncologist speak about his experiences made me realize that health care professionals face just as much uncertainty as patients, although it takes different forms and has different implications. I realized that practitioners have to face each day with the same kind of pragmatic courage that says, "This is my situation and I have to do the best I can." When I asked Bernard if he thought that the increasing public scepticism around science and the move towards CAM might be a reflection of a desire to avoid all the complexity and the ambiguity and find a simpler solution to the problem of cancer, he pointed out the discrepancy between the unpredictability of life and the promise of control held out by the CAM Discourse.

Certainly, the (public) awareness is, as I am aware, that the complex hasn't given the answers. We say, "Let's try something else," (i.e., CAM). But at some point when does that something else become an authority? Because they are certainly telling you what should happen and this sort of thing. . . .

³ The NHS is the National Health Service, a government body that funds and oversees public health care in Britain.

Except there is another thing that comes along with it, and it is this idea that you then can take control.

It is sold as that. And I suppose the problem I have is that the more I learn, the more I'm sure I have less and less control in my life in every aspect. And to think that I have control wilfully over any illness flies in the face of everything I see. And yet that's sold. And it's very powerful for a whole genre of society.

Reflections

My conversations with oncologists and nurses at Vancouver's large tertiary cancer care centre revealed the perspectives of those who are "inside" Biomedicine about the issues they face with the convergence of CAM and Biomedicine. It seemed to me that I saw features of the private face of the Biomedical Discourse that are usually kept hidden from public view.

The conventional practitioners I interviewed seemed very clear about what CAM is. Like the patients I met, they did not need clarification of the term. However, in contrast to the patients who usually spoke about specific treatments and rarely referred to "CAM" as a whole, the conventional practitioners did seem to have a conception of "CAM" as a cohesive, meaningful entity. There was a shared understanding that the CAM Discourse includes ideas about the nature of the mind-body system and about patient-practitioner relationships that are different from traditional biomedical views. In general, conventional practitioners seemed to believe that complementary approaches such as mind-body therapies, meditation, and psychosocial support have merit, but that patients are taking a number of substances whose safety and efficacy are in question.

The prevalence of the CAM Discourse does not seem to be motivating most of the biomedical professionals I interviewed to reconsider their own personal or professional

identities or their allegiances to master cultural models. However, professionals are creating situated meanings to explain patients' use of CAM. Most professionals linked patients' use of CAM to market forces. Not only were the commercial aspects of CAM mentioned explicitly (e.g., "there's a naturopathic store on every corner"), but words that reinforced the connection between CAM and the market appeared throughout the conversations (e.g., "it's a different marketplace out there," CAM practitioners are "peddling" hope, and ideas are being "sold"). The connection between CAM and proponents' financial interests seemed to make CAM suspect in some practitioners' eyes. Practitioners seemed especially suspicious of CAM treatments that were expensive (e.g., these are "offered by charlatans").

The CAM Discourse is raising some fundamental questions about the distribution of society's resources, (e.g., Which treatments should be covered by public insurance? How should public research funding be allocated?). In the current atmosphere of governmental restraint, the movement of health care consumers (i.e., the public) toward CAM may eventually threaten biomedicine's access to limited funds. While the professionals I interviewed did not explicitly report feeling any such threat, they were certainly aware of the economic and social clout that CAM is developing. They were also aware that public discourses include conspiracy theories that accuse "the cancer establishment" of making decisions aimed at maintaining its own financial interests (e.g., Moss 1989). Being inside this establishment means that individual conventional health care professionals do not have to "sell" their treatments the way that CAM practitioners do. While their insider status removes conventional practitioners from direct participation in the marketplace, it does not completely exempt them from its influence. Discourses

related to consumer or patient choice and empowerment are prompting changes in conventional practitioners' roles in relation to their patients. Patients are coming to their appointments with questions that conventional practitioners cannot answer. Patients are sometimes more knowledgeable about CAM than the professionals. Further, as can be seen in some of the comments in the previous chapter, some patients believe they know more than the professionals about their own particular case.

These changes are requiring practitioners to spend more time with patients reviewing their diagnosis and their treatment options. Practitioners are being expected to educate themselves about CAM therapies and enlist the help of other health care resources (e.g., the pharmacist) when they reach the limits of their knowledge. While the practitioners I interviewed supported the increased engagement of patients in the decision-making process, this more collaborative process puts pressure on professionals whose time is already limited. Thus, the CAM Discourse is destabilizing professionals' activities and may be having indirect effects on the efficiency of the cancer care system as a whole.

In their efforts to make sense of the apparent growth in CAM use, some of the professionals suggested that CAM proponents are deliberately exploiting the public's awareness of the limitations of conventional cancer treatments. The growth in CAM was also linked to the appeal of its proponents' promises that people can control the course of their disease, e.g., through the powers of the mind. From the perspective of those inside the fortress, who have seen hundreds of people go through the cancer experience, this notion "flies in the face of everything (they) see." The attractiveness of this promise of control was seen as linked to society's unrealistic expectations about avoiding illness and

death. The contrast between CAM models about the innate healing powers of the mind–body system and the models of biomedical insiders was striking. The practitioners I spoke with seemed convinced of the unpredictability of cancer and each person’s response to the disease.

The readiness of practitioners to admit to the limitations of biomedical cancer treatment and research and to the profound uncertainties they face as a result of what they do not know was surprising to me. This seemed to be a discourse practitioners were willing to express in private, but it is not a perspective that appears in the official Biomedical Discourse. For example, this is not the view of state–of–the–art cancer treatment and research that is promoted in B.C. Cancer Foundation fund–raising materials.⁴ Nor is it the view that seems to be presented to patients. As was noted in the previous chapter, some patients express frustration about conventional doctors’ unwillingness to admit the limits of their knowledge about cancer. The image of oncology practice revealed to me in the interviews profoundly undermined the cultural model of the infallible, all–knowing physician.

Models that assert the infallibility and absolute veracity of science also were undermined in my conversations with those who practice biomedical science. But, while the practitioners admitted the weaknesses of science, they did not seem to see these as being sufficient to undermine the legitimacy of the fundamental Discourse of science. Even though practitioners were aware that some of what appears in medical journals is

⁴ The B.C. Cancer Foundation is the fund–raising arm of the BCCA. The section of the BCCA Website for donors is headed “A Vision Beyond Belief.” It says, “Most of us try not to think about cancer or even say the word, believing that by mentally shielding ourselves it will only touch the lives of others. But statistics tell us this just isn’t so. . . . Today our pace of learning about cancer is accelerating, taking us to higher levels of understanding, closer to the answers we need.”

(<http://www.bccancer.bc.ca/DON/Visions/default.htm>; accessed July 2002)

suspect, they still looked to science to provide new developments in cancer treatments and to determine the legitimacy of CAM treatments. To an outsider, these statements may seem contradictory. How can people continue to have faith in an approach to knowledge development that, in some important respects, fails to deliver?

From an insider's perspective, science may be flawed in the way it is carried out by fallible human beings, but systematic, controlled investigations theoretically provide an antidote to blind spots, misinterpretations of experience, and the weight of tradition—they keep people honest. From this perspective, to jettison science because of its apparent weaknesses would be to throw out the baby with the bath water. To those inside Biomedicine, even though science in its current state of evolution has limitations, the centre of the Discourse is holding. The ontology and epistemology underlying conventional science are not being questioned.

These insiders' perspectives are no doubt linked to all the times when these professionals have seen the scientific method work effectively. It may also be linked to the power of the Discourse itself. Conventional practitioners are ensconced within a Discourse with so much weight and stability, where there is so much at stake, that to question its fundamental underpinnings would be to court disaster. Even the CAM Discourse, for the most part, tries to align itself with the Discourse of science. As will be seen in later chapters of this dissertation, CAM proponents would like to see some changes in the way medical science is conducted, but few try to undermine its central tenets.

This reluctance to question the essential legitimacy of science may also be connected to one of the issues that practitioners talked about in relation to the

predicament of patients: the need for control. It seems to be a natural human impulse to want to control the circumstances of our lives, especially circumstances like cancer that cause pain, fear, and suffering. Some research asserts that cancer patients use CAM as a way of regaining a sense of control over their disease (see chapter 1). Chapter 4 showed how important it is for patients to be able to maintain a feeling of hope in the midst of their fear and uncertainty. But what about health care practitioners? How do practitioners maintain a sense of control given the uncertainties they face? How do they engender feelings of hopefulness given the suffering they encounter every day?

A comment made by one of the nurses I interviewed provides some insight into these questions. We had been talking about the overall state of cancer research and treatment. She pointed out the successes in cancer treatment, e.g., the reduced death rates in childhood leukemia and the cures for some kinds of lymphomas. She talked about the discoveries related to the genetics of cancer. But she acknowledged that many of the discoveries made by laboratory scientists had yet to make a difference to patient outcomes. Then she said,

We have to rely on the experts to tell us what the standards and guidelines are based on what we know today. We can't know any more than that, and we have to say, "That's okay, and that's what we base our treatments on." And you kind of have to go with that. If you think, if you really thought about the whole illusion, you know, you might as well just throw your hands up and go home. Really.

You have to keep chipping away at it 'cause we learn something every day by treating those people with what we know so far. And we have to keep hoping that (we can keep) them living long enough so that the bench scientists can do their wonders. And that's what most people hope for, right? Is to live long enough for the next cure.

So, it seems practitioners approach their encounters with cancer in much the same way patients do. They "chip away at it." They "do the do-able." And, like patients, they place

their hopes on science. Science, after all, is essentially about prediction and control—the overcoming of ignorance and uncertainty.

But it is important to note that practitioners keep their perspectives on the limitations of science to themselves. And they do not talk publicly about the sometimes tenuous connections between science and medical practice. During one interview, the professional mentioned that there were lots of gaps in the scientific knowledge about CAM. I pointed out that the same was true for conventional medicine. She agreed and then said, laughing, “But we don’t necessarily share that with people.” This comment demonstrates that much of the “insider discourse” is also private discourse.

Chapter Six

Complementary and Alternative Medicine: Inside the Margins

Introduction

This chapter reports on Complementary and Alternative Medicine (CAM) practitioners' perspectives on some of the same issues I discussed with biomedical practitioners: reasons behind the public's use of CAM; what the apparent growth in CAM use means for patient-practitioner relationships; and the role of science in legitimizing different approaches to healing. The chapter also describes some of the ways in which different CAM practitioners view the nature of the body-mind and conceive of health and illness as well as illustrating how these models vary within CAM. Data from settings in which I did participant-observation show how some of these non-mainstream cultural models are being promulgated. The chapter also includes a discussion of some of the dynamics that occur at the interface between CAM and Biomedicine based on the perspectives of some of the eleven CAM professionals I interviewed who had at one time been insiders within the Biomedical Discourse. The experiences and insights of these "hybrid" professionals help to shed light on the central theme of the dissertation. This discussion leads into a consideration of integration. In particular, CAM practitioners' visions of integration are

presented and challenges to the implementation of integration are discussed. The chapter closes with a series of analytic reflections.¹

CAM Practitioners' Perspectives

The Use of CAM by Cancer Patients

The complementary and alternative practitioners I interviewed expressed a range of perspectives on the current usage of CAM by people with cancer. One complementary physician named Michael² explained the growth of CAM by pointing out the failings of conventional medicine.

Many observers have commented on the lack of progress in the treatment of diseases like cancer in the last 60 years. Nothing very much has changed, and this is heartbreaking for people who are touched by this disease. I think there's a clamour by the public now to get on with finding new and better ways and more acceptable ways to treat the disease.

A traditional Chinese medicine (TCM) practitioner named Eric agreed that patients' frustration with conventional medicine causes them to turn to CAM. He noted that new developments with respect to CAM's legitimacy such as the creation of the College for TCM practitioners and the establishment of the Tzu Chi Institute were making it easier for patients to decide what treatments to use.

What makes people come in here? The fear. Despair. Something has to be done. Feeling rejected. Not helped. . . . In the last ten years, in the nineties, people, society, the public, has a sixth sense. They knew Western medicine was not enough. Of course some people will deny that. But (the public) feels something was strange, even cuckoo. But actually a lot of research now is based on tofu, things that only a few people were taking ten, 15 years ago. Now there's a lot of research on it. So, sometimes it takes a few strange people to push, but the public has a sixth sense.

¹ For a detailed description of the types of CAM professionals I interviewed and the settings within which I did participant-observation, refer to chapter 3.

² The names of practitioners given in this chapter are pseudonyms.

So it was more a kind of being rejected, of being totally in despair because they faced such a terrible diagnosis, so they come. And then it was a jungle. You could find everything. Now it's starting to clear up, I think. And doing some official things, like the TCM (College). So people will go to the more official things—the Tzu Chi.

Sophia, a counselor, observed that the extent to which CAM is marginalized by biomedicine has changed, but the overall situation for patients remains difficult.

Embedded in her comments are CAM cultural models about the need for patients to actively participate in their healing and to respond holistically to a cancer diagnosis.

It has changed because people (in the conventional system) have actually lost their jobs and they were ostracized, black-listed literally, if they even talked about alternative treatments or suggested maybe visualization. But it's changed a lot.

So I have seen *that* change. But I don't see a huge change . . . in our average oncologist or the average person with cancer. They may be much more aware of vitamins and things like that but they're still, at least the people that I see, they are still reluctant to *do* anything. The doctors are still very reluctant to recommend things and the people who have the cancer seem to be reluctant to do anything beyond a doctor telling them to take a physical treatment. When they become very ill, it's different, so that hasn't changed. .

It's still the exceptional person, if you want to call it that, or the person that's highly motivated, that will seek out things. It's not still the average person with cancer that is looking at their whole lifestyle, their responsibility in their health, questioning their practitioners. It still seems to me that people are not aware that they need to be very well-informed about what they can do.

So I would say it's not a huge change. I would say there's less animosity between the so-called alternative practitioners and the orthodox medical practitioners and there's less persecution. But I still see it as a huge leap before it becomes a normal practical thing to do that people have psychological assessments, their diet and exercise are assessed, they are told about complementary treatments that are useful for their particular type of cancer.

So you still have this mass confusion, still dealing with people who come to us who really don't know what to take and they are taking all sorts of things and spending thousands of dollars, some of which seem to be helping people and others, people are dying just as rapidly, in my opinion, as they would if they hadn't taken these things. So there is still something missing. And I think what is missing is an overall plan, perhaps like we have for heart disease, where people have the option to go into a program right away, which

looks at all aspects of their life and that is done through our Cancer Agency, because that is where most people with cancer go.

Sophia asserted that the current situation is extremely confusing for patients.

When (patients) go through regular medical channels (they) are still mainly going to get information about chemotherapy or radiation, surgery or hormone treatments, some immune therapy. But people are still not being told that they need to eat well, exercise, look at the stresses in their lives and also anything that they can do to strengthen their bodies. We have clients that have been told by their medical doctors that (these things) are not going to make any difference. And then we have people who are being told by their alternative practitioners that they should never take chemo, they should never take radiation because it poisons their body. So here you've got conflict in the views that are going on. And you've got (the patient) in the middle, (saying) "What's the use in trying because I'm being told this or I'm terribly afraid ever to take any medical treatment because they will kill me."

A second counselor, Martha, agreed that something was missing and the situation for patients is more confusing than it needs to be.

What I see happening is that it's either-or and there is very little communication between the different, you know, areas—alternative/complementary and conventional. So that worries me a great deal because I think that we're missing something. . . .

And I think it's about choice, and . . . trying to create some kind of . . . real working together. And there's lots of reasons why I think that's not happening. It worries me—people's agendas, (on) both sides, about what (patients) need, you know, what's *right* for them and I think what's missing is how do we help (patients) find their own voice within that. Because it's confusing and it is very much, I think, about the providers' agendas.

These comments suggest there has been a lessening of hostility at the interface between Biomedicine and CAM in the last ten to fifteen years. These practitioners' observations about CAM entering mainstream discourses are congruent with those of conventional practitioners. But some CAM practitioners still see a need for patients to have access to information and care that is less fragmented and confusing. This was not the only problem identified by CAM practitioners. Other important issues relate to the cost of complementary/alternative therapies. While the biomedical practitioners saw this

problem as one of exploitation, the CAM practitioners saw the issue as being accessibility. The question of who should pay for unconventional treatments is one of the most troublesome aspects of the growth of CAM. Michael, the complementary physician, emphasized the issue saying:

I think we have to realize that there's a certain segment of the population — and I don't know how much that represents, whether it's 10% or 25%—who can't afford the sources of information, who can't afford a television set, who can't subscribe to magazines or newspapers and who are on the periphery of this new enlightened age and not right in the midst of it. So that's a great concern. How do we reach the disadvantaged people who are the ones least of all that get the help they need?

Models about the Nature of the Body–Mind and about Health and Illness

Some of the CAM practitioners I interviewed espoused cultural models about the nature of the mind and body that they saw as being different from the reductionist views held by biomedical practitioners. Eric, the TCM practitioner, described how he sees the difference between his discipline and Western medicine.

The Chinese medicine tries to approach the body and the disease as an ecological system. I mean, if you take a mountain, you can describe a mountain in terms of ecology, the climate, the vegetation . . . if there is a snowcap . . . and so on. And the Western medicine will be just to take a core of the soil and to analyze the mountain that way. So both are true images of the mountain. But one is a micro view and the other has a more macroscopic view of the mountain. I think we need both.

Martha said that not everyone within the CAM field uses a holistic approach and that this contributes to the confusion in the field. She made a distinction between complementary medicine, which for her refers to holistic approaches that can be used alongside biomedicine, and alternative medicine, which she sees as promoting therapies and substances that are not accepted by biomedicine but are similarly reductionistic. Martha

sees CAM as consisting of multiple "worlds" rather than being a unified entity. Martha suggested that those who are trying to use a holistic model of the body-mind as a foundation for their work still have much to learn.

I think the complementary world (tries to) say, you know mind-body-spirit. I think in the alternative therapy world it is still very mechanistic. Some of the naturopaths and the homeopaths and all those people, I think, are very physically oriented and I think it's the same model as the conventional system. So I think it's very individual.

Whereas in some ways, you know, in the conventional system it's narrow but it's clear. There's a sense of, you know, "I'm here to treat your cancer. Yes, I care about you as a person." Some of them definitely do, some of them don't particularly, but I think generally they're clear.

I think the other worlds are confusing. I think some of the practitioners are very much, you know, "Here's what I think you should take to cure your cancer or to boost your immune system or something." But it's still really oriented to the physical body.

I think there's attempts to integrate mind and spirit, but I think we're very young, especially with the spiritual integration. I think there's spiritual healers but again they're not integrating mind-body. So again, it's like everything's separated out.

Some practitioners voiced beliefs about the link between mental factors and illness that were congruent with cultural models about individual responsibility for healing that have been characterized as central to the CAM Discourse. For example, Michael stated it this way.

We know that we're born to heal. We have this incredibly effective, comprehensive defense against every possible hazard, right from the moment of conception. So if we weren't intended to be ill, and we're given this protection system, then we have to help people realize that if their mind and body are malfunctioning, there is nothing wrong with the design of the equipment, there is something wrong with the way you are using that design. This means that people who get into illness without any clues about what's doing it to them are at a major disadvantage in knowing how to deal with it. And so, all of the major health problems that confront people today are obscured by the invisibility of the approach of that disease.

So if you can't see how you're on a collision course with stroke or heart attack, or cancer, or arthritis, or diabetes, or whatever, if you can't perceive anything that suggests you're on this collision course, why would you, how would you make any changes? By the time you've got into the difficulty, by

the time you get pain, or weakness, or a lump, or bleeding or whatever, the disease is usually in a fairly advanced state. So it would be very difficult for the average person, medically-trained or otherwise, to understand what has caused the thing to happen in the first place. . . .

This notion of being born to heal is very inspiring, confidence-building in people. And then asking, "If you are not healing, you must be continuing to do something that is in conflict with your health, or you're not doing something that is instrumental in being healthy."

Other CAM practitioners objected strongly to the notion that individuals should be held responsible for their state of health. For example, Martha saw this model as essentially an attempt to create a protective, exclusionary boundary around the person with cancer. She related this to society's fear of death and the weakening of social networks.

Part of the trouble with, whether it's the cancer culture or other cultures is, "You caused your cancer, so it's your job to get better." . . . It's a very sensitive topic because I think our culture has really gone toward, "It's your fault."

And I don't believe that. I think there's much more mystery to illness and healing. But it's deeply held within our culture around cancer. You know the whole story about TB and how before it was known to be a bacillus, all the writings were that people were weak of character and that it was your fault basically, if you got TB.

I think it is very complex and we don't really understand the causes (of cancer) and what triggers it in each person. I think it's open then to complete interpretation. And I think the fear of cancer then leads to, "Well you're different than me. I don't have it and I don't have it because of *this*. You have it because of *this*." It separates us again, right?

I often ask people, "Well, why do you think you got cancer?" And everyone has a belief system about it. Some people say it's just luck, but I think, you know, it's very shaky ground. And I think our culture has really gone off on the individual, you know, away from community. Which makes sense from what's happening in our society. And therefore the blame attached and therefore the responsibility to cure yourself, and then the sense of failure. I think it's also around death. We've become—death is a personal failure. The doctors feel it's their fault, I think that's a big part of that, too, is the sense of *I have failed*. . . .

I think it's about people separating from each other. You know, like it's that need to make you different. That keeps me safe and keeps me away from death. Right? It keeps me, well *I'm* not, you know, it's not *my* thing, and the professionals do that.

It's in a millisecond that that changes—the professional becomes the patient. And we're all the same. I mean it could just as easily be you or I sitting there with cancer and I just don't believe it's that simple.

Sophia, the other counselor I interviewed, expressed similar views about the link between the sense of responsibility that cancer patients feel and cultural models around the disease. She proposed a new metaphor for cancer that would reflect cultural models associated with the CAM Discourse that see life-threatening illness as providing the impetus for change.

When I see (cancer patients) there's still the shame, there's still the embarrassment, there's still this reluctance to tell other people, there's still a feeling that they've done something wrong. And there's also the feeling that it's somehow, I don't like to use the word "unclean"—almost akin to leprosy. It's a bit better, but people still have a lot of guilt around it.

If cancer was curable then I don't think there would be so much fear about it. But there is, I mean, there's years and years of mythology about the disease itself and cancer as well. I mean, the symbol for cancer is crab, which you know is not itself the most beautiful creature in the world. And it hangs on, it's persistent. There isn't really a nice symbol for cancer. You could have a phoenix instead—you know, the transformation.

Models about Patient-Practitioner Relationships

The patient profiles in chapter 4 give examples of new ways in which patients are viewing their relationships with health care professionals. That patients' expectations of these relationships are changing is confirmed by the observations of biomedical professionals reported in chapter 5. The CAM practitioners I interviewed generally agreed with the cultural models about patient choice and empowerment. Some believed that, in general, practitioners in the CAM field exemplified this model more effectively than conventional physicians, spending more time with patients and being more hands-on in their care. Some practitioners believe that this difference is patient-driven. Eric

noted that there is a difference in the expectations of women in his TCM practice compared to men.

Totally, yeah. (There is a change in patients' expectations.) Subtle change, but change. Because men are coming. Which is more challenging. It's challenging to treat, for me, prostate cancer—making them take herbs every day. But they are willing to do that. They are more aware, yes.

It's a social thing, (Men have been) running for years, it's the identification, the role of the male and female in their society. I mean, it's very deep roots, you cannot change that. But it changes, slowly. (Men) still think, "Doc, fix me." Like a car.

Some CAM practitioners pointed out the importance of the human connection with patients and asserted that the quality of this relationship is crucial to the process of healing. Some CAM practitioners agreed with the patients who identified this as an area of weakness in conventional medicine—its "Achilles heel." For example, Freda, a CAM practitioner who had been working within an integrated setting, said,

In the big picture a lot of what we're suffering from in our society is a lack of connectedness, and it's a lack of personal connectedness and spiritual connectedness. And my belief is that if we are able to allow our humanness to come through in our work that will foster a connectedness at a deeper level than what's been in existence in North America. It's a classic example of the white coat syndrome where physicians have kept themselves so separate that clients feel that it's a negative experience to work with a physician. I think sometimes the boundaries are so strict that it's overdone. . . .

Part of this shift that is what differentiates complementary/alternative therapies and practitioners from conventional practitioners—it's maybe a way of seeing things. Or it's not about seeing, it's about feeling—a way of feeling—a connectedness and a compassion and allowing oneself to feel that.

Martha reinforced this view based on her experiences counselling cancer patients.

I think the (conventional) system itself doesn't necessarily facilitate healing in relationships. I think relationships are really so crucial to healing . . . (T)he relationships are where I see the most damage happens within that system . . .

I think the people who choose that specific line of medicine (oncology) . . . I feel that the only way they know how to be with people is to close off their heart. I don't want to generalize 'cause there are some very wonderful (professionals), but when you're talking about the hurt within the system, I think it's the relationships that the people who really separate themselves as

the experts, you know, "I'm the professional, you're the patient" . . . which harms both parties. I can't see it helps either. So I think we're really in trouble. . . . There's so much accumulated grief in that profession that, you know, how can we actually *be* with people in their fear of death and their pain if we haven't even gone anywhere near our own pain.

The other counselor, Sophia, made the same point and suggested the situation can be changed.

A lot of our time is spent just getting people past how they're told their diagnosis—not what they've been told really, just *how* they've been told. People that have optimistic oncologists are much (more) able to deal with their diagnosis, even if it's a bad one. Most of the people that come here are very, very intelligent human beings. They know what's going on. They know the odds they're in. What they're devastated by is being dismissed. Or being treated as if they were totally stupid and that they have no choice.

That is something that we can change now. It doesn't have to come with the cure for this disease or even better treatment.

But Sophia acknowledged that this change would be difficult.

(Being an oncologist) is a job that requires someone with saint-like qualities to be able to deal every day with people who are afraid and in despair, or who are dying. It's a lot to ask somebody to go into that profession. They really need to think about it before choosing it, too.

So our doctors have to be healers. It's not just administering drugs. . . . (The qualities of a healer are) compassion, love—which I'm sure where you fill out the application form for medical school you would not be accepted if you put that down. (laughs) And someone with curiosity who is committed to learning throughout their lives. Someone who is not in a hurry. Someone who does not have a cell phone. (laughs)

You can be perhaps a good surgeon without all these qualities. You would probably be a brilliant surgeon if you did have those qualities. You're only a technician if you don't. How can we heal others if we haven't healed ourselves?

These practitioners articulated a model regarding patient-practitioner relationships that not only requires patients to be more involved in their health care. It requires a different quality of engagement by professionals than is expected in biomedicine. Their comments recall an injunction ("Physician, first heal thyself") that has been a foundation for medical practice (along with the injunction about doing no

harm) for centuries. It seems that there are aspects of the model being promoted by the CAM Discourse that are not really new models but traditional ones that, many believe, need to be brought out of their rhetorical display cases and put into practice.³

Science as a Source of Legitimacy

The CAM practitioners I interviewed were sceptical about biomedical science and its ability to be the arbiter of CAM's legitimacy. For example, Michael suggested that the use of clinical trials to prove safety and efficacy is unethical.

Scientific medicine isn't really that scientific. Because if you simply treat the disease and not the patient, you're not aware of the fact that there may be extraordinary stress in the home situation or in the workplace, and that people are trying to cope with very, very difficult circumstances.

In our experience, nobody ever asks cancer patients, from an orthodox point of view, what they ate, or how much sleep they get, or how much exercise they get, or whether they have a lifestyle other than alcohol and tobacco that's important.

Without that information, you really don't have a scientific basis. So, if you apply a comprehensive approach to the treatment of a disease like cancer, then it's pretty difficult to be scientific about it, because on one hand, you want people to be doing everything that's possible and within their capability, to restore their health.

So, it's almost immoral, when people are on a downward trend, with their illness, to withhold anything that might be helpful to them. So, to try and apply the scientific process or the scientific method to treatment, it would eventually be withholding some of the things that might make a difference.

Sophia expressed frustration at the lack of a coherent body of science regarding CAM and suggested the current methods of biomedical science may not be adequate to the task of evaluating CAM.

You can look things up on the Internet now, but there are so many things. There's still no, shall we say, governing body that people recognize and *trust*—because people lost trust or else they wouldn't be running around all over the place—that can say, you know, this works, this doesn't. And it's

³ Some of the proponents of CAM explicitly use models from the ancient Greek discourse on medicine as the foundation for their argument about the need for a different emphasis in health care (e.g., Weil 1995).

hard for me to believe after all these years that there isn't some evidence, in some area, that some things work better than others. And if there isn't, then someone needs to say that and we need to look at another way of doing things.

Sophia believed that the reductionism that lies at the core of biomedical science is the wrong way to approach the questions related to cancer and its cure.

It's the same as isolating the individual, in the context of society and nature. So the very way we do research, even if for instance we find a substance that works, it may be for instance Taxol from the yew tree. Maybe instead of refining it and refining it and refining it, maybe the whole thing, in the natural state

If we're treating the cancer cell, which is really what is happening, we're not (treating) the whole organism. And if we have a human being that is isolated . . . we (are) again treating it as a little tiny speck that has no relationship to the rest of the world.

(But) everything is interconnected. It's ridiculous to think that it isn't. The air we breathe, the food we eat, everything. This world is very efficient. Why would we think that by breaking it into little tiny pieces that it's going to cure something. I mean, we can attack the cancer cell, but if the body has the ability to produce other cancer cells, unless we kill the body, that's the only way we kill the cancer.

Eric, the TCM practitioner, agreed with these criticisms of science. He asserted that most of the research reported in the leading Western medical journals is "BS." He also said that only about 10–20% of the science practiced in China is accurate. He argued that science needs to be done differently and talked about some research that is combining Western and Eastern diagnostic concepts as an example of a better approach.

Most people still think science will fix me. I'm sorry. I think it will take multidisciplinary teams, including (those who are) open to alternative, to make sense.

We need to run clinical research on Chinese medicine, for cancer, whatever. We need to define new protocols of research, not those that have been used. It's very narrow-minded.

In China, (they take) the same diagnosis of lung cancer, whatever the stage, and then they classify it, (into) three, four, five groups, like the Chinese pattern differentiation. We won't individualize the treatment for each person but at least there is sub-categories, so at least we have something. That's the way to go,

you know, not to just rely on the Western diagnosis and give the same formula for all people—you don't respect them.

Not only did CAM practitioners undermine the tenets and practice of biomedical research, they were suspicious of the connections between such research and bodies with special interests (e.g., pharmaceutical companies). Some observed that, given the way research is funded, the field of CAM is in a Catch-22 situation. The Biomedical Discourse criticizes CAM approaches for not having enough science to demonstrate their safety and efficacy. But funding for research is tied directly or indirectly to pharmaceutical companies and others with a vested interest in preventing some CAM treatments from acquiring legitimacy. Freda argued that research regarding CAM approaches should not be limited to traditional biomedical methodologies.

I think that we have to look at what has science been in the last twenty years. What research has been done has been ruled by who can get research grants, and who can get research grants is ruled by who has the money for the grants in the first place, and does this research in any way support . . . the profit motive.

