

## The 1996 Schering Lecture sponsored by Schering Canada

# An inquiry into the experience of oncology patients who leave biomedicine to use alternate therapies

By Muriel J. Montbriand

### Abstract

*Minimal attention has been given to the experiences of oncology patients who abandon biomedicine to use alternate therapies. This presentation explores the abandonment experience. It also examines this group's emotions, perceived stress, and coping strategies through stress theory. Congruent with past research, these patients tend to be younger, attain higher education, and are interested in changing their health regimens. Analysis suggests that anger precipitates the abandonment and remains a residual force for these patients. While their expressed initial fear of cancer changes to hope with the use of an alternate therapy, the hope for cure seems to be carried to the extremes of illusion and denial of possible death.*

*The study, conducted with a network sample, included individual interviews and a focus group. The value of this ethnography lies in the revelation that a) some similar experiences appear for patients who remain in biomedicine and patients who abandon biomedicine, and b) insights are provided for health professionals wishing to avoid situations of abandonment and wishing to facilitate estranged patients' return to biomedicine.*



The 1996 Schering Lecturer,  
Muriel Montbriand.

### Introduction

I am delighted to have this opportunity to present a recent inquiry into the experiences of oncology patients who leave biomedicine to use alternative therapies. It is my pleasure to introduce this group of individuals to you. There is nothing striking or unusual about them, except, you probably will never (or rarely) meet them in your clinical practice. Your first reaction may be: why is this of interest? It is my impression that these individuals have much to tell about themselves and their experience with biomedicine. Most important, they have much to tell about health professionals.

First, let me provide you with the definition I use for alternate therapies. This definition draws its origins from Kleinman's (1984) Health Care Systems Model and has been consistent with my previous research (Montbriand 1989, 1991, 1993a,b, 1994, 1995a,b). An alternate therapy is any health care practice initiated or prescribed by the patients themselves, by their friends or family, or by an alternate healer. An alternate healer is any health practitioner whose prescriptions are not endorsed by the American or Canadian Medical Associations. A biomedical therapy is any health care practice initiated or prescribed by biomedical health care professionals, working within the jurisdiction of their discipline. The emphasis in this definition is on the prescriber or initiator of the health care.

The individuals I am introducing became estranged from biomedicine and decided to prescribe alternate therapies for themselves, or, they decided to use therapies prescribed by healers. In this discussion I will refer to these individuals as participants or informants, since "informants" is a term suggested for ethnographies (Spradley, 1979).

Ethnographies are only one type of qualitative research. The purpose of an ethnography is to provide the reader with a picture of the informant's experience. Unlike quantitative studies where participants are often called subjects, with the researcher doing research on the subject, in an ethnography the researcher and informant work together. Together, they endeavour to understand and record the informant's story. My intent for this special presentation is first, to provide you with a brief overview of the ethnography; second, to provide the post-analysis through stress theory; and third, to leave you with some insights for clinical practice.

A complete presentation is found elsewhere (Montbriand, in press-a, in press-b)

### The ethnography in brief

The purpose of the ethnography was to understand the experiences of oncology patients who decided to leave biomedicine and treat their cancers with alternate therapies.

My initial introduction to this group occurred during a study with 300 oncology patients in a hospital setting (Montbriand, 1993a). The first informant to come forward was a native Indian woman with cancer of the bowel. I will name her Arlene. (Pseudo names are used for all informants.) Arlene was in hospital for her diabetes. She refused treatment for her bowel cancer, believing herbs from her medicine man had cured the cancer. The second informant (Emma), who was diagnosed with breast cancer, made herself known after hearing about the hospital study. Emma became a key informant, assisting in finding two more participants for the 1992 interviews, gathering a network sample for the focus group in 1995, and maintaining contact over three years. There are eight informants in this ethnography. Letters from the cancer clinic confirmed the diagnosis of all participants except one; this

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participant was a registered nurse who diagnosed her own cervical cancer based on a positive Pap smear.

The 1992 ethnographic interviews were conducted using the protocol described by Spradley (1979) and the 1995 focus group was guided by the instructions of Krueger (1994). Confidentiality was assured, and all data was coded to prevent identification except to the researcher. Rigor for reliability and validity was as advised by Guba and Lincoln (1982) and Goetz and LeCompte (1984); this included member checking, overlap methods, and leaving clear audit trails. Audio tape recording, field notes and memo notes were used for both interviews and focus groups. Research colleagues were involved in peer debriefing sessions. Analysis and interpretation relied on instructions from Lofland and Lofland (1984), Miles and Huberman (1984) and Bogdan and Biklen (1982).