For me if I'm going to look at scientific research I would want to know who's funding this research, why are the researchers looking at this, what's their history of looking at this topic. So I would really have to be convinced that they were legitimate and there are no conflicts of interest.

I personally think there's this whole missing piece (of) qualitative research (although) it's being recognized in a bigger way in the scientific community. That's one other thing that I would look at, certainly for complementary and alternative therapies because they're so multi-factorial. I don't think you can use anything but qualitative research. So I would really want to have some set of different research methodologies being used. And then when you ask about how much weight I would give personal experience versus scientific evidence, I would weight it in favour of personal experience.

CAM practitioners pointed out some of the same problems related to medical science that Biomedical insiders did, e.g., the weaknesses of what is published in medical journals. But, the CAM practitioners went further. Like some of the researchers whose methodological concerns were cited in chapter 1, CAM practitioners asserted that

conventional medical science as it is practiced now is not capable of evaluating CAM. The ontology and epistemology of conventional science are not commensurate with CAM models. But CAM practitioners are acutely aware that science holds the key to their legitimacy. So, like the biomedical practitioners, they look to science to provide answers. But unlike, the biomedical practitioners, the CAM practitioners want the rules of the scientific game to be changed. From their perspective, it is not just that more science needs to be done, but different kinds of science need to be done. In addition, other forms of knowing need to be granted legitimacy.

Cultural Models that Legitimize and Undermine

My fieldwork provided an opportunity to participate in and observe settings where processes of legitimation and delegitimation were being enacted. This section of the dissertation presents descriptions of three public settings where I did participant-observation. I went to the public events described here because of what I was hearing from cancer patients. The first setting was a lecture given by Deepak Chopra. Several of the patients I interviewed said that they had read Chopra's books and were impressed by the ideas he expressed about the mind and the nature of healing. In attending Chopra's lecture I hoped to gain an understanding of his appeal and his message.

The second set of field notes presented here describes a lecture and workshop given by Marion Woodman. I attended these events because I knew that Woodman was a Canadian who had something of a following in the local community and that she had recently published a book about her recovery from uterine cancer (Woodman 2000). I also knew from having read some of her books that Woodman was a strong proponent of

some of the models in the CAM Discourse about the healing powers of the mind or the psyche that I had heard patients express (e.g., in chapter 4, both Angela and Marcia express models about the mind and healing that are similar to those presented by Woodman). As was the case with the Chopra lecture, I hoped that participating in the Woodman events would help me understand the appeal and perspective of a leading proponent of some of the cultural models patients were drawing on in their explanations of their treatment decisions.

The third event was a public consultation on the regulation of natural health products (NHPs). Some of the patients I interviewed reported concerns about access to alternative cancer treatments such as Iscadore (an extract of mistletoe that is difficult to get in Canada), about the purity of products such as traditional Chinese herbs, and about the excessive cost of products such as shark cartilage. I attended the consultation on NHPs in order to find out more about how the government was intending to address concerns such as these and whether treatments for cancer were of particular concern for members of the public.

The following excerpts from my field notes illustrate how cultural models that support the use of CAM as well as those that undermine Biomedicine are being expressed and promoted. The public articulation and reinforcement of these models is a crucial aspect of the legitimization of CAM.

The Nature of the Body–Mind: Deepak Chopra

In the spring of 2001 I attended an evening event featuring Deepak Chopra. Chopra is a former Boston endocrinologist, now based in California, who espouses a philosophy of

healing rooted in Ayurveda, an ancient Indian system of philosophy and medicine.

Chopra has written more than twenty books that have been translated into thirty-five languages (Chopra 2000). More than 10 million copies of these books have been sold (Beers 2001). In 1999 TIME magazine selected Chopra as one of the Top 100 Icons and Heroes of the Century and called him "the poet-prophet of alternative medicine" (Chopra 2000). On Saturday, April 21, 2001 Chopra lectured to a crowd of four to five thousand people at GM Place stadium in Vancouver.⁴ The following is an excerpt from the notes I made during and after this event.

The audience is large but not a full house. The crowd is mostly white but with some Indo-Canadians and a few East Asians. They are of all ages, all classes, all sizes and shapes. I am surprised by the audience. But then I am surprised that Deepak Chopra would "perform" at GM Place. What will he do? What has brought all these people out on a Saturday night? This is a venue usually reserved for sporting events and rock concerts. I can't figure out what most of these people are doing here: sixty-ish women with managed silver-grey hairdos dressed in silk dresses festooned with gold costume jewellery. Young edgy twenty-somethings with black t-shirts and clear skin. Aging boomers and their parents. Lots of them look like they drove in from the suburbs. They seem pretty conventional and working or middle class.

We have paid from \$50 to \$125 per ticket to be here. I paid the least amount and had my ticket upgraded at the door, as did everyone else from my section. Obviously the response was not as large as expected. Chairs have been set up on the stadium floor, close to a T-shaped podium. These are the most expensive seats, closest to the "star" of the show. The club section (where the corporate types watch hockey) is mostly dark. The highest tier (where I was supposed to sit) is dark and unoccupied.

Before the show, three young blonde women wearing lots of jewellery who are seated on my right are regaling each other with stories of "New Age" treatments they have received. ("Ooh, when she worked on my third chakra the energy just went . . .").

Chopra is given the usual glowing introduction by a young male Indo-Canadian news anchor from a local TV station. Chopra comes on stage and takes up a position at the base of the T. He stays there most of the evening, occasionally shifting position, turning from side to side, walking up and down the length of the T. Not so much that it's irritating, but enough to keep us interested. He stands against a deep blue backdrop that has stars twinkling here and there.

⁴ Chopra makes about \$25,000 for each lecture he gives (Goldstein 1999).

Early on, Deepak asks how many in the audience have never been to a live talk by him before. Most in the audience raise their hands.

Chopra seems very much in his body. Very relaxed. Very integrated. He wears an impeccably tailored black suit with Indian style tunic jacket with stand-up collar. He seems fit. He is on the declining side of gorgeous. He uses no notes. Towards the end of his lecture he uses overheads that are handwritten. I wonder if this is a lack of planning or intended to convey a down-home, low-tech, "just an ordinary guy" kind of impression. Except when the overheads are being projected, his image is displayed on two screens on either side of the stage. So we get him as he is, full-body and distant at centre stage, and also as we would see him if he were on TV, head and shoulders, close-up, bags under his eyes, thick, dark hair and all.

Chopra talks from 7:30 to 9:00, then takes a break. There's an intermission until 9:30 during which Deepak signs books for the faithful who have lined up on the stadium floor. Not everyone gets their books signed. At the intermission, two middle aged couples seated near me debate whether to stay or go. "Well, I haven't heard anything new," says one woman. The other three agree. But they do return. When the intermission ends at 9:30 Chopra resumes his position on the stage and continues talking.

The event is not a show but a lecture. Chopra covers the essential points from his many books. My guess is that this lecture draws on the content from his latest book, *How to Know God*, which Chopra promotes gently but unmistakably. He uses quotes from poems and stories of amazing synchronicities to reinforce his points. At the end he gives advice about how to manifest good things in your life: health, happiness, financial abundance—he gives seven affirmations to say before your meditations, e.g., around the power of intention, the balancing of masculine and feminine energies, the power of love. These are all very generic and abstract.

His talk is basically a representation of the perennial philosophy (which he refers to as philosophies—plural). He uses the word "quantum" a lot. Chopra talks about acausal knowledge, about events that are not tied to cause and effect relationships, but to karmic relationships. He talks about non-local phenomena.

He says that, "yesterday's miracles are today's science." He invokes science and scientists a lot (e.g., "my friend, Dr. X who is a physicist at Y University says . . .") He asserts that science is confirming/validating/(legitimizing?) the truths that have been contained in the Eastern traditions for centuries. He uses software/hardware analogies to explain his points. He also makes paradoxical claims, in the manner of a Zen teacher, although he doesn't strike me as very Zen-like. For example, after listing and talking about the various parts in the hierarchy of material substance, from sub-atomic particles to organisms to the cosmos, he states that they are all nothing.

I can't understand what has drawn so many people here. And so many unlikely looking people. They are not the people I see at Banyen Books. Or at meditation retreats. Or at workshops I've attended that have a spiritual

flavour. The only clue comes when Chopra is telling a story about synchronicities and mentions finding himself in a limo with the guy who wrote *The Celestine Prophecies* (James Redfield)⁵. When he mentions the name and the book, a wave of recognition (ahhh!!!!) runs through the audience. It is the biggest audience response he gets all night. (The sceptic in me says, "Aha. So that's it, these are the people who are into spirituality lite—Let me visualize for ten minutes occasionally and get all my prayers answered. Let me "manifest abundance" and realize all my materialistic, egocentric, and narcissistic desires.)

After 10:00, people start leaving, two or three here and there. At the end Chopra gets an acceptable round of applause, but nothing very rousing. He is presented with a "peace flame" which seems to be contained in some kind of silver metallic cylinder, in recognition of his work. The TV anchorman encourages us to give Chopra a warm thank you, which the audience does, with some cheers, but it is not prolonged.

Around the time of this event, several stories about Chopra appeared in the local print media. One story in the *Vancouver Sun* entitled "Deepak Chopra's enduring appeal" mentions that,

A lot of . . . credentialed scientists take . . . runs at Chopra's "factual errors" and "absurd ideas." All of them are wasting their time, because their angle of attack clearly misses the appeal of Chopra in today's society. What pulls people to Chopra is a yearning to pull free of scientific rationality, or, more accurately, to escape the unenchanted world that two centuries of The Age of Reason has bequeathed us (Beers 2001).

Another *Vancouver Sun* story headlined "Chopra's talk leaves fans inspired" summarizes the main points of Chopra's lecture including representations related to the body-mind and healing.

(Chopra) became disenchanted with his medical practice when he realized physicians only studied sickness and knew nothing about real healing, because they didn't take into account the human soul.

The human body is 99.99 percent empty space. The traditional scientific view that the universe is made up of hard bits of matter is wrong. Consciousness is the root of life. "We spring forth out of nothingness; nothingness is the womb of life" (Todd 2001).

⁵ *The Celestine Prophecies* was an apparently autobiographic account of a spiritual journey that was a run-away best seller in North America for several years.

This story continues with reports of reactions from members of the audience. Rex Weyler, the then-publisher of *Shared Vision*, one of the large alternative magazines in Vancouver is quoted and then the *Sun* writer goes on to say, "Given that humans can make themselves sick with their own thoughts, Weyler didn't see any reason not to believe Chopra's claim that adherents could learn how to live to age 120" (Todd 2001).

This event and the media coverage surrounding it reached thousands of local people who were thus exposed to CAM models about the nature of the body-mind and about health and illness that stand in direct opposition to analogous models in the Biomedical Discourse.

The Self and Healing: Marion Woodman

Another speaker whose name is well-known among those with an affiliation with CAM appeared in Vancouver around the same time as Deepak Chopra. She drew a smaller but seemingly more committed audience. Marion Woodman is a Canadian who has written nine books about various aspects of emotional and spiritual healing. She practiced as a Jungian analyst for many years in Toronto and has travelled widely in Canada and the U.S. giving lectures and workshops. Woodman gave an evening lecture in March 2001 to a crowd of about 1,000 people and followed this the next day with a day-long workshop attended by a smaller group.

It is a March evening, cold and rainy. I step inside the sanctuary and look around for a good seat. This large, Christian church downtown is already almost full. I slide into a pew on the side, near the back. It is as close to the podium as I can get. The audience is mainly women over 40. Some people are in quiet conversation with their neighbours. Others are roaming through the crowd exuberantly greeting familiar faces. I pull out my little notebook and begin writing.

Shortly after 7:30, the crowd, now a more-than-full house, stills. After the introductions, Marion Woodman takes her position behind the podium. She is small and slim, with grey hair. In her early seventies. Dressed elegantly. Although she is small, she has a clear, strong voice that commands attention.

Marion begins her lecture with the story of her cancer diagnosis. "The word cancer goes through you like a knife, when it's you," she says. She goes on to say that medical doctors are interested in curing, but she sees healing as different. She says illness is a call to wholeness. If you are cured and not healed, the symptoms will come again. She advises us to watch our dreams and pay attention to our symptoms so that the voice of the soul can come through the body.

She asks rhetorically, "What is the meaning of cancer in our society? This is an obvious question. So many of our diseases are auto-immune breakdowns. Why would your own body refuse to play host to your soul? Why would the body turn against itself?"

Woodman answers these questions. She cites environmental pollution. She says that a death wish is often found in the unconscious. She asserts there is often a disconnection between the life force or the spirit and the body. She says, "The world you're thrown into when you have a life-threatening diagnosis is spaceless and timeless." She talks about her search for meaning, not in the sense of, "Why me?" but a search for the purpose of the factors behind her illness. She refers to her cancer as a call to a new maturity. She says, "The new medicine is about the energy body, the subtle body. It is about the development of new sensitivities. Part of the cause of an illness is that you have repressed energy that wants to go in a new direction."

Woodman talks about her achievement of a new balance between the feminine and the masculine. She says these opposites are paradoxes not contradictions. She describes how she had to develop a new sense of the masculine in her interactions with her doctors because she had to figure out what symptoms to pursue and which ones to ignore. She had to unleash new passion, new desire for life. She says, "If you believe you are going to die, the cells get the message."

Marion closes her talk with the story that ends her book. After eighteen months of conventional and alternative treatments, and much self-analysis, she was alive but barely. She went to a friend's birthday party, hardly able to walk from the car to the house. As she and her husband were about to leave, a brass band arrived and began playing polkas, waltzes, fox trots. As a former dancer, something in Marion could not resist. Gradually her body responded to the music until finally she rose up and began dancing. She describes it as being possessed by the archetype of the Gypsy—a 24 year old, vibrant woman, possessed by life. She says, "If I had left five minutes earlier, I would not be alive today."

Marion gets a standing ovation, not a dry eye in the house.

The next morning I attend a day-long "workshop" with Marion. The other 100 to 150 people here and I have each paid \$125 to attend. Again,

most of the audience is female, mostly over 40. Marion spends the morning lecturing, expanding on the messages she gave last night. She says that the new medical sciences such as psychoneuroimmunology, have moved into a new consciousness, a consciousness of energy—energy bodies and energy medicine. She says that in concretizing we kill the imagination, that our society's loss of symbolic, metaphorical thinking has repressed the shadow and prompted people to become monsters. She asserts that metaphor accomplishes transformation at the soul or spirit level and neurotransmitters accomplish transformation at the physical level. She says that neurotransmitters and metaphors are the bridges between mind/spirit and body. She advises us to follow the metaphors, to find ways to make blocked energy available to consciousness.

At the break I notice a bald woman who looks familiar. When I hear her speak, I realize it is Angela, one of the cancer patients I have interviewed. I am saddened to see that she must be under treatment again. I approach her, smiling. When she recognizes me, she beams at me, eyes sparkling. "Margo!" she exclaims and opens her arms to embrace me. We talk a few minutes. She tells me of her current course of treatment, but spends most of the time enthusing about Marion's talks last night and today. When we part, Angela thanks me for acknowledging her. I wonder if her experience has been that some people avoid her. The sign of her vulnerability is perhaps too obvious for comfort.

After lunch, Marion continues her lecture. She focuses on the concept of the archetype and its role in healing. She says an archetype is an energy field we are born with, similar to a morphogenetic field. "What the DNA is to the body, the archetype is to the psyche." She says an archetype is the magnetic field in the unconscious onto which we put images. "Without archetypal life there is no passion and no healing. You need that energy to push through the ego. You need an ego strong enough to relate to the archetype without identifying with it."

Near the end of the day, the audience finally gets to engage in some "workshop" activity. We break up into groups of three. We do the kind of experiential exercises common to this kind of gathering. A guided meditation while we lie down, eyes closed, to get us centred and relaxed. An exercise to spark our imagination and get us grounded in our bodies. We are each given a role to play, an animal to be, and encouraged to dance with a partner. To express that animal's personality. To communicate with the other. Then we share our experiences with our partner and the third person in the triad, the observer. I play my part in these exercises. I am seasoned enough to know how to participate genuinely in the forced intimacy that these settings encourage without revealing anything I will later regret.

There are people in the audience who are Woodman followers. They have read all her books, been to all her local lectures, workshops, and retreats. Some have traveled some distance to be here. I understand her appeal. But I am not deeply affected by her or her teachings. She is not my type. Not my archetype?

The Chopra and Woodman events show how public figures who could be described as CAM leaders promote cultural models about the body–mind and about the nature of health and illness that are not congruent with biomedical views. The patient profiles in chapter 4 show that some cancer patients are adopting these kinds of models (e.g., Marcia’s attempt to find the message in her breast lump and her belief that she had to address her willingness to die; Angela’s questioning of whether cancer is a “real” disease). The third public event I will describe illustrates that some members of the public have adopted cultural models that explicitly undermine the legitimacy of biomedical science and government’s role in relation to non–biomedical approaches to healing.

**Science and the Legitimacy of CAM:
Health Canada’s Consultation on Natural Health Products**

In August 2000, Health Canada (the federal government ministry responsible for regulating food products and drugs) held a series of public consultations as part of the process of preparing new policies to govern the regulation of Natural Health Products (NHPs), products that are neither food nor pharmaceutical products (e.g., nutraceuticals, vitamin supplements, and herbal remedies). I attended an evening session in downtown Vancouver that was open to the public.

I sign in at the registration desk and get a packet of information, including a lengthy workbook designed to serve as the basis for the consultation session. I go into the meeting room. The room is long and narrow. There are about twenty large, round tables arranged in front of a podium on which sits the standard skirted conference speakers’ table with microphones and pitchers of water. A projector displays the title of the meeting on the wall behind the podium.

About ten minutes after the advertised start time, two athletic-looking thirty-ish men in suits and two women, one slender and dark-haired, the other blonde and dumpy, take their places on the podium. The tall, blonde man picks up portable microphones and steps down into the room from the podium. The other man steps up to the podium. The introductions begin. The dark-haired man is an official in the recently-created Office of Natural Health Products. He is a naturopathic doctor. The other man is a consultant. His role is to facilitate the session. The blonde woman's area of expertise is policy and regulatory affairs. The slender woman is from legal services.

The consultant goes over the agenda and lays out the structure for the evening's session. There will be presentations, a question and answer period, small group discussions at our individual tables (the consultant calls this "table work" in the best bureaucratic tradition) followed by a plenary to summarize the input received. The consultant points out that this will not be a town hall kind of meeting. If people have briefs they will be accepted and included in the consultation, but they are not to be presented.

I can see that the evening has been structured to contain and constrain the participants. To get input, yes, but only within certain limits. The message to us citizens is clear: no grand-standing, no soap-boxing, be nice. All this is peppered with reminders that it is *really* important for them to hear what we have to say and the assertion that they want the Office of NHP's work to be transparent. I wonder how many others in the audience feel as I do that it is the attempt to manipulate and control the meeting that is transparent.

There are about two hundred people here, eight to ten at each table. About 70% are over 50 years of age. About 60% are women. About 75 to 80% are white, the other predominant obvious ethnic group is Chinese. Almost all of the Chinese people in attendance are men. It is a full house.

The Health Canada official goes over the Office's mission statement: "To ensure that Canadians have ready access to natural health products that are safe, effective and of high quality, while respecting freedom of choice and philosophical and cultural diversity." He acknowledges that some people who use NHPs have different medical paradigms, that not all people use the same thought processes. He asserts that Health Canada is trying to incorporate all perspectives.

The official goes on to give an overview of what is included in the proposed regulatory framework: product labeling, product licensing, site licensing, good manufacturing processes, and adverse event reporting. He reiterates the concern for safety, quality and effectiveness. He summarizes the history that led to tonight's session. He goes over the definition of NHP that is being used and points out that they are mainly concerned with off-the-shelf products, the things people can buy in health food stores and drug stores. They are not concerned with individualized formulations that practitioners such as TCM practitioners prescribe and provide for their patients. The Health Canada official says, "We are not wanting to interfere with the practice of medicine."

Then the consultant opens the floor for the question period. At least he partially opens it. He instructs us to confine ourselves to questions that aim to get clarification of the presented material only. It is about 7:00. The question period is scheduled to go for 30 minutes.

As soon as the official passes the baton to the consultant to introduce the question period, a small, elderly man at the table in front of me begins raising his right arm every few seconds, trying to get the consultant's attention. As he raises his arm, his hand twitches, closing into a fist, then opening, the hand moving faster and faster as the man gets more and more agitated, waiting for the consultant to stop talking. The consultant passes the mike to the elderly man and he stands up.

The man is short, bald, with square, metal-framed glasses on a round, wrinkled face. He is wearing khaki cotton pants and a ski sweater. The man grabs the mike and faces the audience. He speaks with a thick, Eastern European accent and I find it difficult to understand his words. He is obviously angry. I manage to make out that he has been a physician since the fifties and ended his career as a clinical instructor at UBC. He picks up the workbook and waves it around. "This is a pack of lies," he says and slams it on the table in front of him. His mouth twitches as he rants, talking about the use of herbal remedies in the 1600s, and the evolution of the use of digitalis from the early use of foxglove. He goes on and on, but it is not clear what his point of view is and he does not ask a question. I watch the Health Canada reps on the podium, wondering what they will do. They sit impassively, nothing registering on their faces.

After several minutes, as the audience is getting restless, the consultant tries to intervene. He walks toward the man. "Sir, do you have a question for the panel?" The man continues talking, seemingly oblivious to the consultant. The young, dark-haired woman on the panel seems to know what the man is getting at and she tries to interject. She says a few words; the man talks her down; she says a few more words; the man continues, his voice getting louder. Individuals in the crowd begin to mutter and make dismissive comments. The consultant continues to try to get the man to ask a question or stop talking.

A fifty-ish man at my table leans menacingly across the table at the speaker and shouts, "Okay, you've had your fifteen minutes of fame, now sit down and shut up." Others in the audience verbally support this intervention. The consultant finally manages to wrest the microphone away from the doctor and he reluctantly sits down, although he continues talking. His right hand is working fast, the fist opening and closing, his wrist now twitching too. The consultant quickly passes the mike to someone else and a question gets asked. Gradually both the doctor and the room subside.

Questions are asked and answered and some audience members take the opportunity to make editorial comments, even though this has been discouraged. One middle-aged man with grey, thinning hair dressed in a white open-necked shirt and tan cotton pants gets up and prefaces his comments by saying, "It is no small secret that people do not trust the

government.” He gets a supportive round of applause. The man goes on to say that these regulations will be exposing people’s secret formulas for remedies that have been proven safe and effective for years. He believes there should be some way to protect people’s work from being taken over by other manufacturers.

Someone else asks a question about research. The official responds by saying that the Office of NHP has a budget of \$1 million for research. Several people snort derisively. The official says that they are hoping to get additional research money from the newly-created Canadian Institutes for Health Research. (“Yes,” I think, “You and every other health researcher in the country.”) The official goes on to say that Health Canada will expect that the research data to support any claims regarding benefits will be appropriate to the risk associated with the product. It will not necessarily be the case that the claims regarding every product will need to be validated through RCTs.

An older woman with short, straight grey hair, dressed in a blue and white striped summer dress with a white cardigan buttoned down the front gets the portable mike. She leans forward across the table in front of her, fixing the panel in her gaze. Her voice is loud, aggressive. She says, “This process is simply window dressing. We are not being allowed to address the real, important questions here. The use of natural products has been going on for years and it has not been the experts, the professionals, or the pharmaceutical industry that has been involved. Now I as the citizen have no choice but to be under the control of experts I do not trust. If there is an inherent history of safety behind a product, why should the government be involved?”

The woman pauses briefly to take a breath and then goes on. “For the last twenty years the pharmaceutical industry has had to grudgingly agree that these things work. These regulations that you are proposing are the things that Codex⁶ would like to see and the pharmaceuticals would like to see. But we as citizens will not stand for being subject to global regulations.” The audience erupts in resounding applause. The woman finishes by saying, “This definition of natural health products is so broad that anything that is vaguely healthy can be brought into it and then controlled.” She passes the mike back to the consultant, leans back in her chair, and folds her arms across her chest.

Attention shifts to a man across the room who is given a mike and then stands up. He identifies himself as someone who was involved in health policy formulation during Brian Mulroney’s tenure in the eighties. He asks what kind of scientific standards Health Canada will be basing decisions on. He refers to the removal of amino acids from the market during the eighties and the banning of comfrey root because a study showed it had toxic effects on rats. He says, “Health Canada has been using bad science to justify the removal of substances that have been proven effective in use with humans for years. This is what I call pornographic science.” The audience claps.

⁶ Codex is an organization created in 1963 by the Food and Agriculture Organization of the United Nations and the World Health Organization to develop international food standards and guidelines.

Behind me, a slight Chinese gentleman in a suit rises. He says he has been asked to raise some questions by his colleagues at the table, all practitioners of TCM. He follows the rules of the game, asking for clarification of the scope of the regulations, confirming that individualized formulations will not be regulated. He asks whether the traditional Chinese pharmacopeia has been officially recognized by Health Canada and if not, why not. He is polite, respectful, dignified. His approach is markedly different from the confrontational attitude of most of the other speakers.

The only explicit appreciation for Health Canada's efforts comes from a tall, skinny, thirty-ish white man who prefaces a question by congratulating the official on doing a difficult task well. He laughs nervously as he says this. He does not get any supportive applause from other quarters.

This description of the public consultation shows that some members of the public are suspicious about the influence of vested interests in health care and sceptical about the links between science, government and big business. Science is not necessarily seen as the best way to legitimize natural health products nor is the government necessarily seen as having the best interests of the public at heart. Although no one raised concerns about particular cancer treatments at this event, the criticisms of science and the calls for a more open marketplace where more control is given to private citizens were similar to some of the views expressed by patients I interviewed (e.g., Jack's belief that he needed to take control of his treatment).

These excerpts from my field notes provide a glimpse into settings where the issues central to my research are being contested. They show that cultural models associated with CAM are being promoted by leaders of the "CAM movement" who articulate alternative models about the body and health and encourage people to incorporate these models into their response to diseases such as cancer. They also show that the authority of science and the role of government in health care are coming under fire in the public realm.

The next section of this chapter presents some of the private thoughts expressed during my interviews with "hybrid" professionals. These interview excerpts provide insight into another aspect of the contestation of medical legitimacy: the process whereby people shift their allegiance away from the Biomedical Discourse and become more aligned with alternative discourses.

Hybrid Professionals: Bridging Worlds

One of the CAM practitioners I interviewed, Michael, was a conventionally trained physician who began using unconventional treatments for cancer after his patients introduced him to such therapies. He described a gradual process of change in his attitudes and practices as a result of his willingness to consider patients and his own empirical observations as legitimate sources of knowledge.

In a relatively short period of time the so-called industrialized countries have gone through an incredible transition of belief systems and therapeutic approaches. So I guess more and more people from the public are asking, "What else is out there besides the conventional?" And in my experience most of the changes that occurred in my approach to therapy was the result of patient-driven inquiry. You know, where people come and confront me with facts and figures and information and make a successful plea to have a chance to at least try something. And most of the people are the ones who have used up the conventional options and they haven't worked and now they're in search of other solutions. . . .

The main factor here is whether or not a physician is open to consideration of new ideas because if you get the reputation of being approachable and willing to consider change then, of course, word gets around and people come in increased numbers. . . .

If you're really busy in a medical practice you have to set very definite limits for how much time you're going to devote to new ideas and I think that the tendency is for doctors who are particularly orthodox to go to orthodox conferences (and) read orthodox books. Many doctors feel a sense of pride in what their profession has accomplished in the last hundred years and feel that the profession is at the forefront of progress and do not question it because they see their colleagues accepting this category of information and they feel comfortable with it. But there's also an overwhelming concern in some

doctors who feel they want to explore (new ideas) but they will be in conflict with the College of Physicians and Surgeons. . . .

I think looking back I would consider that I've got most of my post-graduate education from patients, but there again, there has to be a willingness to listen and to learn and to acknowledge people who have brought in new and exciting ideas. . . .

There's a distinct advantage in having had the experience of watching incurable cases get well. Once you see that happen, it alters the way you look at things. It changes your perspective.

Martha, a counsellor who spent more than ten years in the conventional medical system as a nurse, described the process of changing her position with respect to Biomedicine. She, too, emphasizes the importance of being open to new experience.

The conventional system, you know, as well as helping people with cancer also hurts people. And so my role in that system became difficult for me because a lot of the work that I was doing was helping people to heal from the experience of the system itself and so then I had to make a choice

My debate for myself at that time was: in the system—out of the system. And someone helped me with this when they described the bridge being an actual place, a position . . . and it just really clicked for me. So I feel that I'm on the bridge, because of my experience in the conventional system and my on-going relationships with the health care providers . . . I do feel the bridge is a position. So what I feel I'm doing is I'm trying to be *on* the bridge. Because I know that all of it has value.

It's hard to pinpoint (the origins of my philosophical base) 'cause it's evolved over 20 years and I think it's evolved from an intense curiosity in, you know, life and death and, you know, meaning—what really is this all about? So I think that comes from my background and my family and all that, you know, it's so intertwined. But I think it's developed, you know, from a scientific training, and then sort of an opening to what else is possible.

Another health care professional I interviewed provided a striking example of the difficult process that some professionals go through as they change their position with respect to the different worlds of Biomedicine and CAM. This man, Andrew, is a retired surgeon who now teaches meditation to cancer patients. During one interview, Andrew was describing some of the personal challenges he had faced as a surgeon. I asked for his perspective on the speculation that I had heard from patients and CAM practitioners

about the stance of objectivity taken by conventional practitioners being a shield against the practitioner's own fear. He agreed with this idea.

That's right. That's correct. Your own fear, your own hopelessness, your own inability to deal with it. . . I was very insensitive when I was working to such matters. And the reason was, I was so worried, exhausted, tired, and in a hurry and didn't know how to deal with, and didn't *feel* it. I didn't feel it, that was the thing.

Because I was so concerned with the technicalities. . . . There was tremendous technical worry. . . . There was anxiety of somebody's health and life, you know. I took that very seriously and so it was, the concern was technical. . . . There was no time for heart-opening or that kind of stuff. . . .

The concern about technicalities was so overwhelming there was no way you were going to worry about being tender. But, you know, one did have a natural care and tenderness, but perhaps it wasn't as much as the patient would have liked. And it often looked as though there wasn't any and that was because your concern overwhelmed you. . . . You have to leave the nurses and the relations and interns or someone to do the open-heart stuff.

In the course of our two interviews, Andrew talked about the experiences that had changed his view of the nature of the connection between the body and the mind and transformed his relationships with people. He participated in a residential retreat that used non-mainstream psychotherapeutic techniques. Subsequently he began practicing meditation. In these contexts, Andrew had new experiences such as the experience of physical pain dissolving once its association with a particular emotion or past experience had been recognized. Andrew came to believe that emotions like anger and grief are held in the body and can manifest as pain or disease.⁷ But he was reluctant to share these new understandings with his biomedical colleagues.⁸

(This new understanding) was surprising. I had never dreamt . . . certainly had no experience of such matters. And if anyone had spoken to me about it,

⁷ There are a number of CAM and psychotherapeutic discourses that include this model. For example, see the description of Marion Woodman's views earlier in this chapter.

⁸ "Andrew" reviewed this chapter and gave permission for his comments to be included even though he had previously been careful to keep these experiences from his colleagues. He now feels that, "It is more important to be authentic than to keep secrets."

I would have been quite impatient with them. . . I wouldn't have believed. I wouldn't have taken it seriously. . . .

(But) ever since that experience I have been totally and utterly convinced . . . Before the experiences, science was the root of my conviction . . . Everything was through my head, I didn't have any feelings. . . .

I keep (the shift in perspective) secret, actually. I don't tell my colleagues. (Laughs) . . . Because I remember what I was like. They would just ridicule me. Some of them wouldn't. But you have to have time to explain. And they won't give you the time.

This interview excerpt shows the critical role played by direct experience in the creation of new situated meanings and the adoption of cultural models that conflict with pre-existing beliefs. It also shows how the hegemonic Biomedical Discourse suppresses competing cultural models and Discourses.

As noted in chapter 1, some "hybrid" professionals who have come to value both Biomedicine and CAM are advocating that the best of these worlds be integrated. The next section of this chapter discusses some of the issues related to integration raised by the CAM and hybrid practitioners I interviewed.

Integration

The topic of "integration" or "integrative medicine" or "integrative health care" is becoming prevalent in debates about CAM. But what does "integration" mean exactly? What issues does the concept raise? What might integration look like, in practice? I posed these questions to the CAM practitioners I interviewed.

Michael, the conventionally trained physician, described the reasons why he preferred the term "integration" and explained his understanding of the term. But he acknowledged that there are constraints that make the implementation of this vision problematic.

Life . . . is a semantic experience. So if you use the wrong terminology you convey the wrong message and so we've abandoned the idea of "alternative" because by definition it means mutually exclusive. And that suggests to our conventional colleagues that we have forsaken all the advances of scientific medicine in favour of something that's unproved, potentially dangerous, and hasn't been exposed to rigorous scientific study. "Complementary" gives people the impression that it's something that you've added on to something that's not particularly effective.

So "integrative" I think is the most acceptable term to use because it would suggest that you're going to apply the best of all possible solutions. So you would be applying the best of scientific methods and scientific medicine and the best of self-care and the best of nutrition and so forth. Striving to cover all of the conditions that people are living under. . . .

One of the concerns that conventional doctors have about complementary and alternative medicine is that not all of these therapeutic methods are effective and many of them have not been exposed to any particular rigid investigation and sometimes the costs are prohibitive for many people. You can't start including things that seem like a good idea without destroying Medicare. Medicare is really treatment oriented and as such it has difficulty coping with the treatment demands of the public focused the way it is. If you started adding acupuncture and herbology and all of the extras, then it would collapse.

Sophia provided a different description of an ideal model of integrative care that would put the patient at the centre of a well-informed web of knowledge based on what has been proven effective throughout the world.

I would really like to see this competition . . . I don't know what else to call it—it's a competition of whose medicine is the best . . . the person that has the cancer is the one that is confused. Often people believe very strongly in their doctors at the beginning, but if the cancer progresses or worsens they become disillusioned. So we still have this dilemma and the pressure on the person that has the cancer and the family to find out what works.

There has to be things that the person feels confident in, both the person that's prescribing them and the person that's taking them. There has to be that trust that people used to have in their doctors, there has to be that faith that whatever they do is going to be useful for them. So I see an assessment, individual assessment of each person and then—within the realms of reality of what can be done for you now—What have you been eating? How do you sleep? Where do you feel the cancer came from? And then say, "This is what we can offer you. We have on our staff people who have researched throughout the world what people who have lived the longest have eaten, for instance" . . . sort of like (the) United Nations of the cancer world.

These visions suggest that integrative medicine would combine a multiplicity of approaches depending on what is likely to be most effective in each particular situation. They imply a pluralistic medical system where different approaches are valued equally. This is the vision for integration that most CAM practitioners espoused.

The three practitioners I interviewed who were working at the Tzu Chi Institute at the time I did my fieldwork had two to three years' experience working within this integrative health care setting and had been involved in extensive dialogues with their colleagues about the concept of integration. They described integration as ideally operating according to the following principles: the patient should be at the centre of a team of multi-disciplinary service providers, including both conventional and CAM practitioners; the goal of providing care should be the patient's well-being, holistically-defined; the organizational structure should be non-hierarchical, with every profession being given equal value and decisions being made by consensus; and the conceptual models and languages of different medical systems need to be respected equally.

However, despite this apparent clarity about guiding principles, the operationalization of integration was challenging. Freda, one of the Tzu Chi practitioners put it this way.

I've thought a lot about the concept of integration and what that means within my practice. I've been very confused about what that actually means because it has not been defined. The whole concept of integration has not been defined and in fact at Tzu Chi what we're trying to do is bring something that's very abstract into more of a finite definition of, what does it mean on many different levels. It involves personal integration, it involves team system integration, it involves global integration. But integration for me means in my professional work that I believe that I can't be fully integrated until I take a look at my personal self. And do my work in a holistic way. My belief is that one cannot be truly integrated unless they're personally integrated, which means looking at one's relationships, one's health, how one lives one's life. And living a seamless integral life and acknowledging that

that's difficult. . . . For me integration means looking at other health belief systems and respecting and acknowledging that there are differences in beliefs and values around health.

Other practitioners from the same setting agreed with this perspective, that to work within an integrative care model, each individual had to live according to holistic health principles (e.g., they had to practice mind-body techniques, eat natural foods, and avoid toxins), i.e., they had to "walk the talk." But they acknowledged that not all their colleagues shared this view.

This model about the need for "personal integration" raises a question that arose in several different ways in my discussions with CAM practitioners about the operational challenges of integration. The question is how to assess the credentials of CAM practitioners, assuming that integration would involve some kind of professional regulation. My conversations with practitioners concerning this question clearly demonstrated that there are divisions and hierarchies within the CAM field. Some practitioners criticized other practitioners within their own discipline, citing their superior training or experience. For example, Eric, the TCM practitioner, said,

The notion of integration comes from the public demand for that. The problem is the education of doctors in Chinese medicine. Most of them have not enough education. There is a long way to go in terms of personal commitment. There is no real structure in place to study Chinese medicine at the post-graduate level.

The key is (knowing) Chinese. If you want to get access to the data, you have to know Chinese. After twenty years I still feel . . . I know what I don't know. The scary part is a lot (of practitioners) think they know. So they don't know what they don't know.

The public has to be educated on the fact that when you have cancer you have to be referred to someone specializing in cancer even if it is a complementary or alternative program.

Other practitioners talked about CAM treatments outside their own discipline using the same kind of derogatory language that biomedical critics use. Still others pointed out the

difficulty in some disciplines of establishing evaluative criteria that would satisfy mainstream policy-makers, e.g., in relation to "energy medicine." Despite these difficulties, many fields of CAM practice have become professionalized (e.g., in B.C. there are professional colleges for naturopaths, chiropractors, and TCM practitioners). Methods for assessing practitioners' credentials that are analogous to those used to credential biomedical practitioners have been developed.

But these methods have not addressed the issue raised by some CAM practitioners regarding the need for practitioners to be themselves exemplars of the integration of body, mind, and spirit. While some CAM practitioners I met seemed comfortable making judgments about other practitioners' state of mind-body-spirit integration, others asserted that this idea that one needs to have certain spiritual qualities or abilities to be a competent practitioner is creating an elitism within CAM that is unjustified and dangerous.

This question of how to assess the competence of health care providers who operate according to holistic models is one among many challenges identified by the CAM practitioners with some experience of integration. Another was the tendency for biomedical practitioners on the health care team to play the most central role in patient care, e.g., to do the initial history and examination and to play the role of case manager. This dominance of biomedical practitioners does not only apply to patient care. According to Elizabeth, an administrator involved in the Tzu Chi Institute, this marginalization of CAM perspectives applies to policy making as well as patient care. Elizabeth described her attempts to bring CAM perspectives to broad policy questions about health care reform and to have CAM initiatives supported.

We are over in the corner, marginalized, going, "We know, we know (raising her hand like a student in school)." But nobody can hear you. Nobody can even hear you. You're too small. You can't compete for (the available) money. You can't propose anything. You can partner—and all you can try to do is influence the people that actually have the God-given right to that money in our society.

Although the association of CAM with biomedicine was seen as presenting some problems, it also brought benefits. Brenda, another one of the Tzu Chi practitioners, pointed out that being aligned with biomedicine conveyed legitimacy.

People feel safe in the (Tzu Chi) environment because there are medical doctors there and we're right next door to a hospital. It's that sense of, well, you wouldn't be here unless you're exceptionally good and you're going to be very careful because, you know, you've been accepted here and you're working with medical doctors.

While operational factors represent challenges to integration, their importance is overshadowed by the fundamental difficulty of finding common ground among different paradigms of health and healing. As Brenda noted,

Part of the problems have been things like just trying to understand each other's language. . . . (for example) when it comes to acupuncture you're looking at a whole different paradigm there. And that's where there's a real language difficulty happening. To understand some of these concepts and accept them from the Western model's point of view can be difficult. Some of the things our traditional Chinese medical doctor would come out with, we'd sort of look sideways and think, "What on earth are you talking about?" And a great sceptic, say from the medical profession, would just think he was talking rubbish.

I observed first-hand the tensions involved in trying to build bridges between some of the fundamental concepts and assumptions that underlie Western health care and new CAM models in one meeting I attended early in my fieldwork. The group that was meeting comprised representatives from two cancer care facilities: one was a conventional clinic and the other was a facility that offered a range of CAM treatments. The group's purpose was to determine whether and how to achieve some kind of

integration between these two organizations that provided care to many of the same patients. This group struggled sincerely and intensely to bridge what we came to describe as "two solitudes in oncology." After much discussion, the group came to the conclusion that the biomedical and CAM "paradigms" were incommensurable. The following description of part of one meeting provides an example of the incompatibilities we could not resolve. The following excerpt portrays an exchange between two practitioners: one aligned with CAM and the other aligned with Biomedicine.

We begin the meeting with a short, guided meditation led by one of the CAM practitioners to "ground us in a shared intention." A draft document describing the CAM organization's policies regarding patient care is presented for discussion. The biomedical practitioner points to the assertion that one of the key components of care is "supporting confidentiality, autonomy and dignity." He asks, "How are the outcomes of these principles operationalized? Is the client's belief system identified?"

The CAM practitioner answers, "Yes, in the first interview."

The biomedical man asks what key elements of a person's belief system are considered relevant. "Is it necessary to have a belief in the paradigm of healing for it to work? How do you know who you can help versus who you can't help?"

The CAM practitioner replies, "The only ones we can't help are the ones who've been dragged here. This is very rare."

The biomedical practitioner asks, "Do your staff consider your relationship with patients or clients to be that of professional and client?"

The CAM practitioner says, "Yes, it's professional and it's personal, too."

The biomedical practitioner nods and then says, "Let's define what we mean by professional. Conventional medicine establishes a boundary between the role of professional advisor and the role of friend. This paradigm believes the professional cannot be both. Does your paradigm see it differently?"

The CAM practitioner smiles and nods, and says that in the view of the CAM facility, "Connection and love between the healer and the client is the most important part of the work. The relationship we have with the treatment is as important as the treatment itself. It's the same for the relationship with the practitioner."

The biomedical practitioner shifts in his chair and leans forward. "This is not the same model as conventional medicine. Friendship is wrong in the context of a conventional medical relationship. Friendship or love clouds decision making."

The CAM practitioner, too, leans forward. "When there is an open, soul-level connection between the practitioner and the client, the practitioner is more open to intuitive ways of knowing what is right for the client."

The biomedical practitioner responds, "If intuition is driving decision making, we have moved away from evidence, away from arms-length evidence."

The CAM practitioner sits back in his chair. "Evidence and intuition are not incompatible. Intuition *is* based on evidence," he asserts.

The biomedical practitioner matches the body language of the CAM practitioner and replies, "In conventional evidence-based medicine, 'evidence' means the results of placebo-controlled trials."

The CAM practitioner assumes a relaxed position and explains that in complementary and alternative medicine, a range of beliefs are important—the patient's belief in treatment, the physician's belief in treatment, the patient's impression of the physician's belief, and the physician's communication of his or her belief in the value of treatment. He asserts that conveying this impression is vital even if the physician does not believe the treatment will help. He concludes by saying, "The intention itself is part of the treatment."

The biomedical practitioner shakes his head and replies, "In conventional medicine, for a physician to convey an impression that a treatment will help if he or she does not really believe it will constitutes fraud."

The CAM practitioner retorts, "But some treatments in conventional medicine *are* guilty of that. Some conventional treatments for prostate cancer are unproven, but doctors give patients the impression they are of therapeutic value. What we're talking about raises the question: What is evidence and why do practitioners believe in certain treatments?"

There is a short silence. Then the biomedical practitioner raises another issue. "If a patient receiving CAM is not doing well, and he or she says it is because there is not enough love in the relationship, what would you say?"

The CAM practitioner replies, "This has not happened, but if it did, we would refer the client to another practitioner."

This conversation clearly shows the kind of obstacles that stand in the way of integration. There are fundamental differences in assumptions, expectations, and models, for example, about the nature of healing, and the kinds of relationships professionals and patients should have. Elizabeth, an administrator who was centrally involved in the Tzu Chi Institute, believes that these differences and contradictions made the initial stages of the Institute's evolution difficult. I interviewed Elizabeth just after the Institute closed.

The foundational stakeholders had competing agendas. . . . Every stakeholder had a different idea about what success would look like or what the goal was. . . . (Eventually it became clear that it) was not about alternative therapies or practices or products and all the politics that go with that, even though that is the environment we work in. . . . Really what we boiled it down to here is a model of health care delivery that espoused certain values. It was more about how we could *be* with people as opposed to what we could *do* with people.

We began to be able to identify some of the core concepts which were different from the beginning. In the beginning, the initial thing was looking at evidence in a big way, you know, it was a very reductionist perspective about how we would prove that something worked or didn't work. And it changed so radically from that to really, "How do people work together and place the patient at the centre of that experience? How do we understand their illness experience? What did personal transformation look like? What characteristics of somebody would lead you to work with them in a certain way?" Our research became more focused on theory generation and measurement of utility as opposed to proving that a particular therapy worked or didn't work. Which is like night and day as far as I'm concerned.

Elizabeth believed that the Tzu Chi had been able to resolve some of the conceptual tensions inherent in the notion of integration by the time its funding was withdrawn and that the staff had achieved increased clarity about how to achieve integration. In an effort to bring these lessons to the conceptualisation of integrative care, this administrator was working with health care professionals from the U.S. that she described as part of "the integration industry" on a set of guiding principles that would identify what anyone involved in integrative health care (including health care providers, insurers, researchers, and patients) would need to use as a framework for integration. The first principle she mentioned emphasized the role of experience.

You need to understand integration experientially before you can apply it to your approach or say you can work in an integrative way or create an integrative environment for other people. You need to intrinsically know what that means. You know, it's sort of like diversity. It's a similar sort of idea. You can't promote diversity if you don't understand marginalization, if you don't know what it *feels* like to be discriminated against. You can create all the curriculum in the world and programs, but you know, they won't nail it.

While Elizabeth saw the differences in paradigms as profound, she did not see them as precluding collaboration. Elizabeth and the other Tzu Chi professionals I spoke with agreed that integration in any form takes respect for difference, a willingness to engage in group learning processes and lots of communication. These professionals acknowledged that finding the time for these learning processes is difficult in a fee for service environment.

Reflections

The most striking feature of my participant-observation in CAM settings and my interviews with CAM professionals was the diversity of opinion and perspective I encountered. In contrast with the Biomedical Discourse, the CAM Discourse does not seem cohesive or coherent. While the Biomedical Discourse appears to have an “inside,” i.e., it seems to be an enclosed entity with external boundaries and defining characteristics, there does not seem to be an “inside” to CAM. In fact, on the basis of my fieldwork I would argue that there is not enough cohesion in the “world” of CAM to conceive of it as a unitary Discourse at all. The diversity of the approaches to healing that have been subsumed under the CAM label and its marginal status means the field is fragmented and dispersed.

Except for those professionals who are associated with organizations whose mission is to provide a spectrum of CAM services, practitioners do not identify themselves as part of a cohesive CAM Discourse. Individual practitioners align themselves more with their own particular discipline, e.g., yoga or Therapeutic Touch, or to their professional association or college (e.g., those for TCM,

naturopathy, or massage therapy) than with "CAM." This observation that the field of CAM is heterogenous and populated by individuals who do not identify with CAM as a whole is confirmed in an article by the former principal of a large naturopathic university in the U.S. whose legitimacy-based hierarchy of CAM was presented in chapter 1 (Pizzorno 2002).

The heterogeneity within CAM can be seen in practitioners' disparate comments about the nature of the body-mind and about healing. Some expressed cultural models usually associated with CAM; others argued against those models. Interestingly, there was consensus among CAM practitioners about the limitations of conventional science and a feeling among hybrid practitioners that they had moved beyond science. But there was also a shared recognition that science provides the route to medical legitimacy.

There also seemed to be some degree of consensus about the ideal way for health care professionals to interact with patients. There are many places in this chapter where a model for patient-practitioner relationships that contrasts with the biomedical model is expressed. A central theme is that health care providers should be interacting with patients in loving, compassionate ways; maintaining a professional distance is not the goal. This rejection of the dominant model for professionalized relationships stands out as one of the primary differences between at least some parts of CAM and Biomedicine. Whereas CAM practitioners were more concerned with the quality of personal engagement with patients, biomedical practitioners expressed more concerns about ethical issues such as informed consent. As noted in the previous chapter, biomedical practitioners work under

more constraints associated with professionalization and legislative oversight than do many CAM practitioners.

This chapter contains descriptions of public events that illustrate the ways in which competing CAM discourses and cultural models are being expressed in social settings. These models undermine biomedical legitimacy and authority and posit alternative models. The influence of CAM leaders such as Deepak Chopra and Marion Woodman would be hard to measure, but, as evidenced by the sales of their books, the activities of such advocates for alternative cultural models are clearly important. Although economic factors were not the most obvious features of the events where these leaders appeared, signs of the economic ramifications of the public's interest in CAM are unmistakable. CAM has become big business (Goldstein 1999). This contributes to the contestation and fragmentation in the field. Most of the CAM field exists outside of socialized health care and is thus directly involved in the market economy. Not only are CAM practitioners in competition with biomedicine, they also compete with colleagues who practice the same discipline as well as with practitioners of other healing techniques.

The economic context within which CAM and Biomedicine are converging no doubt affects the push for integration. Given the profound differences in ontologies and epistemologies between Biomedicine and some CAM approaches, one cannot help but wonder if advocates would be so enthusiastic about integration if Biomedicine had no social legitimacy. If Biomedicine did not have the kind of hegemonic status and power it enjoys, would there be the same motivation to struggle to find ways to bridge these seemingly incommensurate paradigms? Does

Biomedicine have aspects that have intrinsic value in the eyes of integration advocates and if so, what are they?

These are not the only questions that are raised by the push for integration. As the cautionary tale of the rise and fall of the Tzu Chi Institute shows, integration presents both conceptual and operational challenges. What is integration exactly and what is being integrated? Would pluralistic juxtapositions suffice or is there a need to blend different healing approaches? Does integration mean the medicalization of CAM or the psychosocialization of medicine? Or the spiritualization of health care? Is it possible to have an integrated health care facility where some professionals believe that illness is strictly a biological process and others insist it is a psychosocial and spiritual process? Where some believe the agents of healing are drugs and surgical interventions while others believe that what is most important are changes in lifestyle or transpersonal phenomena such as prayer? Where some believe the role of professionals is to keep their distance and make objective, evidence-based recommendations and others believe their role is to care deeply about the patient, to relate from the heart as well as the head, and to individualize their treatment recommendations? And what about the role of the popular sector with respect to health care? It must be noted that there are those who decry the professionalization of caring and the loss of community that has already occurred because of professional activities in realms of life previously managed by families and other social networks (e.g., McKnight 1995).

The most profound difficulties inherent in the notion of integration seem to stem not from the addition of non-biomedical therapies to a treatment regime, but from the collision of different worldviews. Given the significance of the ontological and

epistemological differences between biomedicine and other approaches to healing and given the pre-existing power differentials, it may be premature to move towards the structural integration of health care facilities or systems before ways of resolving these fundamental differences are found.

The world of CAM is fragmented and marginalized. It embraces many alternative treatments for cancer as well as alternative ways of thinking about cancer. The fact that CAM products and services are provided primarily through private market mechanisms adds other dimensions to the ways in which CAM contrasts with conventional medicine. For patients who need to make decisions about what treatments to undergo, entering the world of CAM can be overwhelming. For example, Linda felt there was always another CAM treatment to find out about until she finally rebelled against the compulsion to continue searching for a treatment that would offer her certainty. While practitioners and policy-makers debate the meaning and implications of integrative health care, cancer patients struggle to find ways to create their own integrated treatment regimes. But people who are diagnosed with cancer are not only engaged in the Discourses of CAM and Biomedicine. They are also embedded in larger social and cultural contexts where medical legitimacy is being contested. The next chapter expands the focus of the dissertation in order to provide a taste of this larger discursive space.

Chapter Seven

Popular Discourses on the Legitimacy of CAM

Introduction

This chapter presents examples of discourses about the legitimacy of Complementary and Alternative Medicine (CAM) taken from three different (but overlapping) arenas in what Kleinman (1987) would characterize as the popular sector of health care. The examples in this chapter show where some of the cultural models that have been associated with CAM come from as well as how the debate about the legitimacy of CAM is being framed by the popular media. The examples illustrate the polarization that is present in the extremes of the rhetoric on both sides of the debate. The examples also reveal the power struggles underlying the debate. The examples in this chapter were selected because of their salience to the research issues and their fit with material presented elsewhere in the dissertation. It should be noted that my choice of examples was somewhat arbitrary. Different examples could have been selected to illustrate the same points.

I will refer to the first arena from which examples are drawn as “the arena of CAM discourses” to highlight the observation from the previous chapter that CAM is not a unitary Discourse but a field comprising many discourses. The second arena, that of the

popular media, tends to be more closely aligned with biomedicine than with CAM, but as the examples will show, this is not always the case. The third arena, the Internet, contains discourses that originate in every conceivable combination of positions and allegiances. These arenas are not discrete. The boundaries that have been established for the purposes of this discussion are somewhat arbitrary.

Since the Biomedical Discourse is a hegemonic Discourse that permeates the culture and it is difficult to delineate discrete cultural mediums through which this Discourse is promulgated, examples of its cultural models will not be presented in a separate category of "the arena of Biomedical Discourse." But these dominant models will be apparent by virtue of their juxtaposition to CAM models.

The Arena of Complementary and Alternative Medicine Discourses

CAM discourses appear in several media. There are hundreds of books that promote individual CAM approaches, including books on special diets, mind-body disciplines such as yoga and tai chi, specific therapies that are identified with their originators, and alternative medical systems such as traditional Chinese medicine and Ayurveda. There are also hundreds of books that contain the cultural models that are being posited as different from those in the Biomedical Discourse. In addition, proponents of CAM produce video and audio tapes and offer workshops, lectures, and other opportunities for people to learn about and practice CAM techniques. This section focuses on excerpts from books written by four of the best-known authors in this panoply. Two of these authors, Andrew Weil and Deepak Chopra, were seen by many of the cancer patients I interviewed as helpful sources of knowledge and insight. The third, James Gordon, is

included as an exemplar because he is active in the field of integrative cancer care in the U.S. Excerpts from the fourth author, John Robbins, are included as examples of how some CAM discourses undermine biomedicine and try to incite activist responses to biomedical hegemony. The excerpts from these authors' books are reminiscent of some of the perspectives on the body-mind and healing that the cancer patients profiled in chapter 4 expressed.

Andrew Weil is a Harvard-trained MD. He has written many best-selling books about alternative health and gives lectures and workshops world-wide.¹ Although conventionally trained, Weil is critical of the biomedical model. He believes that the body can heal itself and sees alternative medical systems, particularly those originating in the East, as being superior to biomedicine.

When I finished my basic clinical training, I made a conscious decision not to practice the kind of medicine I had just learned. I did so for two reasons, one emotional and one logical. The first was simply a gut feeling that if I were sick, I would not want to be treated the way I had been taught to treat others, unless there were no alternative (*sic*). . . . The logical reason was that most of the treatments I had learned in four years at Harvard Medical School and one of internship did not get to the root of disease processes and promote healing but rather suppressed those processes or merely counteracted the visible symptoms of disease (Weil 1995:13).

In the West, a major focus of scientific medicine has been the identification of external agents of disease and the development of weapons against them. . . . In the East, especially in China, medicine has had a quite different focus. It has explored ways of increasing internal resistance to disease so that, no matter what harmful influences you are exposed to, you can remain healthy. . . . Although the Western approach has served us well for a number of years, its long-term usefulness may not be nearly so great as the Eastern one (Weil 1995:4).

The biomedical model('s) . . . materialism leads to emphasis on form rather than function. . . . Worse, the biomedical model discounts or entirely writes off the importance of the mind, looking instead for purely physical

¹ In 1997, Weil's website, which had been receiving 85,000 hit per day, became part of the Time-Warner conglomerate. In addition to links to other sites that enable visitors to purchase Weil's books and the vitamins and other products he recommends, his website is linked with other Time-Warner publications such as *Fortune* and *Money Magazine* (Goldstein 1999).

causes of changes in health and illness. My experiences and observations of healing suggest that the mental realm is often the true locus of cause. Despite growing public interest in mind-body interactions, professional interest remains at a low level (Weil 1995:65).

James Gordon is another Harvard-trained physician who has turned to alternative medicine. He was the Chairman of a White House Commission on Complementary and Alternative Medicine Policy that submitted its report to U.S. President Bush in the spring of 2002. Gordon is an active proponent of the integration of CAM, especially in the area of cancer care. He believes integrative medicine represents "the new medicine."

In the last thirty-five years, . . . we have begun to realize biomedicine's shortcomings. It is inadequate to explain the origins or treat the consequences of the chronic illnesses, the disabilities, and the distresses that afflict more than 80 percent of those who seek medical attention. Its overuse and misuse has produced a deadly host of mutated bacterial and viral life-forms, and an epidemic of iatrogenic—physician—and-treatment-caused—illnesses. Its economic cost—almost one trillion dollars a year and close to 15 percent of our gross national product—has become insupportable. Even its metaphors of regulation and conquest, which once seemed fitting and hopeful, now strike increasing numbers of us as both grandiose and inappropriate. . . . We are in desperate need of a new medical model, new metaphors, and a new kind of medical practice, one adequate to the illnesses from which the vast majority of us suffer. . . . It is precisely because biomedicine is so powerful and attractive—because it has grown so strong, explained so much, and helped so many—that it is hard to see that it too is a stage in, and not the end point of, medical evolution (Gordon 1997:22).

Gordon argues that this new medical model should include a different set of expectations about the relationship between patients and practitioners.

It would be far better and healthier for everyone concerned if we abandoned the very concepts of compliance and adherence and regarded the doctor-patient relationship as a full collaboration, a genuine healing partnership (Gordon 1997:87).

Like Weil, Gordon argues that the mind and body are not separate. He believes that healing from chronic illness almost always requires emotional or intellectual change

(Gordon 1997). Gordon also asserts that the mind provides access to forms of knowledge that may not be “scientific” but are nevertheless legitimate.

Maybe by going within, we really can know everything we need to—perhaps not in the special language of our science but in some way that is quite real and useful. Each of us comes to our knowledge differently and uses it differently (Gordon 1997:57).

Gordon also posits an individualized view of the body and illness that is contrary to assumptions about generalizability and universality that are foundational to biomedical science.

Maybe every person’s illness is different from everyone else’s. . . . Not in the sense simply that my interpretation of my condition or my reaction to it is different, but that in some radical, deeply biological way, it is different enough to make a real difference. Not only that, it can be different from one hour to the next, and different depending on who assesses it. This perspective is quite—no other word comes to mind—“different” from any we adopted in medical school (Gordon 1997:58).

Both Gordon and Weil make extensive use of the stories of individuals who have experienced healing through alternative means to substantiate their arguments. They are both critical of biomedicine, but respectful of its accomplishments. Not all proponents of alternative medicine are so generous. John Robbins uses a journalistic, muckraking style to challenge both the practices and beliefs of biomedicine.² Like Weil and Gordon, Robbins uses anecdotes to support his points. But Robbins not only tells stories of healing but he also includes “horror stories” of orthodox medicine’s mistreatment, not only of patients, but also of practitioners who threaten the dominance of biomedicine. Robbins also uses epidemiological and clinical research data to support his condemnation

² John Robbins does not have medical or scientific credentials. He is the author of an earlier book, *Diet for a New America*, which criticized the meat and dairy industries and argued for the adoption of vegetarian diets. He was the heir to the Baskin-Robbins ice cream empire but chose to reject his inheritance and follow an alternative lifestyle.

of Western orthodox medicine. He describes the U.S. health care system as being in crisis and argues that the “patriarchal, dominator, medical myth” needs to be “exploded.”

Doctors and patients alike feel depersonalized and used. . . . Increasing numbers of us are seeing that we cannot remain passive bystanders to our own health, and then expect the medical system to rescue us. We’re seeing how false and destructive is the belief that the more money we spend and the more technology we have, the healthier we will be. We’re seeing how alienating and harmful it can be to think that experts always know more than we do about our bodies and our lives. . . . By disrupting our blind faith in the medical system, the current crisis is throwing us back on ourselves, and compelling us to ask such questions as: What can I do to optimize my health and healing? How must I live in order to attain and preserve well-being? For which conditions is orthodox medicine of value, and for which conditions are alternative approaches more appropriate? How can I become less dependent on an impersonal system and more connected to and trusting of the sources of true healing within me (Robbins 1998:3–5)?

Robbins connects American cultural models regarding freedom of choice with the new health care system he envisions. He also makes connections between the alternative health movement and the values and positions of other social movements such as feminism and the environmental movement.

I see how much healthier and happier people can be when they are educated and able to act wisely and make their own choices regarding their bodies. Freedom of choice is essential to the American way of life, and I believe that people ought to have a right to do with their bodies what they want to do, as long as they aren’t hurting anyone else (Robbins 1998:9).

The movement to reclaim our bodies and our lives may in fact represent the most powerful grassroots movement that has yet emerged to challenge the underlying paradigm of our society, the basic philosophical assumptions that have us marching, in the name of progress and control, toward ecological disaster and social chaos (Robbins 1998:9–10).

If we are to create a society dedicated to supporting and maintaining health for all peoples, then it is up to us to do everything we can to place genuine responsibility for our lives into our own hands. **The medical establishment will only get off its pedestal when we get off our knees.**

If we are to take back our lives from the institutions that have lost their sense of commitment to the common good, we need to release ourselves from the belief that our health is primarily dependent on medical technology, and restore our faith in ourselves, in our own minds and hearts, and in the activities that truly generate and protect health. Wherever we are in our lives,

each of us can always ask, "How can I take more responsibility for my health? In what ways can I help create a world with less suffering and more health, with less violence and more cooperation?" (Robbins 1998:373) (emphasis in original).

The authors cited above undermine biomedicine's legitimacy and posit alternative models, especially about the nature of the mind-body system, and the role of the patient in healing. They also legitimize ways of knowing other than the scientific method: they rely on anecdotes as substantiating evidence; they tell stories of their own conversion to alternative medicine because of personal experience; and both Weil and Gordon express appreciation for the epistemologies that underlie Eastern medical systems.

Other alternative health proponents go farther in their efforts to unsettle conventional cultural models and assumptions. Deepak Chopra, the former endocrinologist whose lecture was described in chapter 6 presents concepts from traditional Ayurvedic medicine and juxtaposes them with concepts from Western science. He describes an ontology that is very different from that held by biomedicine.

In a book chapter entitled "Invitation to a Higher Reality," Chopra describes a young boy with multiple personality disorder who has allergic reactions only when one particular personality is dominant. Chopra explains that this is because the boy's cells decide whether to react to the allergen or not.

To say that molecules can make decisions defies current physical science. . . . Once we absorb the fact that (the boy) is choosing to be allergic . . . then we confront the possibility that we are choosing our own diseases, too. We are not aware of this choice, because it takes place at a level below our everyday thoughts. But if we have such an ability, we should be able to control it (Chopra 1991:11).

Chopra uses Western science and technological metaphors to substantiate his claim that healing ideally occurs on non-material planes.

Every year, fully 98 percent of the total number of atoms in your body are replaced—this has been confirmed by radioisotope studies at the Oak Ridge laboratories in California. This constant stream of change is controlled at the quantum level of the mind-body system, and yet medicine has not taken advantage of this fact—it is still waiting to take the quantum leap. To change the printout of the body, you must learn to rewrite the software of the mind (Chopra 1991:12).

It is fascinating to see how perfect health dovetails into a broader intellectual movement that is rocking the foundations of science. Ilya Prigogine, Nobel Prize winner in chemistry in 1977 and a pioneer in this movement, calls it “the reenchantment of nature”—the realization that nature is not a machine but a wondrous environment whose hidden possibilities are barely guessed at today. Nature is like a radio band with infinite stations; the reality you are now experiencing is only one station on the band, completely convincing as long as you stay tuned to it, but masking the other choices that lie on either side (Chopra 1991:14).

Chopra promises complete freedom from illness and old age.

If we learn to live in balance from the deepest level, our inner growth has no foreseeable limits. . . . Growth is automatic; it is in nature’s plan, built into our very cells. It is only a question of following the silent river of intelligence to its source. That is the final secret of perfect health. If we could allow the mind to expand and to explore higher realities, the body would follow. Wouldn’t that be enough to save it from disease and old age (Chopra 1991:17)?

Chopra describes research that supports his point of view (but he neglects to cite the reference).

A study of four hundred cancer cases that went into spontaneous remission revealed cures which had little in common. Some people drank grape juice or swallowed massive doses of vitamin C; others prayed, took herbal remedies, or simply cheered themselves on. These very diverse patients did have one thing in common, though. At a certain point in their disease, they suddenly knew, with complete certainty, that they were going to get better, as if the disease were merely a mirage, and the patient suddenly passed beyond it into a space where fear and despair and all sickness were nonexistent. They entered the place called perfect health (Chopra 1991:19–20).

This perspective that individuals bear the responsibility for health and illness is not a particularly new aspect of alternative health discourses (e.g., see Simonton et al., 1978) nor is it limited to alternative discourses (Good 1991; Stacey 1997; Vincent and

Furnham 1997). But Chopra extends the view that disease is linked to psychological or emotional factors by connecting this cultural model with ideas based in Eastern ontologies and epistemologies. He introduces planes of reality foreign to Western conceptions and suggests that human nature is radically different from what Western models would lead us to believe. Thus, he challenges fundamental master cultural models about the nature of reality and identity.

The influence of the kinds of models about the nature of the mind-body link, about the nature of healing, about patient-practitioner relationships, and about the value of different ways of knowing presented in these examples can be seen in the views expressed by the cancer patients profiled in chapter 4. For example, Marcia and Brian spoke about the importance of intuitive ways of knowing; Angela believed that she played a role in the genesis of her cancer although she did not believe it was a simplistic cause and effect relationship; Marcia saw biomedical treatments as the source of illness, including possibly her own cancer; Joel and Brian thought that Western medicine was too limited in its scope; Joel and Brian felt that treatments needed to be individualized rather than standardized; Angela and Marcia expected their health care practitioners to work with them as partners; and Jack wanted the freedom to choose what treatments were right for him.

The Popular Media

Stories about complementary and alternative treatments in mainstream newspapers, magazines, TV, and radio abound. Some of these stories describe different alternative approaches and highlight the extent of their use. Some "human interest" stories tell of

miraculous cures while others offer cautionary tales of people who have been exploited and harmed by unproven therapies or unethical practitioners. What follows are examples of stories about CAM taken from four different sources. These examples focus on the ways in which the themes that are central to this dissertation appear in the popular media.

On Friday December 21, 2001, the *Vancouver Sun*, a local mainstream daily newspaper published an editorial headed, "Alternative therapies should be fully explored." The editorial commented on a new Statistics Canada survey that showed that 22% of British Columbians visit an alternative health care practitioner.

However, the survey gives no sense of whether alternative care is effective, or how its use should be governed and paid for. Alternative therapies are still hobbled by the gulf that exists between Western science and Asian tradition, and between various curative and preventive models of care. And governments are struggling with how to fund and regulate an amorphous but increasingly significant field of medicine. . . .

There's too much at stake—in terms of our health and our wallets—for us to ignore or dismiss the field. One estimate puts U.S. spending on alternative care in 1997 at \$27 billion. In Canada, in that same year, we spent \$3.8 billion, if books, vitamins, herbs, equipment and the like are included.

However, we don't have the data we need to know how much of that spending is wise. There's certainly no shortage of last-hope artists peddling dubious cures to the desperate. There's also compelling evidence that chiropractic and acupuncture (used as a surgical anaesthetic in Asia) can be beneficial and extremely cost-effective. Some research supports the efficacy of traditional Chinese herbal medicine, naturopathic and homeopathic therapies. For those looking for a cure, though, there isn't enough credible information. . . .

We need more research and education to bridge the gulf between different schools of thought on health care (Editorial 2001).

It is interesting that the editorial writer identifies the opposing forces as being Western science and Asian tradition. It is also interesting that the writer looks to Western science to bridge "the gulf." The *Sun* editorial writer notes that in the U.S., CAM research is "now treated seriously by the federal government" and reports that the 1999

budget for the U.S. National Center for Complementary and Alternative Medicine was \$68.7 million.

However, an article that appeared in the *Washington Monthly*³ in April 2002 questions the value of this U.S. investment in research. The article refers to CAM as “one of the most important medical movements in decades” and describes it as “the push to incorporate nontraditional or ‘alternative’ healing methods into the canon of Western medicine.” The author describes the goal of CAM research as being “to determine which treatments hold legitimate medical value and which are mere superstition.”

After a decade of studies, the truth about CAM is proving much harder to pin down than anyone imagined. This uncertainty hasn’t hurt proponents; indeed, it’s probably helped them. They’ve made inroads at all the top medical schools. Philanthropic organizations have showered money on programs and scholarship to boost CAM’s visibility. The simple fact that medical schools are taking it seriously has lent alternative and complementary medicine an air of legitimacy. But the benefit to traditional science is much less clear. While a few techniques have proven reasonably effective—meditation, acupuncture, music and massage therapy, and some herbal remedies—they’re the exception. The trouble has been identifying, once and for all, what doesn’t work. . . . Rather than submit to scientific testing, (CAM proponents are) using CAM’s ambiguity to their advantage, and have often been frustratingly circumspect about conceding their failures. Some fall back on the old mantra that “more testing” is necessary. Others try to bend science to their own specifications. Still others . . . (claim) that scientific testing simply cannot measure some kinds of CAM effects—claiming, in essence, that the scientific establishment should just take their word for it.

CAM supporters are trying to have it both ways—and succeeding. Today, a guilty silence shrouds an increasingly important question: Can a field like alternative and complementary medicine, which in many cases is inherently hostile to science, survive its arrival into mainstream medicine? Or are American taxpayers the victims of an expensive medical swindle being abetted by the nation’s leading medical schools? . . .

CAM’s proponents must do more than simply assert its medical value. They must finally cop to the rules of scientific rigor—no exceptions, no special pleading, no postmodern philosophy, and no hiding in the skirts of more legitimate treatments (Mooney 2002).

³ The *Washington Monthly* describes itself as a non-partisan publication that aims to present critical, informed perspectives on current issues, especially issues that relate to government policy.

Like the *Sun* editor, the *Washington Monthly* author views biomedical science as the appropriate institution to determine the legitimacy of CAM approaches. Both authors use loaded language that suggests a scepticism about alternative medicine and an allegiance to biomedicine (e.g., “last-hope artists peddling dubious cures,” “mere superstition” “medical swindle,” “the canon of Western medicine”). They agree that something must be done in response to the high degree of public interest in CAM, and they want to find a way to either bring CAM into Biomedicine or resolutely justify its exclusion from that Discourse.

The next example from the public arena comes from a less mainstream source: *Alternative Therapies in Health and Medicine* is a “peer-reviewed” journal edited by Larry Dossey, a physician who has written books on the healing power of prayer. It could be argued that this example belongs more in the preceding section with other CAM discourses. But the example shows how the boundaries of the discourses are blurring. The magazine is available in bookstores and other retail outlets whose customers are not necessarily aligned with alternative medicine. The other reason for including the example here is that the selected article provides a fruitful counterpoint to the *Washington Monthly* article.

The article was co-authored by a traditional Chinese medicine practitioner and a surgeon who teaches at Yale (Beinfield and Beinfield 1997). The article discusses conventional treatments for breast cancer and argues that conventional medical practice is often not based on science. It contends that despite studies demonstrating the efficacy of lumpectomy, and despite the National Cancer Institute’s declaration in 1990 that lumpectomy followed by radiation is the preferred therapy, only 26% of American

women diagnosed today receive breast-conserving surgery. The authors describe the origins of the Halsted radical mastectomy and the entrenchment of the modified version of this procedure in present-day medical practice. They explore possible reasons why the mastectomy remains the dominant form of treatment despite the scientifically demonstrated equivalency of a procedure that conserves the breast.

Medicine acquires cultural authority by dictating definitions of reality and forwarding judgments about which schema of meaning will triumph as valid. It is ironic that in an attempt to implement scientific advances, verification is sometimes ignored and the principles of science are set aside. At times the mere newness of a technology is taken as evidence of its superiority. An intrinsic contradiction in medicine also exists: because solutions are often fragmentary and incomplete—sometimes merely analytical and speculative—doctors try to avoid saying, “we know,” yet they must act as though they do! There is a grand expectation on the part of patients for deliberate, confident action to relieve suffering. . . .

The preference for intervention over reflection is codified by tradition and practice. . . . It is paradoxical that a blind faith in reason sometimes supersedes the doctrine of proof (Beinfield and Beinfield 1997:42). . . .

Although remuneration for mastectomy is more than triple that of lumpectomy, financial motives do not account for the hegemony of this procedure. Habits and traditions assume an authority of their own. Is it reasonable to liken surgeons, men or women, to the tribal Africans who perform clitorectomies with the unshakable conviction that they are acting in the best interests of the woman? In both instances, what is best for the woman is associated with maintaining conformity with an outmoded belief. It is neither the women nor the doctors who are to blame; both come to the matter with honorable intentions. Cultural forces conspire: professional recommendations conflict, an irrational fear of keeping the breast is planted in women, and mastectomy constitutes a conclusive sacrificial act that permits women to feel as though they are doing *everything* they can (Beinfield and Beinfield 1997:45).

Unlike the previous two examples, the article on breast cancer challenges the master cultural model regarding the extent to which biomedical practice and science are connected. The authors suggest that medicine may be as much a cultural practice as a scientific one, that the beliefs and expectations of both patients and doctors play a significant role in treatment decisions. By drawing an analogy between mastectomy and

a cultural practice that is considered primitive, brutal, disfiguring and unnecessary in North American culture, the authors try to dispel the legitimizing aura of science that surrounds mastectomy and conventional medicine more generally. They undermine the position that medical practice is objective, separate from vested interests, or beyond the reach of subjective human needs or beliefs.

The *Washington Monthly* article was written from the perspective of the biomedical Discourse. The *Alternative Therapies* article was written from a position sympathetic to CAM. The final example from the popular media includes voices from both sides of the debate. This example comes from a series of Canadian Broadcasting Corporation radio programs. The *Ideas* series entitled "Rethinking Medicine" was aired in March 2000.

Anne Harrington, a professor of the History of Science at Harvard, discussed aspects of the debate from a broad-based, historical perspective.

We're in a period in which I think we're quite fragmented or fractured in our understanding of what we are as human beings, the extent to which we imagine ourselves to be biological entities, the extent to which we want to reclaim some view of ourselves as spiritual creatures. I don't think we have as much consensus around even our starting definitions as we might wish for or hope for (CBC Ideas 2000:6).

Harrington sees the opposition in the debate as follows: on one side are the experts who believe the future of medicine lies in technology and the mapping of the human genome; on the other side, pushing back at the experts, are consumers who "vote with their pocketbooks" by going to alternative practitioners. Harrington sees these two forces representing two contrasting impulses: one pulling to the future, the other to the past.

There's an enormous emphasis (in Chinese medicine) on the way in which this is a 3,000 year old tradition that is grounded in Taoist and Buddhist religious texts and has this ancient and impressive and rather exotic lineage.

And yet we will not appropriate it on its own terms. We will appropriate it in our terms, and we will translate it into a language that will give it respectability in the circles of the present, which is the circles of scientific language and understanding (*sic*).

It's certainly the case that in the world of medicine and largely in the modern world in general, the language of science carries an authority that no other disciplinary language has quite managed to compete with. It carries the authority because it claims to speak the truth, independent of human opinion. It is simply the language of "what is."

And so if you want to say that Chinese medicine is not simply a lot of nice ideas, very interesting and treating exotic people from many, many thousands of years ago but actually things that can be viable and usable for us, then they have to be translated into that neutral language that appears to be independent of culture and context and time and simply speak of "what is."

In that sense, it really isn't the past that we're appropriating. It's a reinvention of the past to serve present agendas, with an idea of building the future that's going to have all the pieces of the modernist enterprise that we still value but taking along with it those pieces of the past that we'd like to use to plug-in the missing bits we think we might have lost along the way to becoming modern (CBC Ideas 2000:7).

James Gordon, the physician whose book was cited earlier, was another participant in the series. He provided a metaphor for his vision of what the convergence of CAM and Biomedicine signifies.

It's sort of like a Copernican revolution. Once we stop seeing biomedicine as the centre of the universe, the way Westerners prior to Copernicus saw the earth as the centre, once we understand we're just one of the planets, a very influential planet, orbiting around the great sun of healing, then I think we'll have a much healthier attitude, and then we'll be able to look at different ways of integrating (CBC Ideas 2000:12).

Much of the radio series focused on the questions regarding the connection between CAM and science. One of the guests was Marcia Angell, the editor-in-chief of the *New England Journal of Medicine*. She asserted that, "most research that's published, even in very good journals, is either wrong, or more often trivial" (CBC Ideas 2000:16). Nevertheless she likened the progress of science to that of a glacier, and defended the use of randomized controlled trials as the only way to proceed.

We developed the method, and we say to nature, do we have it right now? And then nature speaks very loudly as to whether we have it right. But it is not an ethnic convention. The scientific method is universal. It's not Western. It's not Eastern. It is what it is because it has to be that way. It's been forced on us by nature. Nature has, over the centuries, told us, this is the only way you're going to uncover my secrets (CBC Ideas 2000:16).

These examples show how questions around medical legitimacy are being debated in public arenas. The sources cited seem to agree that there are two different worldviews involved. But there are diverging opinions about how to resolve those differences. The voices that are aligned primarily with Biomedicine implicitly speak from within the cultural model that affirms the objectivity and veracity of science. Science is expected to be able to provide unequivocal answers to the question of CAM's legitimacy. If science has so far been unable to provide those answers, it is simply because the standards of science have not been upheld sufficiently. From this position, the legitimacy of conventional medicine and the science that is assumed to underlie it is not open to debate. These dominant cultural models are not seen as requiring revision, even though alternative cultural models related to other aspects of the debate (e.g., the nature of the body or the nature of the patient-practitioner relationship) may merit acceptance, if they can be incorporated easily into existing models:

Those who are aligned with alternative medicine agree that science is one source of knowledge but see it as limited. They do not accept the view that science is separate from culture or belief systems. Nor do they see science or biomedicine as being "the centre of the universe." Thus, they are attempting to diminish the power of science, and undermine the perspective that science is the only bridge that can effectively achieve a resolution of the tension between the worlds of CAM and Biomedicine. The importance

of the role of science in the debate about legitimacy is inescapable in the examples of the discourse from the Internet that follow.

The Internet

The Internet includes an overwhelming amount of information on cancer as well as a vast array of perspectives about complementary and alternative medicine and its relationship to biomedicine. This arena is different from those considered previously in this chapter in that there are no restrictions on whose voices can be heard. Anyone can create a website. There are no institutionalized regulatory processes whereby some voices are determined to be more legitimate than others (e.g., there is no peer review; and there is no need to convince a publisher of the merit of your perspective or its likely audience).

The following examples focus on two categories of Internet discourses that relate directly to this dissertation. The first category includes information about alternative treatments for cancer that patients encounter when they search the Internet. The second category illustrates the contentiousness that can be found in some of the public discourses about the legitimacy of CAM.

When people go to the Internet searching for information about cancer and possible treatment options, they are faced with an overwhelming volume of information, much of it contradictory. Some of this information originates with sources associated with the biomedical establishment. For example, the Canadian Cancer Society, the American Cancer Society, the U.S. National Cancer Institute, and the B.C. Cancer Agency all have sections of their websites devoted to providing information about complementary and alternative therapies for cancer. In general, the descriptions of CAM

therapies on these mainstream websites use relatively neutral language. The websites summarize the available research data, emphasize the lack of scientific evidence regarding the therapies, and recommend that patients discuss their options with their physicians. Speaking at a conference on integrative cancer care in 1999 whose session transcripts are available on the Internet, Dr. Barrie Cassileth, a researcher with an interest in CAM, described the approach of the American Cancer Society (ACS) to CAM as changing significantly over the last 50–60 years. She pointed out that the ACS has ceased using derogatory terms to refer to unconventional treatments. The conference transcript says,

Dr. Cassileth explained that this change in terminology represents a major and long-fought shift in perspective, openness, and willingness of the ACS to look with greater interest at the potential benefits of many complementary therapies

(<http://www.cmbm.org/conferences/ccc99/transcripts99/burton.html>; accessed July 2002).

There are other websites that offer information and advice (and usually, access to treatments on a fee-for-service basis) whose position on the spectrum between mainstream and marginal is not so easy to discern. For example, the Cancer Treatment Centers of America offer “patient empowerment medicine” or “integrative” medicine. This is contrasted to the “segregated care” model where the patient and oncologist are separate and the patient uses CAM on his or her own as well as to the “gatekeeper” model where the oncologist controls access to CAM. Integrative medicine is said to put the patient at the centre of a team of professionals including both conventional and CAM practitioners. This network of private hospitals in the U.S. provides both conventional and CAM treatments (e.g., naturopathy and mind-body therapies) as well as what it calls “emerging therapies” (e.g., immunotherapy, hyperthermia, and arterial embolization).

Their website has a "Decision Guide" for patients that gives instructions for evaluating practitioners and hospitals according to criteria the patient establishes. It recommends that patients "begin to think critically about the level of care you *currently* receive compared to the level of care you feel you *deserve* to receive."

(<http://www.cancercenter.com>; accessed July 2002)⁴ The description of the staff at the affiliated treatment centre in Seattle emphasizes their educational and professional connections with established medical institutions and describes their research interests, thus establishing their scientific credentials.

There are many websites that offer access to well-known alternative cancer therapies such as the Gerson diet, shark cartilage, high-dose vitamins, etc. Others offer access to less familiar therapies. Consistently, all these websites seek to associate their therapies with mainstream science. For example, the Advanced Alternatives Cancer Centre website describes the mechanism underlying a genetic therapy called R-A therapy as follows.

Apoptosis is a scientific word which can be described by a very simple phrase . . . cell suicide. Yes, the most recent research in bio-medical science (shows) that certain substances can at times cause cancer cells to kill themselves . . . that is, they commit suicide. Why would cancer cells do this? Scientists believe that normal cells possess an internal mechanism whereby they can sense that they have turned malignant, and then "self-destruct." Many malignant cells also possess this ability, but it is weakened. R-A Therapy seeks to stimulate the cancer cells to either self-destruct or begin a gradual return towards a non-malignant state (<http://www.aacancer.com/treatments/html>; accessed July 2002).

Another website offers a psychologically-based cancer prevention and treatment approach. This website, too, substantiates its claims with references to science.

⁴ It is interesting that the section of the guide on palliative care does not include the words death, dying, end of life or any other reference to death but describes this kind of care as focusing on alleviating pain and managing side-effects of treatment.

The evidence that diet, exercise, effective coping styles and strong support networks are connected to healthy living is NOT new! We scientists know that lifestyle choices have a lot to do with healthy living. . . . For a long time, the conventional wisdom in medicine supported the idea that for the most part we are passive victims of cancer, and, that there is little that we can do to prevent it. Morph2Health™ is an offer of research-based information that will place you on the path to healthier living. . . .

You can learn how to influence the communication between the various cell communities located in your organs and tissues, and you can learn to direct your conscious awareness so that you can monitor your risk for cancer.

By strengthening the innate self-healing mechanisms of your inner physician, you can literally block cancer from taking control of your body.

By using our program, Morph2Health™, you will immediately benefit from over 30 years of focused, cutting-edge scientific clinical research that definitively shows that rather than being an inevitability, cancer can be kept at bay by making specific wholeness-based, inner physician directed choices (<http://www.alternative-breast-lung-cancer-treatments.com/capabilities.html>; accessed July 2002).

A final example shows how websites promoting therapies that appear to be far from the medical mainstream still try to establish their legitimacy through science. This website markets a herbal remedy called Lymphotonic PH-2. The website advises patients to keep their use of the remedy secret from their health care providers.

Let them take the credit. All you care is that you have survived when all the odds were against you. Most "closed" practitioners or specialists, would rather see you die than allow you to try an alternative cure. Surely they would not prevent you taking an inoffensive nontoxic herbal drink. But no! Our experience dictates that 88% will tell you that they will STOP treating you if you do go our herbal root (*sic*). Why? They are afraid that you will get better and they will lose face, or worst still they may lose a patient. . . (*sic*)

We have made in vitro, pre-clinical and clinical tests in Russia, conducted under one of Russia's top scientists and Microbiologists . . . (<http://www.goodbyecancer.com>; accessed July 2002).

In addition to providing access to conventional medical sources that present information about CAM therapies for cancer in a neutral way and sources that are clearly promoting alternative cancer treatments in order to gain financially, the Internet also provides a venue for organizations whose sole purpose is to discredit CAM treatments for

cancer. The following example illustrates the kind of contradictory information regarding a treatment's legitimacy that can be found on the Internet. A website called "Quackwatch" has a section on "Questionable Cancer Therapies" written by two MDs. It makes a distinction between categories of alternative cancer therapies.

Promoters of questionable methods often misrepresent their methods as "alternatives." *Genuine* alternatives are comparable methods that have met the criteria for safety and effectiveness. *Experimental* alternatives are unproven but have a plausible rationale and are undergoing responsible investigation. *Questionable* "alternatives" are unproven and lack a scientifically plausible rationale. When referring to the latter, we use quotation marks because they are not true alternatives. Some promoters of 'alternative' methods are physicians or other highly educated scientists who have strayed from scientific thought. The factors that motivate them can include delusional thinking, misinterpretation of personal experience, financial considerations, and pleasure derived from notoriety and/or patient adulation (<http://www.quackwatch.com>; accessed July 2002).

The Quackwatch list of questionable "alternatives" includes a description of a metabolic therapy used by Dr. Nicholas Gonzalez of New York. The description mentions a book manuscript by Gonzalez that includes data on 50 cases treated with his therapy. The website says that the "experts" who evaluated the chapter on these cases "found no evidence of benefit." It also describes a 1994 judgment against Gonzalez by New York state licensing authorities requiring Gonzalez to undergo retraining and supervision by the Office of Professional Conduct. Two other judgments involving litigation by former patients are described (<http://www.quackwatch.com/01QuackeryRelatedTopics/cancer.html>; accessed July 2002).

Information about Dr. Gonzalez and his treatment also appears on the U.S. National Cancer Institute's website in the context of testimony given to Congress by

Robert Wittes, an NCI official,⁵ in June 2000. In his testimony, Wittes gives an update on the NCI's "progress in the fight against cancer." He mentions recent advances in conventional treatments and also outlines NCI's activities in the area of CAM research. As an example of the collaborative research being undertaken, Wittes describes a randomized, prospective evaluation of Dr. Nicholas Gonzalez's therapy being conducted at Columbia University and funded by the NCI. These two different websites leave very different impressions regarding the legitimacy of Gonzalez and his therapy.

As a postscript to this example, a book co-authored by James Gordon⁶ describes the legal judgments against Gonzales as arising from prejudice against alternative medicine rather than being based on science. The book points out that the NCI trial was undertaken after a pilot study showed that patients with pancreatic cancer treated by Gonzales fared much better than patients treated with standard chemotherapy. It also mentions that the NCI-sponsored Phase III trial has required re-design because of its inability to recruit patients. People who have pancreatic cancer who are willing to commit to the Gonzalez protocol are not willing to take the chance of being randomized to standard chemotherapy. They all want Gonzalez's therapy (Gordon and Curtin 2000).⁷

The preceding examples provide a taste of the confusing and contradictory information that greets cancer patients when they go to the Internet seeking direction about treatment decisions. Most sources of information regarding cancer treatment attempt to establish their credibility by associating themselves with the Discourse of

⁵ Wittes, an MD, is Deputy Director of Extramural Science, and Director of the Division of Cancer Treatment and Diagnosis at NCI.

⁶ This is the same James Gordon whose work was cited earlier.

⁷ This book appears on the Quackwatch list of non-recommended books about cancer.

science. In many cases, it is difficult for the layperson to differentiate between claims that are legitimate and those that are not.

This tendency to invoke the power of science as a legitimizing strategy appears as well in Internet discourses related to the more encompassing debate about the legitimacy of CAM in general. The following examples demonstrate the extreme polarization that is occurring in some arenas of public debate.

The U.S. White House Commission on Complementary and Alternative Medicine Policy whose chairman, James Gordon, has been referred to earlier, submitted its final report in March 2002 (White House Commission on CAM Policy 2002). Before the report was complete, Gordon predicted that the Commission's findings would have a significant impact.

I believe that the report we are going to provide the president . . . has the potential to be, for medicine in the 21st century, as important as the Flexner report was to medicine in the 20th century (<http://www.no-whccamp.org/>; accessed July 2002).

The report makes a number of recommendations regarding the need for more research into the safety and efficacy of CAM treatments, the need to incorporate training related to CAM into conventional medical curricula, the need for better public information about CAM, the need to regulate CAM products, and the need to remove barriers to public and private insurance coverage for CAM therapies, once their safety, efficacy, and cost-effectiveness has been scientifically proven. The report also recommends the creation of a federal body to oversee the integration of safe and effective CAM practices and products into the U.S. health care system. The executive summary to the report includes the following statements.

The Commission recognizes that most CAM modalities have not yet been scientifically studied and found to be safe and effective. The fact that many Americans are using CAM modalities should not be confused with the fact that most of these modalities remain unproven by high-quality clinical studies. The Commission believes that conventional and CAM systems of health and healing should be held to the same rigorous standards of good science. . . .

The Commission also notes the lack of an appropriate definition of complementary and alternative medicine and the need to differentiate between interventions that have been, or have the potential to be, found safe and effective, and those that lack any scientific evidence of safety or effectiveness. Including the entire mix of CAM interventions under one umbrella fails to identify the merits and shortcomings of specific interventions. It is essential to begin separating the safe from the unsafe and the effective from the ineffective (White House Commission on CAM Policy 2002).

Two of the twenty members of the commission wrote a letter detailing a number of concerns about the report's contents. They state that the report focuses too much on the potential benefits of CAM and fails to acknowledge the limitations of unproven and unvalidated CAM approaches and does not adequately address the minimization of risk. The commissioners also criticize the report for failing to distinguish between approaches for which there is some scientific evidence and others that "either stretch the realm of logic or are demonstrably unsafe." In addition, they express concerns about the medical co-optation of spirituality through its inclusion as a CAM modality. The authors endorse the report's recommendations regarding CAM research, but express concerns about how these might be implemented.

Asking for more research money to investigate an approach, practice or product simply because it is "CAM" is an ideological, not evidence-based approach to science. Recommendations for research on "frontier areas of science" without a strategy for building this research on scientific foundations may result in spending precious health care research dollars on areas that are unlikely to yield any beneficial data such as "iridology", "psychic healing", et al. While the dogmatic disbelief of everything that is not currently explainable is foolish and indeed unscientific, it seems equally foolish to ask

the taxpayer to bear the enormous expense of sorting out those areas that are plausible from those that are improbable (Fins and Low Dogs 2002).

Reactions to the White House Commission's report and the minority perspective appear on several websites. One website sponsored by "Citizens for Science in Medicine" is devoted entirely to opposing the Commission. The inflammatory language used leaves no doubt about the sponsors' position.

A pro-quackery tract with the imprimatur of a White House Commission represents a serious national threat: many in the public will be bilked and injured, scarce federal and foundational funds will be wastefully diverted, and third-party reimbursers will be forced to pay for bogus or useless remedies. In addition, medical science itself will be forced needlessly to re-fight the battle it won almost a century ago against the vitalists, homeopaths, and mystics; it will consume much time, money, and brainpower that would be better spent pursuing legitimate ventures (<http://www.no-whccamp.org>; accessed July 2002).

A second website sponsored by the "National Council Against Health Fraud" has a position statement regarding the Commission's report. This statement also opposes the report and the CAM movement.

No published data indicate the extent to which "CAM" practitioners use proven therapies or the extent to which they burden patients with medically useless methods. However, there is good reason to believe that most provide substandard care and seek to undermine their patients' confidence in standard care. . . .⁸

The report is carefully contrived to suggest that CAM is close to the mainstream and that its critics are on the fringe. Just the opposite is true.

(The report's) recommendations are a perversion of the trust placed in Presidential Commissions, an affront to medical science, and an assault on consumer protection. Without science-based safeguards, any scam artist with a far-fetched idea can open for business and bilk the public (<http://www.ncahf.org/pp/whcpp.html>; accessed July 2002).

⁸ It is worth noting that despite the website sponsors' stated commitment to science, they are still willing to make a public claim that, by their own admission, is unsubstantiated by published data.

A second document on this website written by a physician who is the Editor of the *Scientific Review of Alternative Medicine*⁹ and a professor emeritus in Medicine from Stanford is equally critical.

The White House Commission appears to be no more than a politically and economically devised arm of the antiscientific and New Age movement that intends to overturn science, rationality, and common sense in medicine. It seeks federally supportive research and federal and insurance payment for unproved, disproved, and implausible methods (Sampson 2002).

The websites that oppose the Commission's report obviously discount the assurances contained in the report about the need for decisions to be based in science. They highlight the "minority report," putting more emphasis on the fact there was a lack of consensus among Commissioners than on the content of the two Commissioners' letter.

These websites and the Quackwatch website do not limit themselves to an attack on the Commission's report. They also attempt to discredit the Commissioners, for example, by pointing out their pre-existing allegiances to CAM approaches and the potential for them to benefit financially if the report's recommendations are implemented.¹⁰ The websites target James Gordon, the chairman, in particular. Gordon is reviled for his previous writings and activities. The websites reveal his previous links with a number of controversial figures including R.D. Laing, the Bhagwan Shree Rajneesh, and Wilhelm Reich. These activities and connections are referred to as "Gordon's sordid past."

⁹ The 1999 conference where this journal was launched has been described as an "unabashedly one-sided assault" on CAM. ('Science meets Alternative medicine' *Medical Post* 35 (11) March 16, 1999. <http://www.mdlink.com/mdlink/english/members/medpost/data/3511/17B.HTM>)

¹⁰ As is usually the case when this kind of charge is leveled, the critics' financial interest in the maintenance of the status quo is not acknowledged.

Not all the responses to the report available on the Internet are so extreme. In a comment on the report, the *Washington Monthly* notes that, "Insurance coverage has become the brass ring of the alternative medicine movement." However, the article's author does not see the report as much of a threat to the established order given that soaring costs have forced a limiting of federal payment for conventional care and other lobby groups have other agendas (e.g., seniors who want prescription drugs covered). The article predicts the report will "gather dust more than support" (Larson 2002).

A reaction to the report from an alternative health website registers a different concern. What makes "some observers from within the CAM universe" nervous is the report's recommendation for a greater role for government. "With respect to Education, usage of terms and phrases like "accredited" and "appropriately trained" designate Big Brother as the determinant of how these terms are met" (Chowka 2002). The author speculates that the report may have little impact. He says that reporters knowledgeable about the Washington health and medical scene point out that the report comes at a time when spending in areas unrelated to security and the military is "not exactly in fashion." But he notes that the potential to save money through CAM might appeal to some influential sectors of the government (Chowka 2002).

The debate about the White House Commission report clearly reveals the political aspects of the debate about CAM's legitimacy. Although the report itself seems to acknowledge the need for scientific justification for any decisions that are made, its critics are not reassured (or, from their perspective, fooled). The language and tenor of the critics' comments indicate that CAM is seen as a threat (e.g., words like "battle,"

“affront,” and “assault,” are used). The affiliation of the critics with mainstream medical and academic institutions suggests who and what is feeling threatened by CAM.

Reflections

This chapter provides examples from popular discourses that express the same kinds of cultural models that cancer patients draw on in their explanations of the reasons underlying their treatment decisions. The chapter also demonstrates the degree of interest in the popular sector in the issues surrounding the legitimacy of CAM therapies and the contentiousness of some of the debate. As the *Sun* editorial points out, there is a lot at stake: health and money. These are aspects of life that touch everyone. For people who are making decisions about treatment for cancer, their lives may be at stake. For people who provide care to those with cancer, their livelihoods may be at stake. For society at large, the stability of institutions such as the medical profession, public health insurance, hospitals, and universities may be at stake. Thus, personal, social, and political issues and their intersection are all implicated in the debate about CAM's legitimacy.

The examples from popular discourses presented in this chapter reinforce the observation that fundamental ontological and epistemological assumptions are being contested in these debates about medical legitimacy. The challenge to the Western materialist worldview presented by some alternative models regarding matters such as the nature of disease and the nature of the body–mind and its capacities is profound. The associated challenge to positivist and post–positivist epistemologies is also significant. Despite these challenges, discourses related to science are nevertheless invoked in order

to establish the legitimacy of alternative approaches to healing. Even those who see science as flawed want to attach themselves to its sociocultural power.

The disparities between worldviews may be at the root of something else that is obvious in the preceding examples from public discourses: the parties to the debate are sometimes not communicating effectively. There is a lack of common ground on which to build a coherent dialogue. Stated another way, one's participation in the debate depends on one's position with respect to biomedicine and CAM. There is a difference between being "inside" a Discourse and being "outside" a Discourse. For example, for those who are inside CAM discourses, proponents' descriptions of the importance of the mind-body connection make sense. Insiders are familiar with the language associated with these models and can attach new ideas (e.g., that mental or emotional or psychic realms are the locus of illness causation) to their own experience or to other associated ideas in the discourses with which they are aligned. For insiders, one's understanding of these ideas may be perceived as an enlightened insight or realization. On the other hand, for outsiders with no relevant understandings, beliefs, or experiences, such ideas are "delusional" and the result of "misinterpretation of personal experience" and show how far the believer has "strayed from scientific thought."¹¹

The importance of one's position relative to a given Discourse can be seen in other examples that have been presented. The critics of the White House Commission are

¹¹ Another aspect to the insider-outsider problem is that much of what is written about CAM by outsiders suffers from a lack of insiders' knowledge. For example, the description of meditation contained on the American Cancer Society's website is, to an insider, superficial. The description asserts that, "The ultimate goal of meditation is to separate oneself mentally from the outside world." It also lists the experience of "negative feelings" as a possible complication or side-effect. Practitioners of some forms of meditation (e.g., those based in Buddhism) would say that the arising of negative feelings is an inevitable and essential part of the practice. And the goal is exactly the opposite of what is asserted. The goal is to see that there is no separation between oneself and the outside world, that these concepts themselves are a result of inadequate apprehensions of "reality."

outraged that the Commissioners were CAM “insiders.” They charge that this makes it impossible for the report to be “objective.” But if the Commission had been concerned with making recommendations about biomedical policy, and its members had all been representatives of the Biomedical Discourse, it is likely that there would be no question as to their legitimacy: they would be regarded as experts in the field.

These examples illustrate the power of Biomedicine’s hegemony. This constellation of practices, symbols, cultural models, and institutions is so pervasive that we don’t think of ourselves as “in” it. It is in us. Most people in Western cultures are inside the Biomedical Discourse, whether we like it or not. Given this shared ground of cultural understandings, coherent dialogues about Biomedicine are possible, even in situations where there might be disagreement about particular issues. But a much smaller percentage of people are “inside” CAM. Without a shared cultural understanding of the basic “truths” or cultural models underlying CAM discourses, meaningful cross-discourse dialogue is difficult, if not impossible.

Another important aspect of Biomedicine’s hegemony lies in the centrality of its sociocultural position. Biomedicine itself is “inside,” whereas CAM is “outside.” This is why some of the debate is so fractious. There are benefits associated with being on the inside. Detractors of CAM want to keep it outside, while proponents want to move it inside. All of the language that invokes the marginality of CAM makes the relative position of these different discourses obvious.¹²

But is there an inside on the margins? The examples from public discourses reinforce the observation from the previous chapter about the heterogeneity and competition within the field of what has been called CAM. The two dissenting White

House Commissioners want to dissociate CAM approaches that are worthy of scientific exploration from those they deem unworthy (e.g., iridology and psychic healing). The articles from the *Sun* and the *Washington Monthly* identify approaches they consider legitimate (i.e., there is some scientific evidence of benefit) but either implicitly or explicitly de-legitimize others (e.g., the “dubious cures peddled by last-hope artists”). It is not hard to imagine that some of the alternative treatments being marketed on the Internet would be considered flaky by even the strongest supporters of other CAM approaches.

It is in the context of this confusing, contested popular sector that cancer patients must make decisions about what treatments they deem legitimate enough to use in their encounter with the disease. The next and final chapter of the dissertation provides an analysis of the sociocultural processes through which patients make these decisions and explains the role played by the kinds of popular discourses that are presented in this chapter.

¹² James Gordon’s analogy of the Copernican revolution explicitly tries to unsettle this metaphor.

Chapter Eight

Sociocultural Legitimation Processes and their Implications

Introduction

The preceding chapters of this dissertation portray various perspectives on what is occurring as conventional biomedicine and the diverse approaches to healing that have been characterized as Complementary and Alternative Medicine (CAM) converge. In the academic literature, attempts are being made to define and categorize the multiplicity of non-biomedical healing approaches that are being used. For the most part, CAM continues to be characterized as anything that is not biomedicine. Recent research has attempted to determine how many patients use CAM, why patients use these therapies, and how conventional practitioners are responding to CAM use. Most of this research uncritically assumes that biomedicine is the medical norm against which CAM should be judged. Even when the diversity of what is considered “CAM” is acknowledged, most of this research assumes that CAM is a coherent entity that can serve as a subject of academic and policy discourses. The primary concern in most of the academic literature, whether explicit or implicit, is whether CAM therapies are safe and effective. There is a

consensus in this literature that more biomedical research is needed in order to definitively determine the legitimacy of CAM therapies.

Similarly, most of the discourses in the popular media concerning the use of CAM take biomedicine as their unquestioned vantage point. While the significance of CAM use is noted and the potential merit of some CAM treatments is acknowledged, CAM's legitimacy and the role of CAM in the health care system remain undetermined, pending the judgments of biomedicine. In public discourses as in academic discourses, CAM is usually seen as a singular entity at the opposite end of the spectrum from biomedicine. Here too, science is seen as providing the means to bridge the gulf.

However, as the previous chapter shows, new cultural models about the body, about the nature of health and illness, and about the legitimacy of different ways of knowing are being promoted through the popular media. In addition, there are discourses in both academic and popular literatures that explicitly undermine the Biomedical Discourse. Many competing discourses are converging. The examples in the preceding chapter from the debate regarding the U.S. Commission on CAM reveal the oversimplification and the exaggeration of black and white oppositions that are signs of the shifting of social legitimacy (Parsons 1963). These public discourses tend to obscure as much as they reveal. The situation is far from black and white for those who are directly involved in these shifting tides of legitimation. As shown in chapter 4, patients with a life-threatening illness face questions that are not easily answered. Patients cannot wait for science to build bridges; they must make decisions and take action in the midst of missing or conflicting information and contradictory advice. Chapter 5 shows how conventional practitioners struggle to come to terms with their lack of knowledge about

how CAM and conventional treatments interact and with their need to respond to patients' changing expectations regarding clinical relationships. For these practitioners, too, the prominence of CAM presents challenges, even though the fundamental legitimacy of biomedical authority has remained intact (Saks 1995). On the other side of the divide, CAM practitioners stand on the margins of medical legitimacy—isolated, on the defensive, but convinced of the superiority of their approach to healing. Even though the market for CAM services and products is growing, so is the number of competing CAM practitioners (Saks 2000). In this private market atmosphere of competition, many CAM practitioners struggle to make a living. For many CAM proponents, the way to bring order to the medical revolution they believe is occurring is to institutionalize a new integrative model that combines both CAM and Biomedicine. However, as chapter 6 suggests, it may be premature to move towards structural integration until ways of bridging seemingly incommensurate worldviews are found.

The research cited in chapter 1 shows that the use of CAM among cancer patients is significant. My fieldwork shows that the issues raised by the use of non-biomedical approaches to healing are complex and have significant effects both on the people who face life-threatening illness and those who care for them. While some of these issues are prominent in public discourses, others are not. Questions about the safety and efficacy of alternative treatments and their interactions with conventional treatments are critically important. But so are questions about the safety and efficacy of biomedical treatments. Concerns about the potential for alternative practitioners to financially exploit patients who are vulnerable are valid. But so are concerns about the potential for organized health care interest groups to benefit from the public's relative lack of clout in the health policy

process. Criticisms of alternative practitioners who give “false hope” to patients or who enter into coercive or abusive relationships with clients are justified. But what about conventional practitioners who “rob hope” or who keep themselves at such a professional distance that their patients feel dehumanized?

These issues are not amenable to simple solutions. But progress can be made, if sufficient conceptual clarity is brought to the dialogue. This chapter attempts to provide a foundation for such clarity. The chapter begins with an overview of the context for the issues that reflects lessons learned through the fieldwork.

The Health Care System: Kleinman's Model Revised

Chapter 1 described Kleinman's model of the health care system as a cultural system. This model identifies three sectors in health care: popular, professional (including biomedical and alternative professionals), and folk. Kleinman (1987) envisions the structure of the system as consisting of three circles, with the popular sector being a large circle in the centre and the professional sector and folk sectors being two smaller circles that intersect with the popular sector at either side of the central circle. My fieldwork suggests a different schematic, at least in cases where care is being provided for cancer. If we take the patient as the centre of the system (which the rhetoric of biomedicine and many alternative systems do), and consider the legitimacy of different approaches to healing as an important dimension of the system, and incorporate lessons from my fieldwork, then we have the representation of the health care system given in Figure 1.¹

¹ This figure portrays some of the specifics of the local setting where I did my fieldwork but its general structure will apply to other settings.

Figure 1: Patient-Centred Health Care System

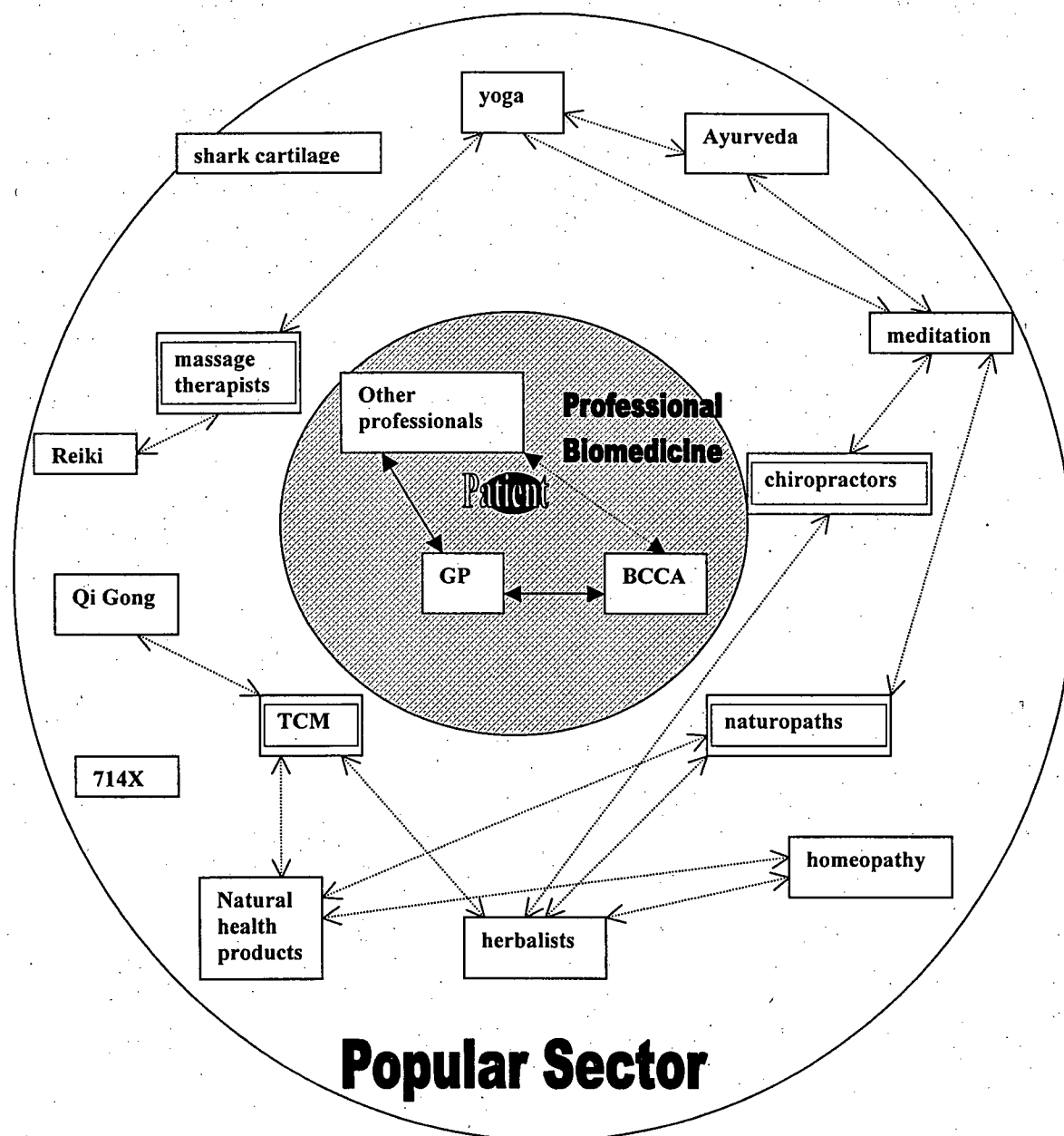


Figure 1 shows how the patient is surrounded, first and foremost, by the central Discourse of Biomedicine. This Discourse includes professionals such as the patient's family physician (GP), various oncologists and other specialists, as well as allied professionals such as nurses. In the case of the local setting where I did my fieldwork, many of these biomedical professionals are located in one institution, the B.C. Cancer Agency (BCCA). The lines connecting different professionals in this space indicate lines of communication between professionals: solid lines mean communication does occur (e.g., between the patient's GP and the BCCA); broken lines indicate communication might occur (e.g., between the oncologist and a psychiatrist the patient might see for depression arising from the diagnosis). While the figure does not portray this (because of the need to keep the schematic readable), it is important to note that, in addition to containing people, the space of the Biomedical Discourse also includes discourses and cultural models as well as the signs and symbols of biomedical power. All of these entities have their own networks of connecting links. The Biomedical discursive space is portrayed as having a dense background to denote the relative cohesiveness and solidity of the Biomedical Discourse.

Outside the institutionally legitimized circle of Biomedicine are the various non-biomedical practitioners and treatments that have been characterized as CAM. Note that these are not represented as being located at the opposite end of a spectrum from Biomedicine, but as surrounding both the patient and Biomedicine in an open discursive space that is the popular sector. Some of the practitioners in this space are professionals, i.e., they are members of self-regulating colleges with government oversight (e.g.,

massage therapists, naturopaths, chiropractors; these are in boxes with double borders.); some are “folk” practitioners (these are in boxes with single borders). The non-biomedical professionals are located closer to the centre of the system than non-professional practitioners (e.g., Therapeutic Touch or Reiki practitioners) to reflect the higher level of legitimacy bestowed by professionalization. The farther away from the centre, the more marginal the therapy is. Some of these professional and non-professional practitioners have mutual affinities and may communicate with each other (denoted by the dotted lines) but most do not communicate specifically about the care of individual patients. Products that might be used to promote healing are also represented in the schematic. Like the professional biomedical arena, the popular sector (where these non-biomedical approaches to healing are located) contains a wide variety of discourses and cultural models (examples of which are presented in this dissertation). Some of these discourses and models support biomedicine and denigrate CAM; others undermine biomedicine and promote alternative approaches. Still others may not relate directly to CAM but they influence people’s responses to biomedicine and CAM (e.g., the variety of discourses and models about how to be healthy and about the state of the health care system).

My schematic suggests some changes to Kleinman’s model. First, it should be explicitly noted that the professional sector includes differentials in legitimacy and power. I want to avoid dichotomizing CAM and Biomedicine, so I am reluctant to suggest making a distinction between biomedical and non-biomedical professionals, but the difference in power and status needs to be explicit in any model of health care. Second, labeling all non-professional healing specialists as “folk” seems outdated and

inappropriate. This sector now includes a wide variety of individuals and groups: e.g., practitioners of Reiki or Ayurvedic medicine, teachers of yoga or Tai Chi, health food store employees who give advice about natural health products, and members of patient support groups and Internet chat rooms. In fact, my fieldwork suggests dissolving the boundary between the folk sector and the popular sector since so many people are becoming "healing specialists" in one sense or another. I therefore suggest simply making a distinction between professional and non-professional healers and drawing a somewhat permeable boundary between the professional sector and the popular sector. If integration occurs and more peripheral therapies are included in the legitimized centre of the system, then that centre would become a more expansive professional sector that would include a variety of biomedical and other approaches.

Two final points must be made about my revision of Kleinman's model. First, the placement of the patient at the centre of the circle of legitimacy is no accident. Individual patients must make their own decisions about the legitimacy of treatments they decide to use. Government-affiliated bodies that make decisions about professionalization and other policy issues are acting as proxies for patients and taxpayers. Thus, the health care system is envisioned with the patient at the centre. Second, while my fieldwork suggests that some features of Kleinman's model require revision, my research strongly confirms the fundamental assumption of his model: the importance of culture in health care.

The Importance of Culture

My fieldwork demonstrates that the use of non-biomedical approaches to healing is an important cultural and social phenomenon. There *is* something going on. But what is it,

really? Many answers to this question have been proposed: it is a Copernican revolution (Ideas 2000); an evolution to more spiritual ways of life (Gordon 1996; Robbins 1998); a social movement (Salmon 1984; Lowenberg 1989; Johnston et al. 1994; Scheirov and Geczik 1996; Crellin et al. 1997); a paradigm shift (MacCormack 1991); a drive for the perfect body-self (Stacey 1997); or a return to primitive, pre-rational modes of thought (Cassileth and Chapman 1996; Wilber 2000). Although these answers reflect a range of judgments about the credibility of what has been called CAM, they are united in their emphasis on changes in worldviews and ways of thinking. My fieldwork suggests that these speculations are correct in pointing to the importance of the cultural aspects of what is occurring at the interface between Biomedicine and CAM. While the social and cultural aspects of the issues seem to be peripheral to most of the academic and policy attention being paid to CAM so far, my fieldwork suggests that it is time to make these aspects of the issues more central. It is not just that people are using non-biomedical treatments. It is perhaps more important that people are thinking differently about the nature of the body, about the nature of health and illness, and about who has the expertise and the responsibility to make health care decisions.

The next section of this chapter attempts to bring new clarity to the debate around CAM by discussing the ways in which individuals, especially patients, come to see different approaches to healing as legitimate. My analysis will elucidate the processes whereby emerging cultural models are linked with personal experience to form situated meanings that take root through social practices.

Dimensions of Sociocultural Legitimation Processes

When I began my research I was seeking to determine how the legitimacy of different approaches to healing is socially constructed. After talking with cancer patients I came to the conclusion that this metaphor is inappropriate. Even though social scientists consider “social construction” to be a complex, contested process, the metaphor of “construction” suggests starting with a solid foundation and having access to precision tools, each of which is carefully designed to fulfill a specific function. It evokes images of lasting, rigid walls and a roof that will protect you from the elements. The reality is that what cancer patients have to do is more like trying to pitch a tent on quicksand in the midst of a hurricane. Further, describing these processes as “social” (and not explicitly “cultural”) fails to acknowledge the importance of patients’ attempts to find meaning. Cancer patients are not only struggling to make treatment decisions; they also struggle to make sense of their suffering—these processes are both social and cultural.

There was a time when being treated for cancer was relatively straightforward: you went to a conventional physician, followed his or her instructions and then hoped for the best. Now there is a plethora of treatments available, offered by both Biomedicine and CAM, and an overabundance of information, much of it contradictory. For some, making decisions about cancer treatment has become an exercise in self-expression, an occasion for scrutiny of one’s identity and cultural allegiances. One’s choices become an embodiment in the most serious way of one’s values and beliefs. The wrong choice can mean the difference between life and death.

Most cancer patients do not reject biomedical treatment, even though they may be aware of its limitations (e.g., Joel is willing to take chemotherapy again even though he

sees it as destructive) or they may have unconventional views on the nature of the body and illness (e.g., Angela questions whether cancer is a disease). The hegemony of the Biomedical Discourse means that its treatments are already legitimate in most patients' minds. In the case of biomedical treatments, it is not a question of *constructing* their legitimacy, but of *deconstructing* it. Marcia does this when she asserts that Biomedicine can tell her nothing about what is going on in her body.

Cancer patients come to see different treatments as legitimate through processes that are mutable. These dialectic processes are a function of the combination of hegemonic Discourses that are associated with social institutions and a variety of contradictory discourses that contest and resist that hegemony. The process of legitimation is a process of inclusion and exclusion; the boundaries change depending on the context. The attribution of legitimacy is seldom absolute. The answer to the question regarding a treatment's legitimacy is rarely a simple yes or no. Legitimacy is not something that sticks to a treatment or a practitioner and stays there. Legitimacy is often determined through trial and error. It is attributed provisionally, in ad hoc ways. For example, Brian believed that the homeopathic remedies recommended by his naturopath were legitimate enough to try because his naturopath had a good reputation and because Brian's changed prognosis made him willing to take risks. But he questioned the theory of action underlying homeopathy and wondered whether his paying for the expensive remedies (i.e., investing in them) was shaping his sense of their legitimacy.

Patients seem to make decisions using different standards or levels of legitimacy. For example, CAM treatments that are perceived to be natural and non-toxic seem to require lower degrees of legitimacy because the treatment is perceived to carry little risk.

This can be seen in Joel's statement that he will try something when it is not likely to do any harm even if it promises little benefit. One's prognosis is critically important here. The standard lowers the less one has to lose and the less conventional medicine has to offer. This process could be seen as analogous to cost or risk-benefit analysis, but the complexity and ambiguity evident in the patient profiles argues against viewing patient decision making in such rational, instrumental terms.

Patients' experiences demonstrate that the granting of legitimacy is intertwined with the construction of identity. For example, Brian is caught between his allegiance to his medical family and his view of himself as someone who is aligned with alternative social and cultural values.

The conferring of legitimacy is also tied into attempts to find the meaning in one's suffering. Marcia draws on cultural models about the links between social isolation and illness to explain the lump in her breast. This leads her to believe that bringing her loneliness and grief to the surface will facilitate her healing.

Trust is another crucial element in the attribution of legitimacy. This is one reason why Biomedicine is in crisis. As noted in earlier chapters, in some respects, the public has lost faith in Biomedicine, in science, and in doctors. Chapter 4 provides many examples of this, e.g., Joel's belief that his oncologist was using him as a guinea pig; Brian's awareness of abuse and incompetence in the conventional system; Angela's dissatisfaction with the way conventional doctors communicate with patients; Marcia's belief that her needs were not met when she had her surgery; Linda's comment that patients are not given truthful information; and Jack's assertion that he was more capable of making treatment decisions than any of his doctors. In some respects, CAM may enjoy

a higher degree of public trust than Biomedicine since CAM treatments are generally assumed to be “natural” and since the shortcomings of the models and treatments associated with CAM are less well known than those of Biomedicine. Nevertheless, public discourses do include questions about CAM’s safety and efficacy and reminders of the field’s lack of institutional legitimacy.

It is clear that the attribution of legitimacy involves parallel processes of legitimation and delegitimation. In the choices they make about the treatment regime they will follow, cancer patients sometimes deconstruct the taken-for-granted legitimacy of Biomedicine while at the same time building a belief in the legitimacy of one or more CAM treatment approaches. A treatment plan is usually provisional, subject to change on the basis of new information from external sources as well as perceptions of harm or benefit based on personal experience. In addition, patients’ assessments of the legitimacy of different approaches to healing are influenced by the meanings they give to their cancer and to the range of possible ways to respond to the illness. The role of cultural models in these processes is crucial.

Cultural Models that Influence Decision Making

My fieldwork shows that patients who are using CAM treatments for cancer draw on a variety of cultural models in the process of making decisions about treatment. Some of these models are linked to the Biomedical Discourse, e.g., surgery can cure cancer if the surgeon “gets it all.” Some are associated with CAM discourses, e.g., treatment regimes should be individualized. Other models have become mainstream enough that they cannot easily be identified as either biomedical or alternative, e.g., models about cancer and the immune system, models about cancer and lifestyle, and models about the “cancer

personality.” The cultural models that patients look to for direction in their decision making that run counter to biomedical master models can be categorized as comprising three themes: models about the nature of the link between the body and the mind and about health and illness; models about relationships between patients and practitioners; and models about the legitimacy of different sources and types of knowledge.

Models about the Nature of the Body–Mind and about Health and Illness

The patients I interviewed expressed a number of beliefs about the nature of the body and how illness or healing happens. Some of these models reflect the influence of holistic health discourses (e.g., Joel’s belief in the benefits of exercise and the avoidance of toxins). Others show the influence of psychotherapeutic discourses (e.g., Linda’s belief that painful emotions need to be expressed). Others are expressions of models actively being promoted by CAM proponents (e.g., Marcia’s search for the meaning contained in her breast tumour). Implicitly or explicitly, the patients I interviewed drew on a number of cultural models which have been characterized as central to CAM discourses and which contradict biomedical models.² These “master CAM models” include: the mind can heal physical illness; illness carries meaning or messages for the self; treatments need to be individualized rather than standardized; the body–mind heals itself rather than being healed by outside agents; and the individual is responsible for healing.

In highlighting the influence of these cultural models, it is important to point out that some observers see the emergence of these models as less than benign. For example, the belief that individuals can heal themselves (and can make themselves sick) has been criticized as victim–blaming (Lowenberg 1989). Stacey (1997) argues that this discourse

regarding the individual's responsibility for health gets its power from its ability to restore precisely the values and beliefs that are threatened by postmodernism: the search for certainty and control; the promise of continuity; and the appeal to universal criteria. She sees this discourse on personal responsibility as a neolegitimation or professionalization of the patient that is dialectically connected to the concomitant delegitimation of biomedical knowledge. Stacey decries the tendency for this model to associate illness with moral failings and sounds an alarm about this post-modern moral project of the self.

Arthur Kleinman (1995) goes farther. In describing the influence of "holistic medicine" in the U.S., Kleinman tells the cautionary tale of the appropriation of the metaphor of holism by the Nazis. Kleinman notes,

This is a sobering reminder of the substantial potential for abuse in the appropriation of criticisms of biomedicine. Holism in the 1930s started out as a movement to reform medicine, but ended up legitimizing political authority and disguising the real sources of oppression. Its salvational ideology came to serve truly dangerous political interests—a serious, destabilizing concern (1995:27).

Models about the Patient–Practitioner Relationship

As the profiles in chapter 4 demonstrate, patients are adopting collaborative models about how patients and health care providers should interact. For example, Joel assesses medical advice in light of his own knowledge and accepts that advice when it fits his ideas and rejects it when it does not. Marcia insists that she is the one who decides about what will happen to her body. Angela believes she and her medical care providers are equals, just two people sharing their different but equal knowledges. Jack becomes his

² Table 1 in chapter 1 summarizes the presumed oppositions between Biomedicine and CAM.

own case manager when he realizes that no one knows his case or cares about its outcome more than he does.

Chapter 7 provides examples of the ways in which partnership-based, consumer-oriented cultural models are being promoted in the popular sector. Chapters 5 and 6 illustrate the unsettling effects of these models: the balance of power changes when a patient knows a lot about conventional treatments and more about CAM treatments than the oncologist; patient demands for a comprehensive understanding of their disease and its treatment make it harder to achieve “informed” consent;³ and expectations about personal engagement and the provision of hope destabilize patient and professional roles.

Models about the Legitimacy of Different Sources and Types of Knowledge

Biomedical and public discourses look to science to determine the legitimacy of what has been called CAM and to provide the bridge between what are envisioned as two different worlds. This is no doubt related to modernist beliefs about the power of science. As Byron Good notes, “Medicine is a domain in which ‘a salvational view of science’ (Geertz 1988:146) still has great force” (1994:21). As the examples in the previous chapter show, proponents of a wide variety of ideas and treatments invoke the rhetorical power of science to bolster their claims. Since the time of the Flexner Report in the early 20th Century, science has been the presumed foundation for medical knowledge and the arbiter of new claims to knowledge. Many discourses in the biomedical and public arenas

³ Coburn and Willis (2000) note that in Canada, at least, legal criteria regarding informed consent are increasingly shifting from judging adequate consent as being what a reasonable physician would divulge, toward asking what a reasonable patient would want to know. This shift in the balance of power is seen as being related to social, cultural and political changes, including the emergence of postmodern discourses such as those that question the ability of science and technology to address critical social issues and the deprofessionalization of medicine that is occurring through the demystification of medical knowledge.

assert that only knowledge that complies with accepted rules of logic and reason and knowledge that is grounded in scientific evidence are worthy of institutional legitimacy. But the use of non-biomedically sanctioned therapies and the emergence of cultural models that undermine conventional Western ontology and epistemology are unsettling this biomedical status quo.

My fieldwork shows that, when patients create situated meanings, socially legitimated, "official" medical knowledge is only one piece of the puzzle. Patients are faced with the challenge of making decisions about treatment often in the absence of definitive answers from science. In addition, the patients I interviewed expressed cultural models that undermine the authority of medical science, e.g., science is made to be overthrown; biomedicine is too narrow in its exclusion of the emotional and spiritual; and science discounts intuition. They also drew on models that affirm the legitimacy of other ways of knowing. For example, Marcia gives credibility to healers who can "read" her body using their psychic abilities. Angela aligns herself with Eastern meditation teachers and practices. Jack relies on information from other patients whose experience he trusts.

The Dreyfus model of the phenomenology of human learning (Flyvbjerg 2001) describes the development of expert knowledge in a way that provides a provocative perspective on the question of whether science can or should be the arbiter of medical legitimacy for patients. The Dreyfus model outlines five levels in the process of learning a new skill (defined broadly to include technical skills, social skills, and intellectual skills): learners start at the novice level, then move to the advanced beginner level, then to the competent performer level, then to the level of proficient performer, and finally advance to the level of expert.

At the novice level, people learn facts, characteristics and rules regarding the skill to be learned. These are independent of context. The learner advances to the next level by engaging in real-life experience. Through trial and error, the learner begins to recognize relevant elements in relevant situations and thus begins to recognize the importance of context. At the next level, the competent performer learns to make sense of the overwhelming array of concrete instances she or he has experienced by developing the ability to apply hierarchical, prioritizing procedures. At this level, the ability to interpret the context and make judgments becomes crucial. Competent performance is characterized by logical information processing and analytical problem solving. At the first three levels of performance, conscious choices are made after reflection about the alternative elements, rules, and plans available.

At the fourth level, a different type of performance emerges. Proficient performers tend to be deeply involved in their actions and use perspectives that have evolved through considerable experience in previous relevant situations. Through the workings of memory, spontaneous interpretation, and intuitive judgment, plans and expectations about actions and their consequences develop. At this fourth level, deep intuitive involvement in performance interacts with analytical decision making. The fifth and final level, that of the genuine expert, the virtuoso, is characterized by the instantaneous fit between the recognition of the demands of the situation and the recognition of relevant decisions, strategies, and actions. This level is characterized by effortless, intuitive, holistic, and synchronous action. "In normal familiar situations, real experts do not solve problems and do not make decisions. They just do what 'works'" (Flyvbjerg 2001:17).

This model describes a qualitative difference between the first three and the last two levels of expertise. Logically based action is replaced by experientially based action. Reason is complemented by intuition. The model explicitly connects increasing levels of skill acquisition with decreasing levels of analytic rationality. The model profoundly unsettles predominant Western views about scientific rationality being the correct grounds for expert knowledge.⁴ After hearing one of the originators of the model speak, Jurgen Habermas reportedly said, "You are talking about skills like hammering and playing chess, but what you really want to do is undermine Western society" (Flyvbjerg 2001:22). The model challenges assumptions about the legitimacy of science and reason by revealing the hegemonic power of the discourse. What Flyvbjerg calls the rational fallacy

consists of raising analysis and rationality into the most important mode of operation for human activity, and allowing these to dominate our view of human activity: so much so that other equally important modes of human understanding and behavior are made invisible (2001:23).

Some elements of the Dreyfus model are reminiscent of the epistemological models associated with CAM. The perspective on the body and health that is attracting so many adherents does not dichotomize the mind and the body, but views the body-mind as a holistic system. Emotions, intuition, and spirituality are valued; they are not seen as inferior to reason. CAM models point out the limits to scientific rationality. Non-rational ways of knowing are seen as legitimate. Like the Dreyfus model, these ontological and

⁴ This model also challenges the move towards evidence-based medicine since tying clinical practice to rules would limit practitioners to the competent performer level; a strict adherence to evidence-based medicine would preclude performance at the proficient performer or expert level.

epistemological models undermine the reductionist, scientific model that the rhetoric posits as the foundation for Biomedicine.⁵

The Dreyfus model suggests a new way to understand how patients make decisions and why they value models about the legitimacy of non-scientific ways of knowing. The patients I interviewed did not claim to be experts in biomedicine or in CAM. But they did seem to see themselves as experts in how to live their own lives. When the patients I interviewed received their cancer diagnosis, they began learning. They read books, searched the Internet, attended lectures, and talked to other cancer patients. They tried to garner as much scientific information as they could. But they knew this information could not promise them certainty. Patients examined costs or risks and benefits rationally, but they understood that this kind of analysis could only take them so far toward the decisions they needed to make. In the making of situated meanings around the legitimacy of a cancer treatment, patients use rational discourses related to science and medicine, but these are juxtaposed with other discourses, other cultural models, and combined with action and experience. For patients, as for learners at the higher levels of the Dreyfus model, context is all-important.

Are these patients acting like experts? Joel did not hesitate to fire his first oncologist or reject his CAM practitioner's advice to go on a fast, given his knowledge of his body and what he needed. Brian relied on his own "felt sense" of what treatments were beneficial. Marcia believed that intuition was a more credible authority than the

⁵ Despite the rhetoric, studies in the sociology of science show that science does not develop simply through the application of objective, rational procedures. The development of science is social, i.e. not only are scientific skills and knowledge learned in social settings but scientific activity is influenced by social factors such as the vested interests of funders, alliances among researchers, and political correctness. (Latour and Woolgar 1979; Collins 1985).

non-specific, standardized guidelines of biomedicine. Linda made treatment decisions intuitively, while doing the dishes, after doing a great deal of research about all the options, with all the contradictory information spinning around in her head.

It is not surprising that cancer patients value non-scientific ways of knowing given the inability of science to provide certainty about treatment decisions. Cultural models that legitimize alternative epistemologies would have some appeal, given patients' need to understand their situation and justify their decisions. In addition, patients may correctly perceive that they are the experts when it comes to personal treatment decisions. But what about the other models that patients are adopting that run counter to hegemonic cultural models? How do they come to be seen as credible?

The Spread of Cultural Models

Processes of cultural legitimation depend on relationships and allegiances and the interplay between interpersonal interactions and personal identities. In the midst of this interplay of the interpersonal and the personal, cultural models get expressed, tested, and adopted, often after being adapted to fit with other models or values. The metaphor of contagion (Sperber 1996) is probably apt. But how have CAM cultural models that oppose master cultural models associated with Biomedicine managed to infect so many people?

Quinn and Holland note that cultural models

are compelling in a way that does not depend on what the experts say and often seems highly resistant to revision in the face of apparent contradiction. Largely tacit and unexamined, the models embed a view of "what is" and "what it means" that seems wholly natural—a matter of course. Alternative views are not even recognized, let alone considered. . . . Cultural models grant a seeming necessity to how we . . . live our lives (1987:11).

But this dissertation presents many examples of people who have adopted alternative cultural models. As noted in Chapter 2, Parsons (1963) theorized that subcultures that deviate from the norm but seek legitimation within the dominant context must convince people of the validity of their own interpretations of cultural value systems and ideologies. Traditional institutions must then be delegitimized with reference to those shared cultural beliefs and values. Parsons asserts that this process is characterized by tension and oversimplification. Chapter 7 provides clear examples of the oversimplified discourses about the legitimacy of CAM vs. Biomedicine that are currently occurring in public arenas. But there is more going on here, since it is not only that interpretations of shared models are being changed, but models that are not commensurate with accepted models are being adopted. The spread of non-mechanistic, non-materialist perspectives on the nature of the body-mind stand out as particularly important.

Frame Alignment Theories

The study of how social movements form and spread provides some insight into the ways in which alternative cultural models get adopted. Frame alignment theorists focus on the ways in which social movement leaders attract adherents. "Frame" here denotes interpretive schemata that render events or experiences meaningful. Frames function to organize experience and guide action (Snow et al. 1986). Thus, the sociological concept of frame is comparable to the concept of cultural model used in anthropology. Snow and Benford (1988) outline three core framing tasks that social movements must undertake: "diagnostic framing" refers to the process of identifying a problem and attributing blame

or causality for that problem; “prognostic framing” suggests solutions to problems and identifies specific strategies, tactics, and targets; and “motivational framing” provides the rationale and impetus for action.

Frame alignment theorists assert that these three framing tasks can be accomplished by four different types of framing activity. “Frame bridging” refers to “the linkage of two or more ideologically congruent but structurally unconnected frames regarding a particular issue or problem” (Snow et al. 1986:467). Linking the public’s concern about the rising costs of Medicare with patients’ dissatisfaction with the way conventional physicians communicate would be an example of diagnostic framing achieved through frame bridging.

“Frame amplification” refers to the “clarification and invigoration of an interpretive frame that bears on a particular issue, problem or set of events” (Snow et al. 1986:469). CAM proponents’ descriptions of the benefits of a holistic, natural way of treating disease where the patient is a partner in the healing process would be examples of prognostic framing using frame amplification strategies.

“Frame extension” refers to the process of extending the boundaries of the movement’s primary framework to encompass interests or perspectives that may be incidental to the objectives of the movement but highly salient to potential adherents. The excerpts in the previous chapter from Robbins (1998) that link CAM with other social movements such as feminism, the peace movement, and patients’ rights movements provide an example of motivational framing using frame extension.

These descriptions of how different framing activities can influence people’s cultural models all help to explain how some of the cultural models associated with CAM

are being strengthened and distributed through Western culture. But the fourth type of framing activity is most relevant to the question of how CAM models that oppose dominant cultural models come to be adopted. "Frame transformation" is required when the movement's values and causes are antithetical to existing values or models. Frame transformation requires that people come to see the problem in an entirely new way. Two types of frame transformation have been delineated. Domain-specific transformation refers to changes in the way in which a contained domain of life is perceived. When Jack realized that the other prostate cancer patients in his network were right about the need for him to take charge of his treatment, his frame or model about the nature of the physician-patient relationship was transformed, but his worldview was not. In contrast, the second type of frame transformation consists of broad changes in the way all experiences and events are interpreted. A new "master frame" displaces a pre-existing one and a global transformation has occurred (Snow et al. 1986). Angela's adoption of Eastern ontologies and epistemologies through her long-term participation in the counter-culture is an example of a global frame transformation.

The effectiveness of framing activities is constrained by several factors, including the extent to which the new frames are relevant to the experiences or the lifeworld of those who are exposed to them (Snow and Benford 1988). This point is crucial to understanding how alternative models associated with CAM discourses "infect" those who come to adopt them. As shown in chapter 4, a cancer diagnosis is profoundly unsettling. Patients are highly motivated to find ways to make sense of the diagnosis and prognosis. They are suddenly immersed in the cancer culture, which includes messages about what it means to be a good cancer patient as well as the conflicting voices of CAM

discourses heard against the background of the Biomedical Discourse. Patients face extreme uncertainty at a time when they are anxious and therefore vulnerable. For some, with a strong allegiance to either CAM discourses or the Biomedical Discourse, the situation may not result in frame transformation. But for others, new alternative models do take root. As Quinn and Holland note,

Among alternative versions of what is legitimate and what is inevitable, a given ideology is most compelling if its rightness engages the sense one has of one's own personal uprightness and worthiness, or if its inevitability engages the view one has of one's own inherent needs and capacities. These matters lie at the heart of our understanding of ourselves and our place in life (1987:13).

If one's interests are seen to lie in the repudiation of an old model and the adoption of a new one, which is often the case when conventional medicine cannot offer hope or comfort, it would not be surprising if any anxiety that might arise because of the adoption of a marginal or socially unacceptable belief or behaviour would be overridden by the need to quell the anxiety about losing one's life.

The Crucial Role Played by Personal Experience

My fieldwork suggests that, while being exposed to a cultural model and having a high degree of need or motivation to adopt a new model are important factors in the way situated meanings around legitimacy are created, these two influences are not enough. In order for new cultural models to be accepted and used in the process of creating situated meanings, the model and the motivation to find meaning must connect with personal experience. This link with experience allows cultural models to be used as sources for the creation of further situated meanings and assemblies of situated meanings. For example,

before being diagnosed with cancer, Joel knew nothing about the disease or its treatment. He was advised by both his conventional and complementary physicians to take chemotherapy, so he did. But his subsequent experience of chronic fatigue prompted Joel to adopt cultural models about the dangerous side-effects of chemotherapy. Interestingly, Joel was aware that a recurrence could prompt him to override this cultural model. As another example, although Brian found homeopathy's explanatory models far-fetched, he provisionally accepted the merit of homeopathy because of the reputation of his naturopath. However, after experiencing no benefit from the treatments, he stopped using them and stopped seeing the naturopath. Angela's case shows how the adoption of models can shape experience. After she decided to adopt the model that "everything is sacred," she discovered that her perspective on cancer changed dramatically. Linda provides another example of how models shape action and experience. She acted in accordance with the cultural model of "the good cancer patient" even though she did not agree with the model because her experience told her she would receive better care when she complied with this hegemonic model.

The patients' stories are not the only parts of the fieldwork that demonstrate the importance of personal experience. The story of the retired surgeon in chapter 6 provides a clear example of how the link between personal experience and a cultural model can bring about dramatic transformations of situated meanings. The comments of the former Tzu Chi Institute administrator in the same chapter about the need for an experiential understanding of integration further reinforces the importance of personal experience, especially when the validity of a model that contradicts earlier models is being tested. But for such models to take root and become ongoing guides to interpretation and action,

the link between models and experience must be reinforced. This occurs in social situations.

Communities of Practice

In their analysis of situated learning, Lave and Wenger (1991) discuss the process whereby new cultural models interact with direct experience within social contexts. They propose that the concept of "legitimate peripheral participation" describes the ways in which outsiders learn to become insiders through their participation in communities of practice. Their theory of social practice

emphasizes the relational interdependency of agent and world, activity, meaning, cognition, learning, and knowing. It emphasizes the inherently socially negotiated character of meaning and the interested, concerned character of the thought and action of persons-in-activity. This view also claims that learning, thinking, and knowing are relations among people in activity in, with, and arising from the socially and culturally structured world. . . . (The world's) meaning . . . (is) produced, reproduced, and changed *in the course of activity* (Lave and Wenger 1991:50–51) (emphasis added).

Byron Good describes a similar dynamic in his discussion of a cross-cultural analysis of illness narratives by Early (1982, 1985, and 1988 cited in Good 1994).

Quoting Early's definition of illness narratives as a "middle level system between experience and theory" Good explains that, these narratives "allow (people) to develop an interpretation of illness in relation to a local explanatory logic and to justify actions taken, thus embedding the illness and therapeutic efforts within local norms" (1994:141–2).

But a story alone will not suffice. Good, like Lave and Wenger, emphasizes the importance of embodied action in a social context.

We should conceive of culture and reality as embedded in activity, in interpretive practices of members of a society interacting with the social and empirical world to formulate and apprehend reality in distinctive ways (Good 1994:174).

The rhythms and disruptions of experience presume a socially organized lifeworld, and a description of the contours of the social world as experienced requires attention not only to the cognitive shaping of experience, but to the sensual body as well (Good 1994:123).

The patients I interviewed were participating in a variety of “communities of practice” or social situations where cultural models and experiences related to both Biomedicine and CAM’s legitimacy were being discussed and interpreted. These included: interactions with health care practitioners; conversations with members of informal social networks (e.g., about others’ experiences with different therapies or their perspectives on different cultural models); group activities such as patient support groups, yoga or Tai Chi classes, or meditation groups; lectures or workshops given by CAM proponents; and Internet-mediated social networks (e.g., Jack’s network of prostate cancer patients).

Biomedical and CAM practitioners also take part in communities of practice where the legitimacy of different approaches to healing is assessed. Bernard’s description of his colleagues’ research to test their observations about lung cancer treatment provides an example of a situation where a model (or hypothesis) was evaluated against experience (using scientific methods) in a community of practice (the medical unit) and found to lack validity. Participation in these kinds of communities of practice allows competing cultural models to be tried out and then discarded or accepted. In these social situations, models or frames are bridged, amplified, extended, and transformed. They are also likely to be contested, since most social settings are pluralistic. Participation in these communities of practice occurs within a larger social context that is similarly marked by

dialectical tensions: the Discourse of Biomedicine with all its institutionalized weight and power is juxtaposed with counter-hegemonic discourses, including the discourses associated with CAM.

The Sociocultural Attribution of Medical Legitimacy: A Model

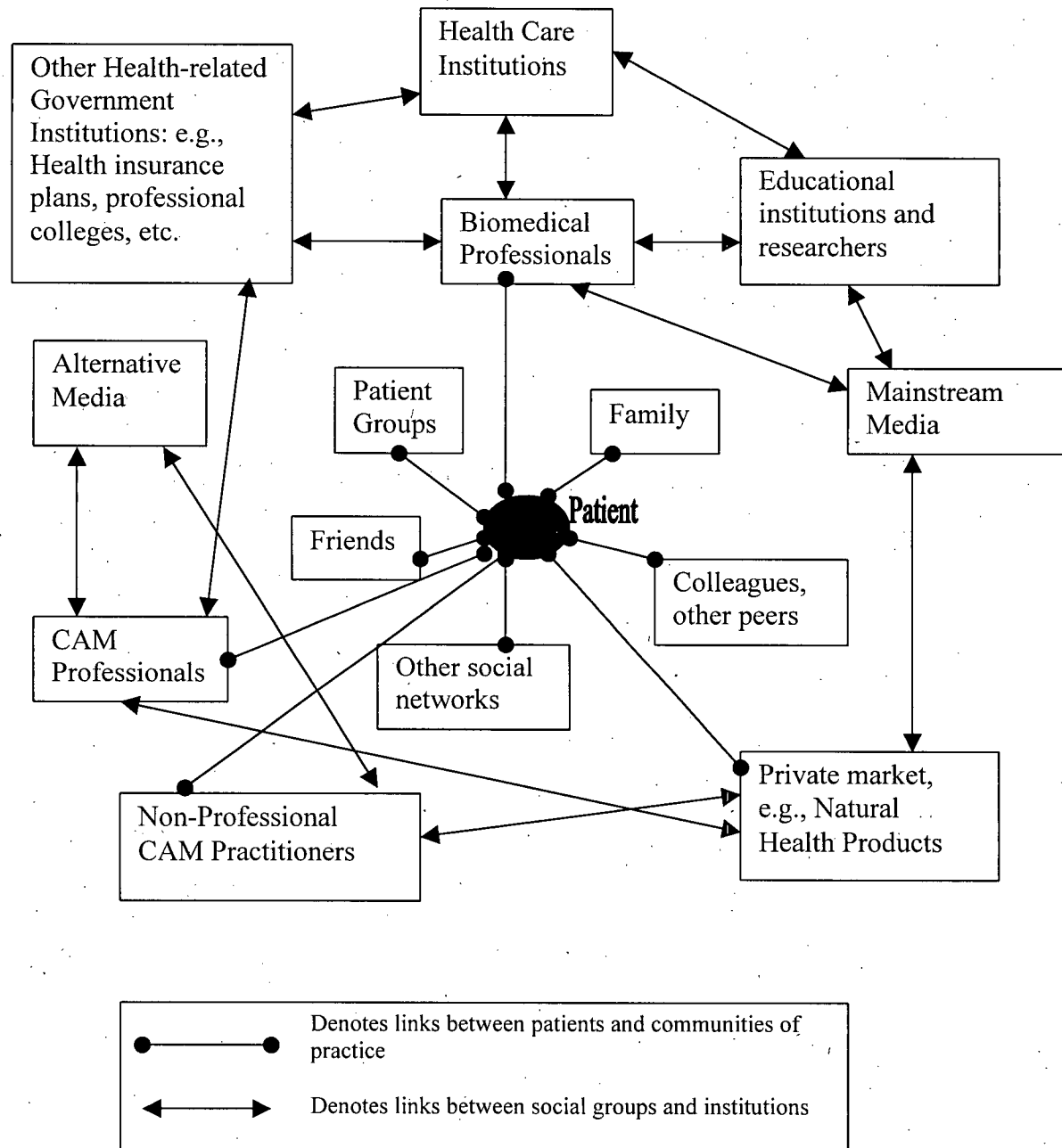
The preceding analysis argues that individuals confer legitimacy to a particular approach to healing by connecting cultural models with personal experiences that occur within social contexts. My analysis shows that legitimacy is attributed in provisional, ad hoc ways, where context is critically important. The individual context includes factors such as one's sense of identity and agency, perceptions of risk and cost vs. benefit, degree of trust in various authorities or experts, and one's motivations, which in the case of cancer patients include the need to create meaning in the face of a life crisis. When making decisions about using CAM treatments, one's ability to pay also plays a role.

A personal, situated meaning regarding legitimacy develops through the interplay of a variety of cultural models that allow the individual to interpret his or her experience. These models may be contradictory, partial, and only provisionally accepted as true. In order for such models to be accepted, especially ones that contradict established models, some kind of personal experience that fits the content of the model is crucial. The testing of cultural models against experience occurs in social settings that are affected by institutionalized social structures and Discourses. Thus, the personal attribution of legitimacy is influenced by cultural legitimacy and by social legitimacy. Legitimation takes place in a pluralistic atmosphere of contestation.

Figure 2 shows how individual patients are embedded in a sociocultural network that includes informal social groups as well as social institutions. All of these can be considered “communities of practice” with respect to questions about the legitimacy of different approaches to healing. The circle of communities of practice closest to the patient includes friends, family, colleagues, patient groups, and other social networks through which patients are exposed to diverse cultural models and within which actions and experiences get interpreted. These individuals and groups would be categorized as part of the popular sector in Kleinman’s (1978) model of the health care system. The primary connections between the patient and these individuals or groups are shown in the figure. There are also connections among the groups represented by the boxes (e.g., family members and friends may reinforce the same cultural models) but these are not shown because of the need to keep the figure comprehensible.

Surrounding the patient and the communities of practice closest to him or her are biomedical and CAM professionals, non-professional CAM practitioners and various social institutions such as hospitals, educational institutions, and the media. All of these convey cultural models, discourses, and Discourses that influence the construction of meaning and the attribution of legitimacy. Some, such as hospitals, are also communities of practice, since they are sites of experience and its interpretation.

Figure 2: Sociocultural Legitimation Network



It should be noted that the model for the personal attribution of medical legitimacy I describe differs from more cognitively-oriented models such as the Health Belief Model or the Theory of Reasoned Action (Poole et al. 2000) that explain health decision making by referring only to beliefs and attitudes. My model also differs from frame alignment theories that similarly focus on cognitive models and language. My fieldwork clearly demonstrates that thought processes are not the only factors that influence patient decision making. Emotions and embodied experiences are crucial, especially when the health of the body and the creation of meaning are at stake.

Implications for Health Care Policy, Practice, and Research

My research was undertaken in a political and historical context where both the legitimacy of different approaches to healing and the grounds for medical legitimation are being contested. My fieldwork revealed aspects of the lived experiences of individuals that are too often obscured by the academic and public discourses about medical legitimacy. This dissertation has elucidated the emic perspectives of those who are inside biomedicine, those who are on the margins of the health care system practicing an approach to healing considered complementary or alternative to biomedicine, and most importantly, those who must make life and death treatment decisions in the face of extreme uncertainty. The dissertation showed how individuals think about and negotiate different claims to medical legitimacy: it demonstrated that these processes link individual identities and beliefs with official, professionally legitimized knowledge and culturally legitimized models.

My fieldwork suggests that while "CAM" may be a useful rhetorical device in some contexts, in the realm of personal health care decision making, the term is too general and encompasses too much diversity to be useful. This may also be the case in the health care policy and research arenas, where conceptual clarity and specificity are needed. My fieldwork suggests that there are two ways in which increased clarity in these fields can be achieved: first, by asking policy and research questions about specific medical treatments, practices, or systems individually rather than asking questions about "CAM" as if it was a monolithic, coherent entity; and second, by making clear distinctions between patients' use of particular treatments or approaches to healing and their adherence to different cultural models. The actions people take to promote health and healing should be distinguished from the reasons why they take these actions. These are obviously not separate phenomena, but to focus primarily on the use of CAM treatments and neglect the complex motivations and contexts surrounding their use could weaken policy, practice and research initiatives by failing to incorporate important dimensions of CAM use.

My fieldwork indicates that some cancer patients are adopting cultural models that have the potential to prompt significant changes in Canada's health care system. These models concern the nature of the body and healing, expectations about the patient-practitioner relationship, and beliefs about the kinds of knowledge that can be used to determine medical legitimacy. Some of the patients I interviewed were taking very active roles in their own treatment. It seems the most important question related to health care policy and practice that is raised by the stories of these patients is whether and how the health care system can better support patients who are willing and able to take this kind

of active role so they can make the best decisions possible. Although CAM proponents and some biomedical professionals are advocating that the professional health care sector become larger and more inclusive, perhaps a more fruitful direction for health care policy and practice would be to strengthen the popular sector. The patients who took part in my research may be pointing to a way to re-orient the health care system that could make health care both more effective and more economically sustainable.

The results of my fieldwork provide some guidance about how to move through the process of considering policy initiatives designed to achieve a strengthening of the popular sector and how to address the questions for health care practice and research that such initiatives might generate. For example, my fieldwork and the Dreyfus learning model suggest that any consideration of these kinds of policy initiatives should take an inclusive view of who might have relevant expertise. It seems likely that the expertise of conventional professionals would need to be complemented by that of patients and non-biomedical practitioners. In addition, my model regarding socio-cultural legitimization processes suggests that rational explanations of unfamiliar or contested concepts or models are unlikely to result in robust understandings unless experiential learning opportunities in communities of practice are available.

My fieldwork and the policy question it raises provoke a myriad of research questions. Investigating these theoretical and applied research questions would contribute to a more thorough understanding of what is happening at the interface between conventional medicine and "CAM" and how the health care system should respond. Examples of the theoretical questions are: How widespread is the adoption of particular cultural models about the body and healing, about clinical relationships, and about

different epistemologies? How do different models or frames extend, amplify, bridge or transform each other? How do various public media spread counter-hegemonic cultural models and how are the agendas of different media controlled? What is the role of CAM leaders in the spread of new cultural models? How is the entry of corporate players into the "CAM marketplace" influencing the situation? What kinds of experiences are most influential in the repudiation of old cultural models and the adoption of new ones? What characteristics of social settings influence the spread of cultural models?

The questions that apply to health care practice and policy include the following: How many patients are willing and able to take highly active roles in their care? How can these patients best be supported to make good decisions? How are patients evaluating the information they get from the Internet and from other unofficial sources? What does informed consent mean in contexts where patients are empowered to take more responsibility for decision making? How can health care outcomes be monitored in cases where patients and practitioners are working in partnership? What are the differences in the cost of health care for those patients who take an active role in their care and use CAM approaches and those who adopt more traditional patient roles? How can practitioners and patients articulate their own health-related cultural models quickly and effectively so they can communicate better? How can conventional practitioners come to understand unfamiliar models about the body and healing, e.g., would experiential training sessions be effective?

This dissertation has shown that there are important ontological and epistemological questions being asked about Canada's health care system in the interface between Complementary and Alternative Medicine and Biomedicine. Clues about how to

resolve these questions can be found in the experiences of the people whose stories and perspectives are presented here and in my analysis of the processes through which individuals struggle to determine the legitimacy of different approaches to healing. But some cautions must be offered. First, this research is exploratory and descriptive only. It is constrained by the limitations noted in chapter 3. The research participants were self-selected and the samples were small, especially the sample of CAM practitioners. The data collection, analysis, and interpretation were inevitably influenced by my own position with respect to the research issues. While I have endeavoured to provide a balanced perspective on the issues that has intellectual integrity, the ethnographic method allows no illusion of positivist objectivity. This dissertation research needs to be verified and augmented by other studies.

The second caution is a reminder that the research focused on the ways in which personal conceptions of legitimacy are socially and culturally constructed, not the larger social processes whereby medical legitimacy becomes institutionalized. The questions that individuals face when confronted with a diagnosis of cancer are different from the questions society faces when confronted with demands to integrate additional approaches to healing into the health care system. While I have tried to situate the experiences of patients and practitioners in the broader social context, I have not attempted to investigate the complex political and economic context surrounding the determination of institutional legitimacy. Political and economic issues that I have not explored include the organization of health care providers into professional groups, the involvement of large corporations in the commercialization of CAM, and the ways in which access to CAM is limited by people's ability to pay for CAM products and services.

The third caution relates to the tendency to look for unambiguous answers and solutions to the debates around CAM's legitimacy. This ethnographic study described the complex and contradictory situations of people with cancer and those who care for them. There are many cultural and social discourses and structures currently at play, and all of them have both helpful and harmful possibilities.

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Appendix A: Profiles of Patients Interviewed Individually

Case #1: Joel

Profile presented in chapter 4.

Case #2: Mary

Mary was a 50 year old medical social worker who had immigrated from Hong Kong when she was a young adult. She was interviewed at a hospice while receiving palliative treatment for recurrent breast cancer. When her cancer was first diagnosed (more than 10 years before the interview) Mary had surgery and radiation. Subsequently she began taking reishi, a mushroom-like plant that in traditional Chinese medicine (TCM) is believed to have cancer-fighting properties. She began taking this on the basis of information from friends and family, especially her brother, who knew people who imported the product from Japan and who told stories of the product's effectiveness.

Mary got a lot of advice from different people about alternative treatments for cancer. She listened to this advice but did not necessarily follow it. She was sceptical about naturopathic doctors, having been to some who she felt were more interested in selling her their medicines than in helping her. She reported similar reactions to some of the TCM doctors she consulted. She believed that it was best to take as little medicine as possible, so she decided not to use anything but the reishi and to exercise and eat healthy food. In making decisions about what treatments to try, she relied more on information from her social network than on scientific research.

When a recurrence in her bones was discovered several years after her first round of treatment, Mary underwent chemotherapy. In the years after that, she received various courses of chemotherapy, which she combined with taking reishi. Mary believed that Western medicine would fight her cancer and that the reishi would boost her immune system and help rebuild her body. Her oncologist knew nothing about reishi and could not advise her about how to integrate it into her chemotherapy regime, so Mary established a routine of integrating the reishi with her chemo treatment based on her own observations of the effect of the herbal treatment. She did not take reishi in the few days before and after a chemotherapy treatment because she did not know how the two would interact. She said that she could feel the difference in her body after taking reishi, that she felt stronger, so she felt it was effective.

Mary was a member of a cancer patients' support group at a local non-profit organization. This group was very important to her, not only because she got emotional support, but because the other members had lots of information about different treatments and this helped her make decisions sometimes.

Mary reported a time when her Qi Gong group tried to send her healing energy (Qi Gong is a Chinese exercise that combines mindful breathing with patterns of slow movement). She did not believe this was effective, since she did not feel any difference. She said, "How can I believe in something which looks a little bit ridiculous, and then after the treatment, I don't feel any change. I have to believe in my body." Mary felt her own observations and intuition were the most reliable sources of information about the legitimacy of different approaches to healing. She said,

I believe in my intuition. If a doctor says how great (something) is but my gut feeling is that this doctor may not be caring enough or may be bragging too much, then I won't go to that doctor. So I look at the doctor as a partner in fighting cancer, so I need some respect from the doctor as well. I won't

accept doctors who try to dictate everything and expect me to just follow blindly.

Case #3: Brian

Profile presented in chapter 4.

Case #4: Jeanette

Jeanette is a 69 year old writer who was diagnosed with breast cancer after having a surgical biopsy. The specimen from the biopsy was difficult to assess, so several pathologists reviewed the slides before the cancer diagnosis was confirmed. Mastectomy and radiation were recommended. The possibility of chemotherapy was raised. A few days after receiving the diagnosis, Jeanette realized that she had "gone into overdrive, mentally" and had become caught up in a belief system with which she did not agree. She sat down and wrote out a list of what she really believed. This list included a number of cultural models that undermine conventional medicine, e.g., "I can heal myself;" "Chemotherapy is poison and will damage my immune system;" and "Radiation is bad for my body and should only be used as a diagnostic tool." Jeanette reminded herself of her long-standing interest in alternative approaches to healing and her previous experiences of self-healing through changing her diet and taking vitamins and supplements and through the use of techniques such as hypnosis and visualization. She realized that her worldview was not consistent with the recommendations of conventional medicine.

Jeanette put the question of conventional treatment on hold and began exploring CAM treatments for cancer. She found out about local CAM resources and began seeing a physician who used CAM approaches. She also joined a support group. On the basis of a recommendation from a CAM centre, Jeanette sent her biopsy specimen to an organization in Ottawa for another opinion. This organization (founded and staffed by people without medical credentials) confirmed the cancer diagnosis but said the cancer was slow-growing and did not warrant aggressive treatment. The organization recommended individualized vaccine and biochemical treatment. Jeanette decided against this treatment because she decided she did not really have cancer. She began taking a myriad of herbal remedies, vitamins and supplements as well as MRV vaccine (an anti-cancer vaccine) and Essiac tea. She also began following an intensive daily regime of visualization, meditation and affirmations. Her healing regime was based on her belief that you can choose to be healthy.

Jeanette's family physician and surgeon were very unhappy with her decision to refuse conventional treatments and responded with "poison pen phone calls" telling her she would die if she did not follow their recommendations. This angered Jeanette. She was offended by their assertions that she was making the wrong decision and did not have the right knowledge. As she said, "If anybody wants to get my attention, just tell me that I don't know about my body. There are lots of things I don't know, but my body, I know."

My second interview with Jeanette took place 18 months after the biopsy. Jeanette believed she was healed since a check-up done the previous month showed no sign of cancer.

Case #5: Angela

Profile presented in chapter 4.

Case #6: Sarah

Sarah had surgery for stage IV malignant melanoma when she was in her late twenties, more than twenty years before she was interviewed. She had a recurrence in her lymphatic system three years later, for which she had surgery. Then a few months later, tumours in both her lungs were discovered. She was told that surgery was not an option, so she began a course of chemotherapy. During this time her oncologist told her that he could guarantee her two more months of life, but no more.

Sarah had a long history of clinical depression so she began seeing a psychiatrist who put her on anti-depressants and recommended she read "Getting Well Again" (Simonton et al. 1978) a well-known book that emphasizes the role of emotions and mental states in cancer and recommends visualization as a treatment for cancer. The psychiatrist also encouraged Sarah to go to a support group for cancer patients. Sarah felt encouraged by the new perspectives she encountered through the book and the group. She began to feel that she could have some control over the course of her disease and her life.

Sarah was very weak and in pain, but during the course of her chemotherapy treatment, she decided not to continue. She felt that the health care professionals at the local cancer clinic were trying to help her die and that they believed she was not being realistic in thinking her life could be saved. One day, in the midst of receiving chemotherapy, she rebelled. She decided not to go back to the clinic because it was too much of a struggle. She felt desperate and abandoned.

Because she was so weak, Sarah felt she needed some kind of physical treatment. She believed that psychological approaches would not be enough. She heard about Iscador, a derivative of the mistletoe plant used as a cancer treatment in Europe and began taking it. She began feeling stronger and decided to go to the clinic in Switzerland that had been supplying her with Iscador. Sarah was treated for three weeks at this clinic and was very impressed. The clinic combined conventional treatments such as radiation and chemotherapy with art and music therapy, homeopathic remedies, good food, and social support. There, Sarah felt totally safe, and that she was cared for as a total human being.

Sarah left the clinic feeling optimistic; she felt it was up to her to cure her cancer. She returned home very excited but was disappointed to find that the professionals at the cancer clinic where she had been treated were not interested in her experience. One doctor told her that she was just imagining that she was feeling better. She replied, "And am I imagining that I am still alive, too?"

Over the next several years, Sarah continued to take Iscador and gradually got stronger. She began working as a volunteer with cancer patients. She also underwent psychotherapy, which she credits with being the most important contributor to her remarkable healing. As she said, "I started to care for myself. I started to want to live." Sarah believes that it was not a coincidence that she started to get better when she became fully engaged in her own healing.

Sarah believes that her conventional practitioners' disbelief in the possibility of her survival was the biggest stumbling block in her recovery. She said, "The practitioners

that treated me in Canada, their heart wasn't in it. They didn't have a belief that it was possible for me to survive. I didn't expect them to cure me but I needed people around me that believed it was possible." Sarah emphasized the enormous impact that physicians' words have on patients who are vulnerable and afraid. She said,

If I had not been the type of person I was, which is extremely stubborn and persistent, I would have died when I was expected to. My will played a tremendous part in healing. . . There is a time when we have to make that choice between living and dying.

But Sarah does not agree with some of the cultural models that suggest that illness should be taken as an opportunity to strive for physical and mental perfection—the search for the perfect body–self. She decries the pressure that is put on cancer patients to be positive, in control, exceptional. She said, "Healing as far as I can see is actually more likely to be cultivating imperfection than perfection because it's just being who you are."

Case #7: James

James was a retired teacher and school administrator who was diagnosed with malignant melanoma a year before our interview. He had surgery very soon after the diagnosis but the melanoma was deep and he had a recurrence in his lymphatic system eight months later. Conventional medicine could not offer curative treatment so James went to a local complementary cancer care centre to be assessed. He was considering what alternative treatments to take at the time of the interview. James had begun reading books by some of the most well-known CAM authors in the years before his diagnosis. He mentioned books by Andrew Weil, Deepak Chopra, Bernie Siegel, and Dean Ornish. Reading these books made James realize that, "There a lot more questions than answers. There is more we don't know as a society or as scientists than we actually *do* know." These authors not only undermined James' previous confidence in Western science and medicine, but they offered alternative ways of looking at health and the mind–body. He suddenly became aware of other alternatives, other possibilities. "The whole scene opened up," he said.

James believed that conventional doctors do not have the slightest idea about what is involved in the mind–body connection. In addition, he described the conventional medical system as expecting patients to hand over responsibility for their care to doctors—"like taking my car in to get fixed." Through his exploration of alternative views on health and medicine, James came to believe that he needed to take responsibility for his treatment, even though this represented a significant shift for him. He said that even though he was slowly realizing that he needed to take charge of his care, he struggled with the idea that his relationship with health care professionals should be a partnership. But his experiences in both conventional and CAM settings where standardized regimes were offered made him realize that he was going to have to take responsibility for designing an individualized treatment regime and determining its efficacy through trial and error. After visiting the complementary centre, James changed his diet (e.g., increasing his water intake) and stopped drinking alcohol. He expressed appreciation for the attention he received at this centre and compared the 1.5 hour appointment he had there with the assembly–line approach taken in conventional medicine.

James had several recommendations about how the health care system could be improved. He thought patients and communities should take more responsibility for

health care. He also thought that more credence should be given to intuition and non-scientific ways of knowing. He believed that it had been a mistake for Western society to "put all our eggs in one basket"—the scientific model. He said it did not make any sense for the scientific community to demand proof for alternative treatments when so much of conventional medicine had not been scientifically proven. But, he said, the challenge was that we do not have the language to talk about some of the important differences between Western medical systems and others, especially those from the East. He pointed out the need for new models—new ways of thinking and talking about health and illness. James believed that these issues would eventually be resolved because patients would demand it. As he put it, "The genie is out of the bottle."

James also asserted that conventional health care providers need re-education. He was very upset by the reaction of the oncologist he saw, who, as he reviewed James' surgery and pathology reports, shook his head back and forth and said, over and over, "Too bad, too bad." According to a family member I spoke with after James' death, this experience continued to haunt him. This is what Andrew Weil (1995) refers to as "medical hexing."

Case #8: Joan

Joan is a divorced school administrator in her sixties. She was diagnosed with advanced breast cancer when she went for a routine mammogram. The tumour was too large for surgical removal, so Joan had chemotherapy and radiation to shrink the tumour. Once the tumour had reduced in size, Joan had surgery. While Joan had an interest in the mind-body connection prior to her diagnosis, she did not want to rely only on mind-body approaches to healing given the size of the tumour. She wanted aggressive conventional treatment, which she complemented with visualization and participation in a relaxation group. She also learned everything she could about what was happening in her body: she read books about cancer and mind-body approaches and asked her oncologist and her family physician lots of questions. She learned to read what was happening in her body by paying close attention to the physical sensations she experienced as well as listening to her intuitions. In one interview Joan spoke of a compelling dream she had that she interpreted as signifying that she would have to sacrifice her breast but would survive. Subsequently she spent time acknowledging the importance of her breast but coming to terms with its loss, so by the time she had surgery she felt prepared. Joan spoke of her approach as combining scientific knowledge with knowledge gained through the imagination.

Joan described how she sometimes encountered the "cancer demons" in the middle of the night. She coped with her fear by writing poetry and writing her thoughts and feelings in e-mails she sent to a colleague who had offered support. In the morning light she would advise this friend to delete these messages. Joan felt it was important to acknowledge her fears and express them. Through the course of her treatment, Joan also came to believe that getting support from others was critically important. But she was careful about which family members and friends she spent time with during her treatment. She learned to avoid people who projected their own fear of cancer and death onto her. Because of the support Joan received from her friends and associates she came to believe that, "Becoming well is a communal effort with people that you really trust." She also came to believe that, "You can be healthy even though you have a part of your

body that's not functioning . . . or even though your body is ravaged by chemotherapy." She believes that it is the mental, emotional feeling of wellness and connection to the body that defines health, not the absence of disease.

Case #9: Marcia

Profile presented in chapter 4.

Case #10: Frank

Frank is a businessman in his sixties. He had high PSA readings for more than a year before having a biopsy that confirmed he had prostate cancer. It was recommended that he have radiation and hormonal treatment. Frank did a lot of reading about conventional treatments but decided against having them because he had seen family and friends go through conventional cancer treatments and receive little benefit while experiencing significant declines in their quality of life. Instead, Frank went to a traditional Chinese medicine doctor because his wife relied a lot on traditional Chinese medicine. He began taking herbs and having acupuncture and learned to practice Qi Gong. After learning about PC SPES through the Internet, Frank started taking this commercial product that combines several herbal remedies, including saw palmetto. (Some time after the interview, PC SPES [aka PC SPEC] was removed from the market because of contamination).

A very short time after he began taking PC SPES Frank noticed an improvement in urinary flow and concluded that the product was effective. He also tried an anti-cancer vaccine available through a local complementary medicine clinic but did not continue with this treatment because he did not perceive any benefits and did not like the idea of putting foreign or toxic substances into his body. Frank also practiced visualization and meditation because he believed in the importance of working on the mental aspects of health. He took this approach to treatment because he believed that his immune system would take care of him if he gave it a chance. During the most intensive period of these alternative treatments, Frank was spending all of his net monthly salary on these treatments.

Frank reported that the oncologist he began seeing when he was first diagnosed eventually refused to continue monitoring him and wrote Frank a letter dissociating himself from Frank's case. Frank said that every time he saw this oncologist, he would tell Frank that he did not want to waste tax dollars on diagnostic tests since Frank was going to die if he didn't have conventional treatment. Frank was able to find another oncologist who was willing to work with him, as long as Frank took responsibility for his care.

Frank was quite mistrustful of the conventional health care system. He said that, "Traditional doctors don't tell you the whole story. They only tell you enough so that you will buy into (conventional treatment)." Frank said that the system should be more pragmatic and focus on what works. He believed that in order for the health care system to improve, lay people would have to motivate the politicians.

Case # 11: Maryann

Maryann is a woman in her mid-fifties who was diagnosed with cervical cancer after a long history of having abnormal pap smears. She had surgery and seemed to recover

well, but six months later, a test showed malignant cells in her vagina. Her conventional doctors wanted to do further surgery to try to discover the source of this new cancer. However, when Maryann learned that the only treatment they could offer would be radiation, she refused to have further surgery since she would not have agreed to radiation no matter what the tests showed. Since the discovery of the vaginal malignancy, Maryann had been receiving regular diagnostic tests, which tended to show ambiguous results. She continued to refuse to yield to her conventional doctors' pressure to have further surgery, since she perceived their interest in pursuing her case to be strictly academic and unlikely to result in any benefit to her.

Maryann had been involved in the counter-culture during the sixties and was a political activist, so she had a long-standing interest in and use of CAM and a strong suspicion of mainstream institutions, including the medical system. After the diagnosis, Maryann did a great deal of research. She read books, talked to women in her social network, got advice from family members with medical knowledge and searched the Internet. She consulted several conventional doctors who used alternative treatments, as well as naturopaths and traditional Chinese medicine practitioners. She came to believe that her family physician had been negligent in not recommending she have regular colposcopies given her history. She also suspected that a mistake had been made the year before her diagnosis when her regular pap smear was judged to be normal. Maryann had seen both her parents die after going through conventional treatments for cancer, so she had first-hand knowledge of the effects of what she called these "barbaric" treatments.

Because of these experiences and her alternative world view, Maryann had great difficulty deciding what treatments to undergo. Despite doing lots of research, she "could not become a doctor overnight." Maryann said that the theory of conventional cancer treatment did not make any sense to her. She wondered how an ailment that has its roots in immune system deficiency could possibly be cured by killing the immune system. Given her scepticism about conventional medicine, Maryann's decision to have the initial surgery was surprising, even to her. She later doubted this decision because she believed the surgery itself might have caused the appearance of the second cancer.

Maryann used a variety of alternative treatments, including intravenous high-dose vitamin C, other nutritional supplements, the MRV anti-cancer vaccine, and Essiac tea. She also changed her diet. Maryann determined the efficacy of these treatments on the basis of whether they made her feel better or not. She felt that she had not received much help from professionals during her cancer experience. Her conventional gynecologist did not criticize her for using alternative treatments, but neither was she curious about CAM or its effects.

Maryann believed that her emotional state played a role in her cancer. She had been depressed for two years prior to her diagnosis. After the diagnosis, she felt pressured to be a good cancer patient and have a positive frame of mind. She said, "I'm worried because cancer patients are supposed to have the future in front of them. You are supposed to have goals and be striving for them. All the books say this. Quick, get some goals. Figure out what you are going to do in your life."

But Maryann could not see into her future. She was greatly relieved when she talked about this with a physician who prescribes alternative treatments, who said to her, "Why don't you just let it evolve?" Maryann's tendency to want to reject these cultural models around cancer was reinforced when she attended a support group session where a

new member told the group about how angry he was. His willingness to express a "negative" emotion touched a nerve. The group erupted in an outpouring of resistance to the cultural messages cancer patients get.

Case #12: Francesca

Francesca is a secretary who works in the conventional medical system. She was diagnosed with lymphoma when she was in her early thirties after having enlarged lymph nodes in several sites in her body for seven or eight years. Although she had brought these to the attention of her family physician on several occasions, no follow up was done, because lymphoma in young women is rare so her doctor did not consider it a possibility. Finally, Francesca's physician referred her to a specialist who recognized the seriousness of the symptoms. A surgical biopsy confirmed the diagnosis. After the lymphoma was diagnosed, the pathology slides from a biopsy done three years earlier of a palpable node in Francesca's armpit were reviewed. This review revealed that the lymphoma had been clearly present at that time, but had gone undiagnosed since the pathologist was looking for breast cancer not other kinds of cancer.

Francesca was very upset by the fact that her physicians had failed to identify the cancer earlier. This failure caused her to completely lose faith in conventional medicine after having been very proud to work within the health care system. Francesca's loss of faith prompted her to explore alternative medicine. She read as much as she could and consulted some alternative practitioners but came to the conclusion that, in order to make a truly informed decision, she would have "had to be a doctor for ten years and a naturopath for another ten years." Even though she had lost trust in doctors and wanted to make her own decisions, Francesca realized there was too much to know. She realized that she would have to trust somebody.

After talking with conventional and alternative practitioners and getting advice from family and friends, she agreed to start chemotherapy. But five minutes before her first chemo treatment, Francesca balked. Something in her would not let her go ahead with the treatment. The next week she went to her family physician to be put on birth control pills, which she should have been given before starting chemo. The doctor did a pregnancy test, which should have been done before the first chemo treatment was scheduled. The test came back positive. Francesca had been trying to get pregnant for several years. When she found out she was pregnant and she might have lost the baby because the correct procedures had not been followed, Francesca's faith in medicine was again undermined. Her faith in her own intuition, in her ability to "hear the voice of my baby" was strengthened.

Francesca decided to proceed with the pregnancy and delay treatment. During the pregnancy the lymph nodes shrank and most signs of the cancer disappeared. However, after the baby was born and Francesca stopped breastfeeding, her lymph nodes became enlarged again. She was experiencing other symptoms as well, so she began a course of chemotherapy that lasted a year. At the time of our first interview Francesca had been off chemo for three or four months and was trying to recover from the chemo and various acute infections. She was taking vitamins and supplements as well as Essiac tea. She was a regular participant in an ongoing support group for cancer patients sponsored by a non-profit organization.

Francesca was angry at the conventional medical system. She was angry about the mistakes that had been made in her case. But she was even angrier at what she perceived as conventional doctors' tendency to "think they are God"—to think *they* are the agents of healing. She was most angry at the ways in which conventional doctors "rob people of hope." She described other cancer patients she knew whose will to live and belief in the future had been stripped away by doctors giving them specific time frames for their survival. She was adamant that physicians should not give cancer patients such time frames.

Francesca also recommended that the conventional system begin recording patients' use of CAM in their charts, something her oncologists refused to do. She believed that the conventional system has a responsibility to track the effects and side-effects of conventional and unconventional treatments.

Case #13: Helmut

I interviewed Helmut, a retired builder, and his wife, Freda, in their home. I had met them five months earlier in one of the settings where I did participant-observation. When the couple greeted me at their home, I was surprised at how much Helmut had aged. When I first met him he looked to be in his early sixties (he was 64). When I interviewed him he looked ten or more years older. Helmut had been diagnosed as having colon cancer with liver metastases a year before I first met him. He had surgery at that time. His conventional doctors recommended chemotherapy, but admitted that this was "only a delay mechanism."

Helmut decided not to undergo chemotherapy since he did not want to be sick and live in the kind of misery he had heard resulted from chemotherapy. On the advice of his wife and many family members and friends, and because he wanted to be in control of his life and make his own decisions, he began exploring alternative approaches to cancer. He began taking vitamins and nutritional supplements, including MGN3, a mixture of Shitake mushrooms and rice bran that is supposed to build the immune system. He also began taking shark cartilage. These substances were expensive: the shark cartilage cost \$1400 per month, while the vitamins and supplements cost about \$200 per month. Since Helmut was not working, these expenses were burdensome. Fortunately, the couple received financial help from family and friends who supported their treatment choices.

In addition to taking these substances, Helmut began doing meditation and visualization. These aspects of his healing regime became a very important part of his daily routine, especially as he became weaker and had to spend more time resting.

Not long after Helmut's surgery, the couple saw a story about a local complementary cancer care centre in *Shared Vision*, a local alternative magazine. They immediately made an appointment. Helmut and Freda were very appreciative of the treatment they received there. They said they always left the centre feeling hopeful and cared for, whereas when they saw conventional doctors they felt discouraged and dehumanized. Another difference between the conventional system and this centre related to access to medical information: the complementary centre freely gave them copies of the information in Helmut's chart whereas they had to fight conventional doctors to get copies of reports. They described having difficulty finding a family doctor who would work in partnership with them and the staff from the complementary centre.

One doctor they saw told them that if Helmut was not willing to do chemo, he should not come back.

Helmut believed that conventional doctors were afraid to get involved with CAM because they were “afraid to step outside the boundaries because they would be called on the carpet” by their professional Colleges. He also believed that the training received by conventional doctors focused too much on diagnosis and not enough on healing. Helmut defined healing as including a good attitude, good support from family and friends, a good attitude from your doctor (e.g., an understanding that the body is very complex and things are not black and white), and a good environment (e.g., good music and avoidance of negative media).

Helmut and Freda did not feel the need for scientific proof for the treatments Helmut was taking, since “science is not always right.” They both felt that intuition and feelings are important sources of knowledge, even though the kind of knowing they bring cannot be rationally explained.

Although the couple spoke of the faith they had in the treatments they were pursuing, there was an unspoken subtext to the conversation because of Helmut’s obvious frailty. Helmut and Freda mentioned that some of their friends and family did not know how to respond to Helmut’s illness. When I asked how they would like people to respond, they replied that people should honour the choices people make regarding treatment and “keep on with the typical—the day-to-day routines.” They pointed out that cancer is a long-term journey: it can go on for years. They said it was therefore important to continue doing the everyday things: going to the park, listening to music, and talking about the weather.

Helmut passed away two months after the interview.

Case #14: Linda

Profile presented in chapter 4.

Case #15: George

George is a retired manager in his late sixties. He was diagnosed with prostate cancer almost two years before our interview. He was told that the cancer was “too far gone” for surgery to be effective. While waiting for an appointment at the local cancer clinic, George went on the Internet and learned about unconventional treatments for prostate cancer. His search for local distributors of the products he read about took him to a local traditional Chinese medicine doctor, who gave him PC SPES, a herbal remedy for prostate cancer. By the time he was seen at the cancer clinic, George’s PSA count had decreased from 8 to 2. He believed that PC SPES was responsible for this decrease. The only treatment offered by conventional medicine was “chemical castration” followed by radiation. Initially George agreed to this course of treatment and began hormonal treatment to reduce his testosterone levels. He continued taking PC SPES. After a month his PSA level had fallen to less than 1. At this point, because George believed that the PC SPES was effectively treating the cancer and because he did not want to “lose his manliness,” he refused further conventional treatment.

George took responsibility for determining his own treatment regime but found it frustrating that he needed a doctor’s approval for the diagnostic tests he needed to track the effect of the treatments on his PSA reading. He continued taking PC SPES and other

prostate health products such as saw palmetto and ginseng as well as vitamins and nutritional supplements such as spirulina. He also increased his intake of foods that are thought to affect the prostate such as soya and tomatoes.

On a trip to the U.S., George consulted with two medical clinics. He had some tests done there that were not done in Canada. The American physicians gave treatment advice that differed from the advice of the oncologists in Vancouver. George was confused by these different interpretations of his case and felt that economic interests in both countries were taking precedence over the interests of patients.

A local naturopath who had treated George's wife told George that he could cure his prostate cancer if he had \$10,000 to pay for the drugs he would need. George did not believe this claim since this naturopath had not been able to cure his wife's cancer.

George asserted that he had become his own case manager. He was making trade-offs between eradicating the cancer and managing the side-effects of treatments while using his own experience of symptoms and the PSA readings to judge the efficacy of his treatment regime. Although George was content to take responsibility for his treatment decisions he was disturbed about the confusion and contradiction in the information he got from different professionals, from medical and popular health journals, and from the Internet. He tended to trust information from sources with medical affiliations. He did not have any philosophical commitments to alternative medicine. As he said, "Medicine is medicine."

Case #16: Jack

Profile presented in chapter 4.

Case #17: Ranjit

Ranjit was a 60 year old former high school teacher who was diagnosed with stage III ovarian cancer about five years before our interview. She had surgery and had been on chemotherapy for much of the time since her diagnosis. She was receiving palliative chemotherapy at the time of our interview as well as taking a variety of treatments recommended by a local complementary cancer care centre. The CAM treatments she was taking included thymus extract, MGN3, hydrazine sulfate, and various vitamins and other nutritional supplements. Ranjit also had taken part in patient support and relaxation groups. She also found meditation helpful. She believed that the CAM substances she was taking were effective because she felt better after taking them and they seemed to help keep her weight up. This was an important consideration since she had digestive problems and a poor appetite.

Ranjit said that she had no hesitation about exploring CAM when she was told that conventional medicine could not cure her cancer because, as a teacher, she had always been eager to explore new ideas and learn. She did a fair bit of reading about cancer and CAM but she did not search the Internet, since she was weak and lacking in energy. She preferred to go the library at the local cancer clinic when she needed information.

Ranjit wished that the conventional and CAM professionals would talk to each other more, since she believed that both systems have value. She said that the professionals at the local cancer clinic did not talk to her about her use of CAM and this disturbed her. She felt that conventional medicine and CAM were going in two different

directions when they should be working together for the benefit of patients. Although Ranjit thought that CAM treatments should be more integrated into health care, she did not expect Medicare to pay for the treatments she was taking since the system could not pay for everything.

Appendix B: Research Participant Recruitment Material

1. Poster for Cancer Patients to be Interviewed Individually
2. Poster for Group Interview with Cancer Patients

1. Poster for Patients to be interviewed individually

Interested in taking part in Research about the Interface between Conventional and Alternative Treatments for Cancer?

Margo Fryer, a PhD candidate in UBC's Individual Interdisciplinary Studies Graduate Program, is conducting research to examine what is occurring in health care settings and in the lives of patients and professionals as alternative and conventional medicine come together. The research will explore the ways in which both patients and professionals come to see different approaches to healing as worthwhile.

This issue of how the legitimacy of different approaches is determined is central to the current tension between conventional and alternative medicine. The debate about whether and why different approaches to healing are legitimate rests on deeper questions about the role of scientific evidence and other sources of knowledge in people's thinking about health and health care.

The research will be relevant to theoretical issues in the social sciences as well as to critical health policy issues. The research will provide a foundation for health policy formulation by developing new understandings of the experiences and perspectives of cancer patients and professionals.

This PhD dissertation research is being conducted under the supervision of Dr. William McKellin of UBC's Department of Anthropology and Sociology and Dr. Joan Bottorff of UBC's School of Nursing. The research is being supported by a studentship grant from the BC Health Research Foundation.

**If you have used alternative therapies for cancer
or are thinking of using them and
would like to take part in a personal interview
to discuss your perspective and experiences,
or if you would like more information,
please call**

Margo Fryer at

The interview will cover questions such as:

- How did you decide what treatments to undergo?
- What sources of information did you rely on?
- How did your experiences affect your thinking about the value of the treatments?

The information you provide will be kept in strict confidence. The results of the research project will be reported in such a way that individuals cannot be identified.

2. Poster for Group Interview with Cancer Patients

Interested in taking part in a Group Discussion for a Research Project about the Interface between Conventional and Alternative Treatments for Cancer?

Margo Fryer, a PhD candidate in UBC's Individual Interdisciplinary Studies Graduate Program, is conducting research to examine what is occurring in health care settings and in the lives of patients and professionals as alternative and conventional medicine come together. Her research will explore the ways in which both patients and professionals come to see different approaches to healing as worthwhile.

**Margo will be facilitating a group discussion at Hope House on
Thursday, March 16, 2000 from 10:00 to 12:00**

The discussion will focus on three issues:

1. What do you see as the differences between conventional and complementary/alternative medicine? How do you define "alternative and complementary medicine?"
2. What sources of information did you use in the process of making decisions about treatment? What sources of information do you consider to be trustworthy and why?
3. What role does your own personal experience play in your thinking about the value of different treatments? What role does scientific evidence play?

**If you would like to take part in this group discussion,
please let one of the staff members at Hope House
know by Friday March 3.**

The results of the research will be relevant to theoretical issues in the social sciences as well as to critical health policy issues. The research will provide a foundation for health policy formulation by developing new understandings of the experiences and perspectives of cancer patients and professionals. Margo's PhD dissertation research is being conducted under the supervision of Dr. William McKellin of UBC's Department of Anthropology and Sociology and Dr. Joan Bottorff of UBC's School of Nursing. The research is being supported by a studentship grant from the BC Health Research Foundation.

Any information you provide will be kept in strict confidence. The results of the research project will be reported in such a way that individuals cannot be identified.

Appendix C: Consent Forms

1. Patient Consent Form
2. Consent Form for Professionals not associated with B.C. Cancer Agency
3. Consent Form for B.C. Cancer Agency Professionals
4. Consent for Participant–Observation

1. Patient Consent Form

Agreement to Participate in Interview

The Interface between Conventional and Alternative Approaches to Cancer: Research for the PhD Degree, Individual Interdisciplinary Studies

Principal Investigator:

Dr. William McKellin, Anthropology and Sociology

Student Investigator:

Margo Fryer, Individual Interdisciplinary Studies Graduate Program

Margo Fryer, a PhD candidate in UBC's Individual Interdisciplinary Studies Graduate Program, is conducting research to examine what is occurring in health care settings and in the lives of patients and professionals as alternative and conventional medicine converge. The research will explore the ways in which patients and professionals come to see different approaches to healing as legitimate. The research will be relevant to theoretical issues in the social sciences regarding the conferring of legitimacy and the ways in which knowledge is developed. The research will also provide a foundation for health policy formulation by developing new understandings of the experiences and perspectives of patients and professionals. This PhD dissertation research is being conducted under the supervision of Dr. William McKellin of UBC's Department of Anthropology and Sociology, Dr. Joan Bottorff of UBC's School of Nursing, and Dr. Simon Sutcliffe of the BC Cancer Agency.

You are being asked to participate in a personal interview with Ms. Fryer to discuss your experiences with conventional and alternative or complementary therapies and your perspectives on the issues being raised as a result of the growing use of complementary and alternative therapies. The interview will take approximately 60 to 90 minutes.

The information you provide will be kept in strict confidence. Interviews will be tape recorded to ensure that your responses are recorded completely and accurately. The tape recorder will be used only with your permission, and you may ask the researcher to turn the tape recorder off at any time or to erase any previously recorded part of the interview. No information will be provided to others or used in publications that will identify you without your specific written consent.

Your participation in the research is completely voluntary; you are under no obligation to participate. You may decide not to participate, or you may decide to withdraw from the research at any time, or you may choose not to answer particular questions in an interview without this affecting your medical treatment or other health care.

If you have any questions about the research project, now or in the future, you may contact Ms. Fryer at _____ or Dr. Bill McKellin at _____. Your rights to privacy are protected and guaranteed by the *Freedom of Information and Protection of Privacy Act of British Columbia*. This act lays down safeguards respecting your privacy and also gives you the right to access, and if need be, correct, any errors in your personal information. If you have any concerns about your rights or your treatment as a research participant, you may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration at _____

Consent to Participate:

I agree to participate in this research project as outlined above. I understand that my participation is entirely voluntary and that I may choose to withdraw from the study or limit my participation at any time.

I have received a copy of this consent form for my own records.

Signature

Date

Please print name

Witness

2. Consent Form for Professionals not associated with B.C. Cancer Agency

Agreement to Participate in Interview

The Interface between Conventional and Alternative Approaches to Cancer: Research for the PhD Degree, Individual Interdisciplinary Studies

Principal Investigator:

Dr. William McKellin, Anthropology and Sociology

Student Investigator:

Margo Fryer, Individual Interdisciplinary Studies Graduate Program

Margo Fryer, a PhD candidate in UBC's Individual Interdisciplinary Studies Graduate Program, is conducting research to examine what is occurring in health care settings and in the lives of patients and professionals as alternative and conventional medicine converge. The research will explore the ways in which patients and professionals come to see different approaches to healing as legitimate. The research will be relevant to theoretical issues in the social sciences regarding the conferring of legitimacy and the ways in which knowledge is developed. The research will also provide a foundation for health policy formulation by developing new understandings of the experiences and perspectives of patients and professionals. This PhD dissertation research is being conducted under the supervision of Dr. William McKellin of UBC's Department of Anthropology and Sociology, Dr. Joan Bottorff of UBC's School of Nursing, and Dr. Simon Sutcliffe of the BC Cancer Agency.

You are being asked to participate in a personal interview with Ms. Fryer to discuss your experiences with conventional and alternative or complementary therapies and your perspectives on the issues being raised as a result of the growing use of complementary and alternative therapies. The interview will take a maximum of two hours.

The information you provide will be kept in strict confidence. Interviews will be tape recorded to ensure that your responses are recorded completely and accurately: The tape recorder will be used only with your permission, and you may ask the researcher to turn the tape recorder off at any time or to erase any previously recorded part of the interview. The results of the research project will be reported in such a way that individuals cannot be identified.

Your participation in the research is completely voluntary; you are under no obligation to participate. You may decide not to participate, or you may decide to withdraw from the research at any time, or you may choose not to answer particular questions in an interview without this affecting your position within the health care organization where you work.

If you have any questions about the research project, now or in the future, you may contact Ms. Fryer at _____ or Dr. Bill McKellin at _____. Your rights to privacy are protected and guaranteed by the *Freedom of Information and Protection of Privacy Act of British Columbia*. This act lays down safeguards respecting your privacy and also gives you the right to access, and if need be, correct, any errors in your personal information. If you have any concerns about your rights or your treatment as a research participant, you may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration at _____

Consent to Participate:

I agree to participate in this research project as outlined above. I understand that my participation is entirely voluntary and that I may choose to withdraw from the study or limit my participation at any time.

I have received a copy of this consent form for my own records.

Signature

Date

Please print name

Witness

3. Consent Form for B.C. Cancer Agency Professionals

Agreement to Participate in Interview

The Interface between Conventional and Alternative Approaches to Cancer: Research for the PhD Degree, Individual Interdisciplinary Studies

Principal Investigator:

Dr. William McKellin, Anthropology and Sociology

Student Investigator:

Margo Fryer, Individual Interdisciplinary Studies Graduate Program

Margo Fryer, a PhD candidate in UBC's Individual Interdisciplinary Studies Graduate Program, is conducting research to examine what is occurring in health care settings and in the lives of patients and professionals as alternative and conventional medicine converge. The research will explore the ways in which patients and professionals come to see different approaches to healing as legitimate. The research will be relevant to theoretical issues in the social sciences regarding the conferring of legitimacy and the ways in which knowledge is developed. The research will also provide a foundation for health policy formulation by developing new understandings of the experiences and perspectives of patients and professionals. This PhD dissertation research is being conducted under the supervision of Dr. William McKellin of UBC's Department of Anthropology and Sociology, Dr. Joan Bottorff of UBC's School of Nursing, and Dr. Simon Sutcliffe of the BC Cancer Agency.

You are being asked to participate in a personal interview with Ms. Fryer to discuss your experiences with conventional and alternative or complementary therapies and your perspectives on the issues being raised as a result of the growing use of complementary and alternative therapies. The interview will take a maximum of two hours.

The information you provide will be kept in strict confidence. Interviews will be tape recorded to ensure that your responses are recorded completely and accurately. The tape recorder will be used only with your permission, and you may ask the researcher to turn the tape recorder off at any time or to erase any previously recorded part of the interview. The results of the research project will be reported in such a way that individuals cannot be identified.

Your participation in the research is completely voluntary; you are under no obligation to participate. You may decide not to participate, or you may decide to withdraw from the research at any time, or you may choose not to answer particular questions in an interview without this affecting your position within the health care organization where you work.

If you have any questions about the research project, now or in the future, you may contact Ms. Fryer at _____ or Dr. Bill McKellin at _____ or Dr. Simon Sutcliffe of the BC Cancer Agency at _____. Your rights to privacy are protected and guaranteed by the *Freedom of Information and Protection of Privacy Act of British Columbia*. This act lays down safeguards respecting your privacy and also gives you the right to access, and if need be, correct, any errors in your personal information. If you have any concerns about your rights or your treatment as a research participant, you may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration at _____.

Consent to Participate:

I agree to participate in this research project as outlined above. I understand that my participation is entirely voluntary and that I may choose to withdraw from the study or limit my participation at any time.

I have received a copy of this consent form for my own records.

Signature

Date

Please print name

4. Consent for Participant–Observation

Agreement to Permit Participant Observation

The Interface between Conventional and Alternative Approaches to Cancer: Research for the PhD Degree, Individual Interdisciplinary Studies

Principal Investigator:

Dr. William McKellin, Anthropology and Sociology

Student Investigator:

Margo Fryer, Individual Interdisciplinary Studies Graduate Program

Margo Fryer, a PhD candidate in UBC's Individual Interdisciplinary Studies Graduate Program, is conducting research to examine what is occurring in health care settings and in the lives of patients and professionals as alternative and conventional medicine converge. The research will explore the ways in which patients and professionals come to see different approaches to healing as legitimate. The research will be relevant to theoretical issues in the social sciences regarding the conferring of legitimacy and the ways in which knowledge is developed. The research will also provide a foundation for health policy formulation by developing new understandings of the experiences and perspectives of patients and professionals. This PhD dissertation research is being conducted under the supervision of Dr. William McKellin of UBC's Department of Anthropology and Sociology, Dr. Joan Bottorff of UBC's School of Nursing, and Dr. Simon Sutcliffe of the BC Cancer Agency.

You are being asked to give your permission to allow Ms. Fryer to participate in and observe the activities of the group you are involved with. Being present during the activities of the group will enable Ms. Fryer to develop an understanding of what happens in settings where alternative or complementary therapies are being provided or discussed and will enable her to understand the processes through which the legitimacy of different approaches to healing is established. Ms. Fryer will participate in the regular meetings of the group.

The events that occur in the group and any information you or other group members provide will be kept in strict confidence. Ms. Fryer will take notes during or after the activities she participates in, but these notes will not contain the full names of participants. The results of the research project will be reported in such a way that individuals cannot be identified.

Your participation in the research is completely voluntary; you are under no obligation to participate. You may choose not to have Ms. Fryer participate in and observe the activities or events you are involved in, or you may decide to withdraw your permission at any time without this affecting your medical treatment or other health care (if you are a patient) or your position within the health care organization where you work (if you are a health care provider).

If you have any questions about the research project, now or in the future, you may contact Ms. Fryer at _____ or Dr. Bill McKellin at _____. Your rights to privacy are protected and guaranteed by the *Freedom of Information and Protection of Privacy Act of British Columbia*. This act lays down safeguards respecting your privacy and also gives you the right to access, and if need be, correct, any errors in your personal information. If you have any concerns about your rights or your treatment as a research participant, you may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration at _____.

Consent to Participate:

I agree to participate in this research project as outlined above. I understand that my participation is entirely voluntary and that I may choose to withdraw from the study or limit my participation at any time.

I have received a copy of this consent form for my own records.

Signature

Date

Please print name

Appendix D: Schematics Depicting Patient Decision Making

These schematics arrange the primary cultural models and the treatment options considered by patients against a grid of five concentric circles.

These circles represent different spheres of influence. The innermost black circle represents the patient's physical body. The next circle (light grey) represents psychological and other personal influences. Factors in this sphere that are important to each individual patient are listed in the box at the top left of each schematic. Moving outwards, the third circle (dark grey) represents the social network of the patient, including family and friends. The next circle (cross-hatched) represents the health care system, including professional and non-professional healers as well as the popular sector, which includes patient support groups, books about cancer, Internet chat rooms, etc. The last, white circle represents the larger social context, i.e., society.

Sources of influence are named in shaded boxes. Cultural models and injunctions to take certain treatments are in white boxes.

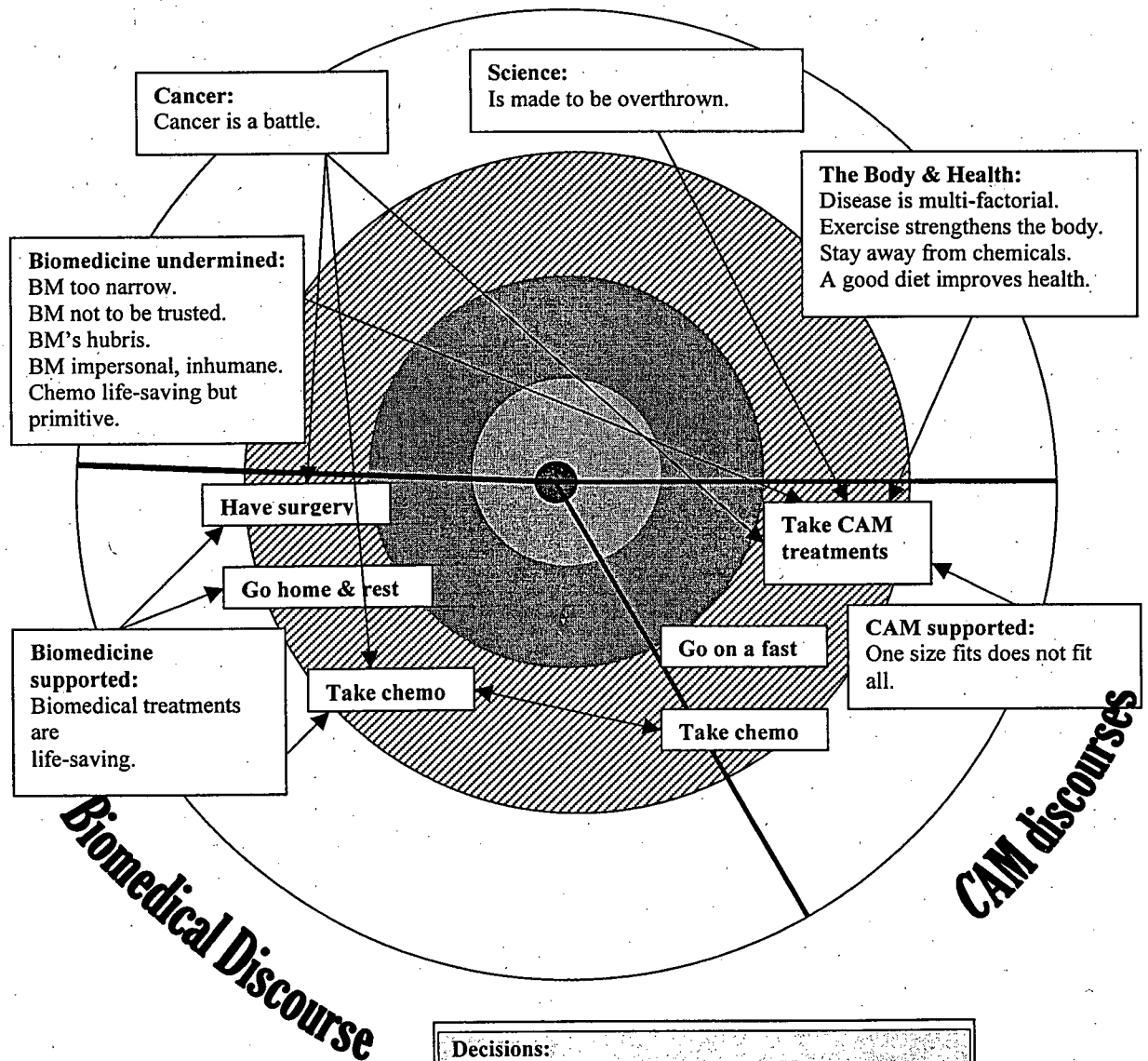
Each schematic is divided into three sections, to represent the discursive spaces of the Biomedical Discourse, CAM discourses, and other public discourses related to health. In the case of different patients, these sections are of different sizes to reflect the patient's degree of allegiance to either CAM discourses or the Biomedical Discourse. For example, in Marcia's case, the area given to CAM discourses is larger than that for the Biomedical Discourse, whereas in Brian's case, the reverse is true.

The arrows denote the direction of influence, e.g., in Joel's case, the models that assert that "biomedical treatments are life-saving" and that "cancer is a battle" point in the direction of taking chemotherapy. Models that have become relatively mainstream about avoiding toxic chemicals point in the direction of taking CAM treatments.

JOEL:

- Poor prognosis, thus high threat.
- Identity: pragmatic, activist, independent thinker, risk-taker.
- Ignorant re cancer.

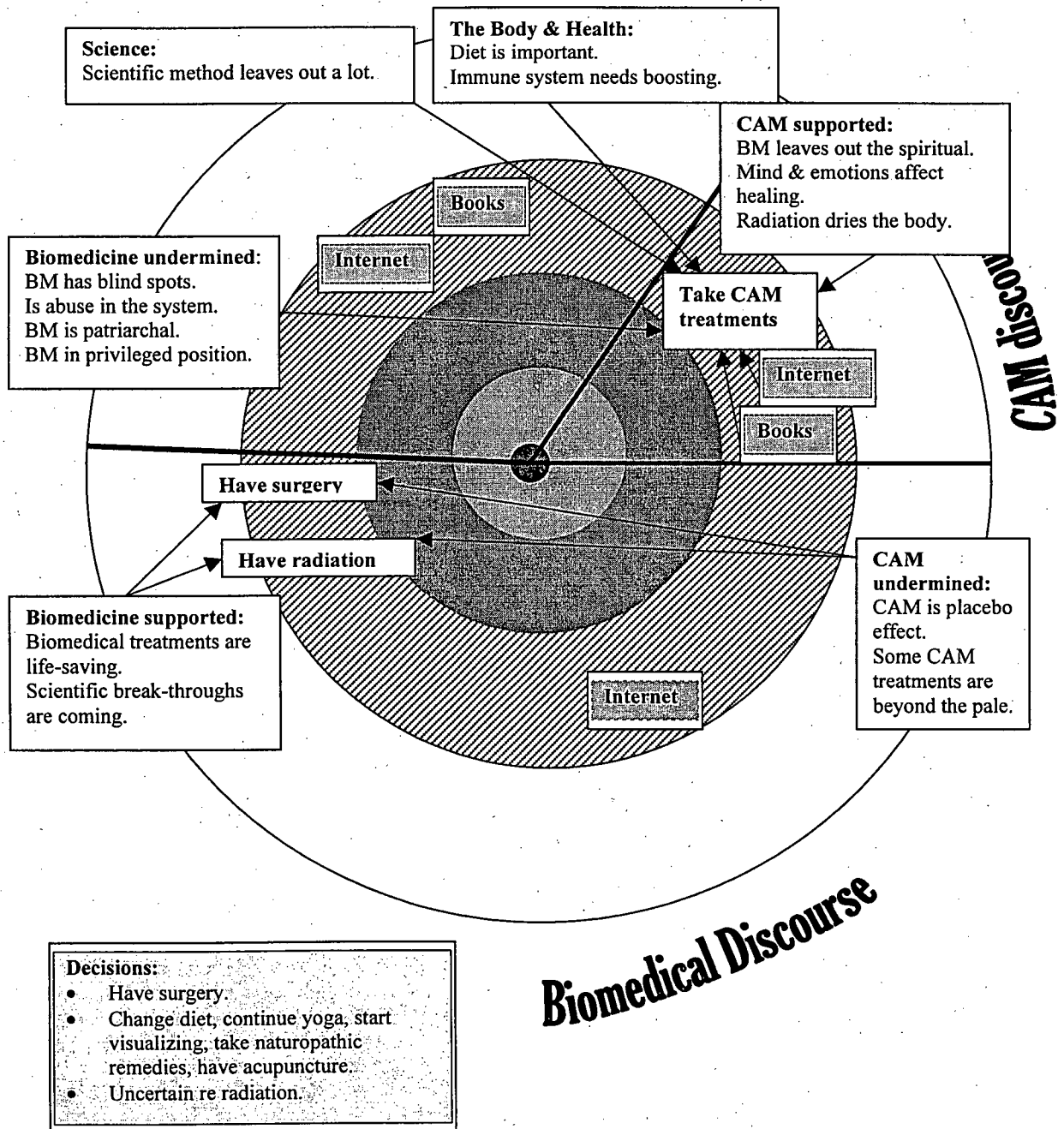
Other discourses



BRIAN:

- High threat from disease & from biomedical treatment side-effects.
- Identity: activist, adventurous, but strong ties to biomedical family.
- Ability to pay for CAM treatments a factor.

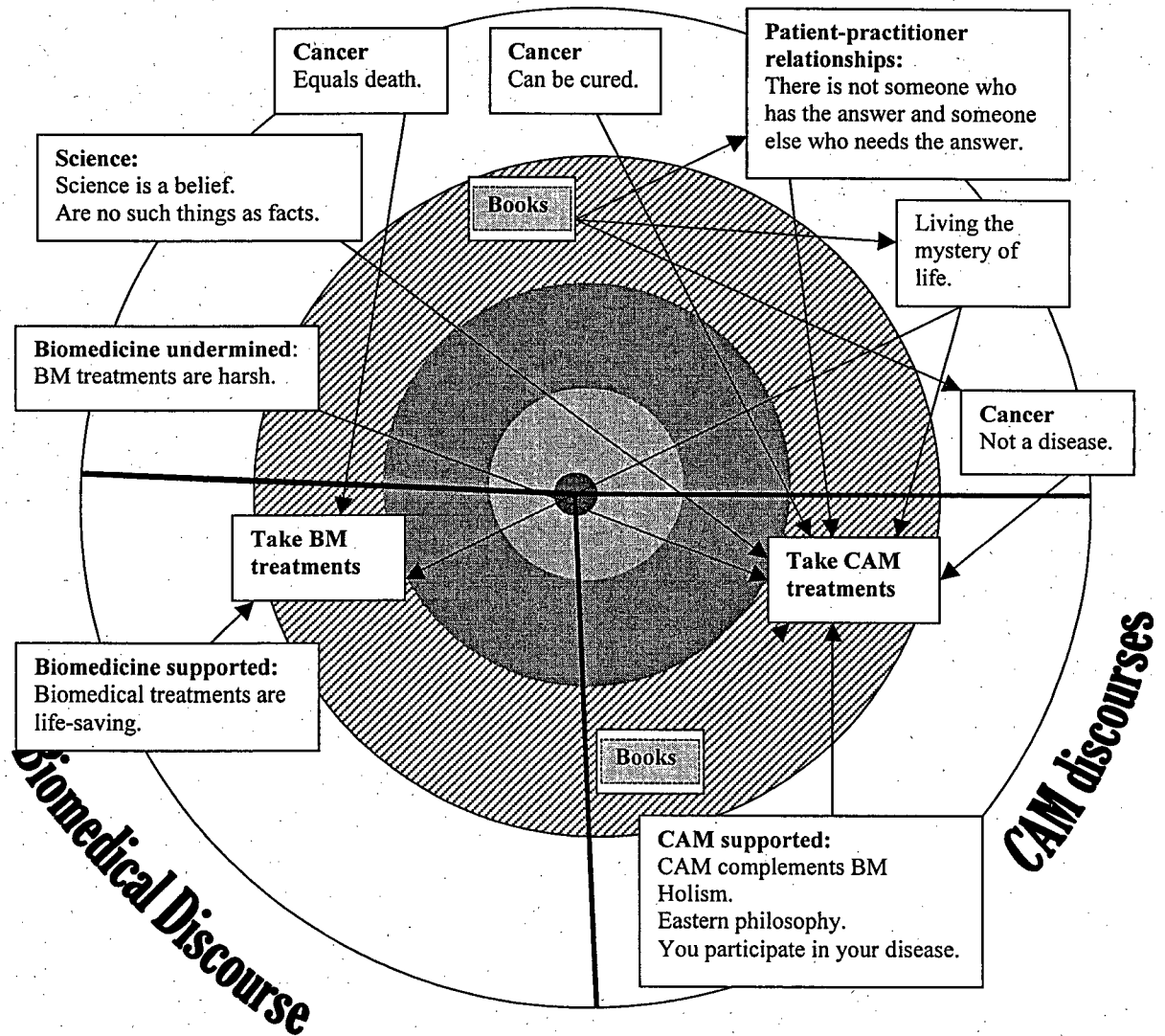
Other discourses



ANGELA:

- Very high threat from disease.
- Identity: counter-culture background, interest in Eastern spirituality, CAM use not new, "I am not my disease."

Other discourses



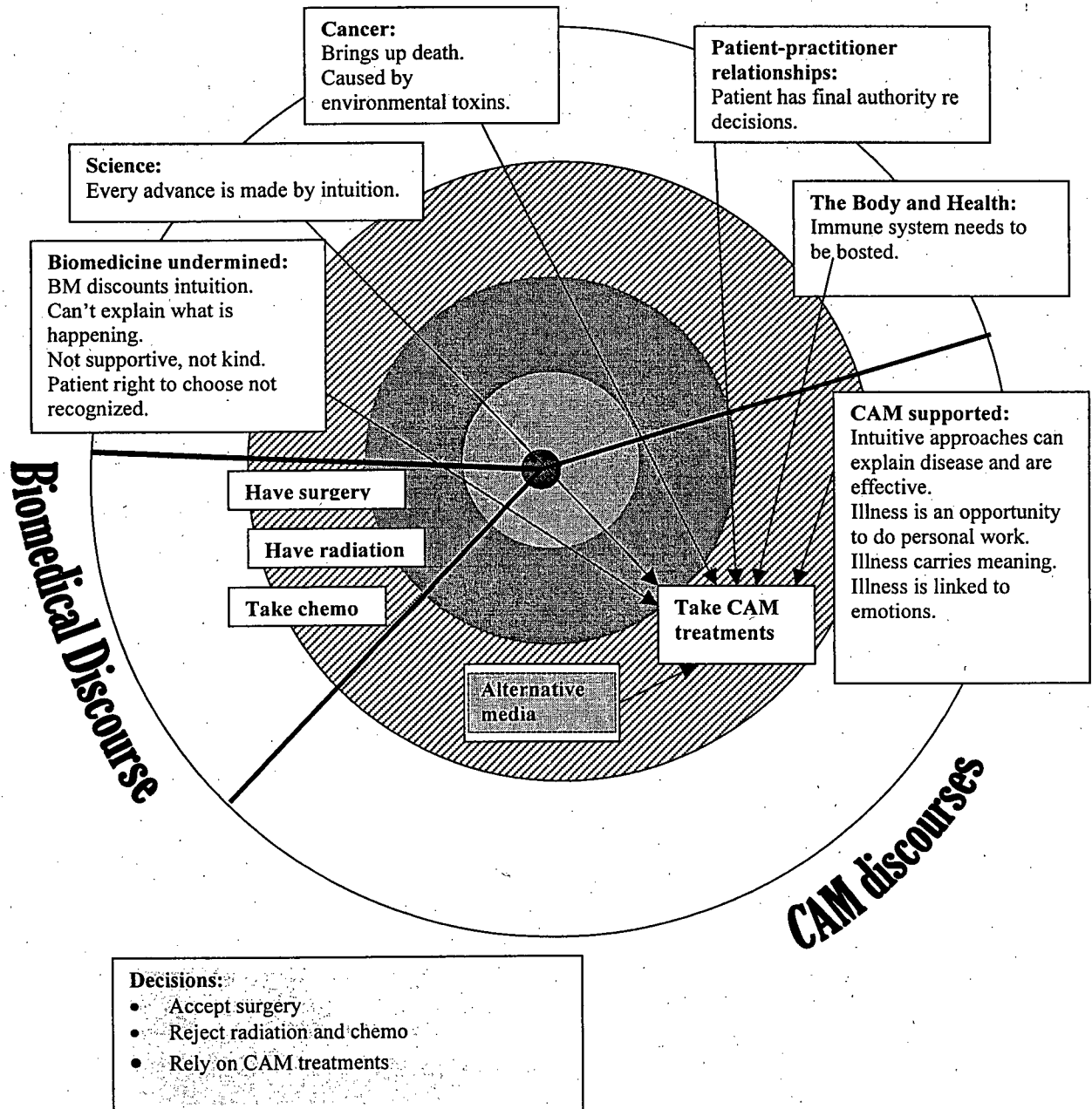
Decisions:

- Use both BM and CAM.
- Respect all equally.

MARCIA:

- High threat from disease; low perceived efficacy of BM.
- Identity: previous use of CAM, allegiance to CAM, personal agency crucial.
- Able to pay for CAM treatment.

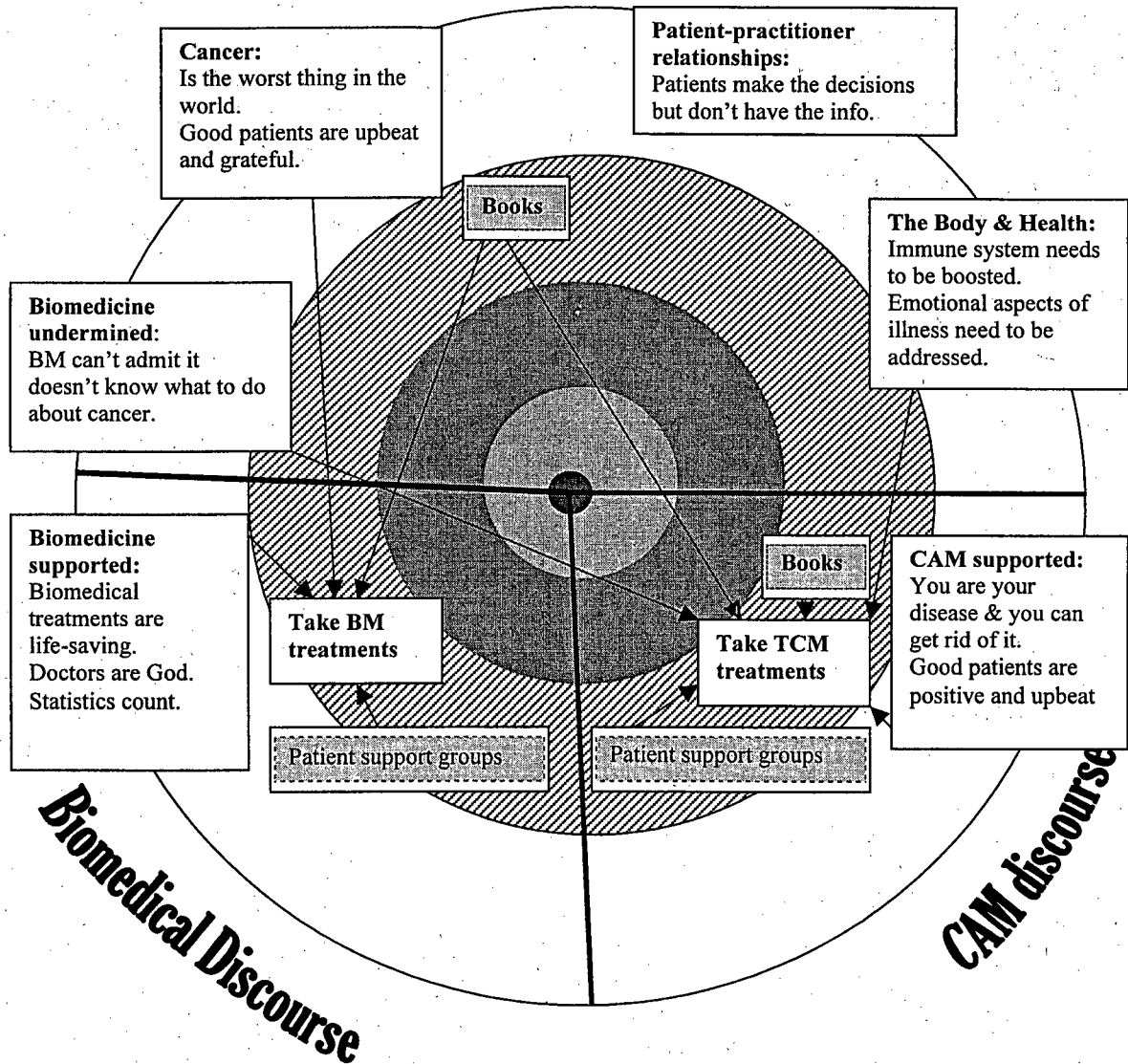
Other discourses



LINDA:

- High threat from disease; moderate threat from BM treatment side-effects.
- Identity: rebellious, pragmatic, TCM use part of culture.
- Cost of CAM prohibited continuance.

Other discourses



Decisions:

- Take BM treatments.
- Take CAM treatments that are affordable.

JACK:

- Threat of disease high; threat of BM treatment side-effects high.
- Identity: mastery, agency important, research/learning as coping style.
- Ignorant re cancer and the health care system.
- Cost of CAM not a barrier.

Other discourses