Let me briefly introduce each of the eight informants to you, providing only highlights for each of these interesting individuals.

**Arlene** is the native Indian woman with bowel cancer. She refused all biomedical intervention for her cancer, believing herbs from an Indian medicine man "dried up" her cancer. Arlene's grandfather was a medicine man. During her interview, Arlene described her spiritual beliefs in the Great Creator, Mother Earth, and the healing of the stones. Healing of the stones included descriptions of the sweat lodge experience.

**Matt** died of pancreatic and bowel cancer prior to the interview, but his story was told by his wife, Karen. Matt and his wife searched extensively for help in the alternate system, visiting a Dr. Nieper in Germany, Michio Kushi (founder of the Macrobiotic Diet) in Massachusetts, and the Bahamas for transcendental meditation sessions. Matt's oncologist initially went along with some of Dr. Nieper's therapies, such as Squalamine (shark's liver), carrot juice and high doses of experimental substances. When a rift occurred between Matt and his oncologist, Matt left biomedicine entirely. In Matt's last hours, Karen said she "panicked", called an ambulance and took him to the hospital. When she arrived at the hospital, she also called the Chinese healer, asking him to do acupuncture on her unconscious husband. The healer refused to come.

**Laura**, a university professor, also left biomedicine to receive a cure for her cancer in Dr. Nieper's clinic in Germany. Laura had a recurrence of breast cancer one year prior to her 1992 interview. She described an angry confrontation she had with her oncologist and the cancer clinic nurse on her return from Germany. Her use of alternate therapy also extended into the use of Eastern religions, transcendental meditation, Shiatsu and Mzah.

**Emma** is the key informant, and expressed complete mistrust of biomedicine after experiencing iatrogenic effects and nosocomial infections in past hospital admissions. Three of her sisters had breast cancer: two had biomedical intervention and died; one used only alternate therapies and remains alive. When Emma was diagnosed with breast cancer she had an angry confrontation with her oncologist and left the system. Emma invited me to see her cancer on my first visit; it was irregular, approximately three inches in diameter, red-purple and engulfing the nipple. Even now, Emma continues to deny this cancer, calling it a "spot", or "infection", or sometimes a "lump", and is annoyed by the letters sent from the cancer clinic. Emma uses a modified macrobiotic diet, Blessed Thistle herbal tea, and Bahai prayer for her therapy.

**Pat**, a registered nurse, decided to treat her own cervical cancer after a positive Pap smear. Anger about her parents' experience with cancer and a growing disillusionment with cancer therapies prompted Pat's exit from biomedicine as a patient and as a professional. The Gerson Therapy (a therapy consisting of five coffee enemas per day, vegetarian diet, no salt, no sugar, and organic food from California) was Pat's treatment of choice. Unable to afford even the minimal cost of this therapy, \$30,000, she was able to follow the Gerson regimen prescribed to another cancer patient. This reduced her cost to \$1,000 per month.

The day before **Sylvia** had a radical breast cancer surgery, she met a metaphysical healer (faith healer) who prayed for her cure. The biopsy after her surgery showed no cancer cells, however the doctors assured her this was not unusual and she began radiation therapy. Sylvia was

angry, shocked and confused when she told her story at the focus group. She firmly believed her cancer had been cured by the faith healer. I learned later, she stopped her radiation therapy.

**Tania**, a registered nurse, had breast cancer surgery but refused all further treatment. She not only lost faith in biomedicine but also abandoned her nursing career, saying she could no longer hang all those chemo IVs; she had seen little or no results. Tania's therapy included Shomberg liver cleaning, Barley Green, and psychological-spiritual therapies. Tania felt her "real life" began when she took charge of her health care to use alternate therapies.

**Helen** was a medical lab technician prior to her total radical mastectomy with lymph gland removal. She described her initial reaction to her diagnosis as "fear to the point of nausea". When she awoke from her surgery and realized the "aggressive treatment" (her words) she had received, she was totally overwhelmed with anger, and left biomedicine. No persuasion from her oncologist or her brother-in-law (a medical doctor) could appease her. Helen went to a local healer and received such things as shark cartilage, bowel cleaning reflexology, and organic foods. She left her work as a medical lab technician when she started alternate therapies, describing her experience as a "reality awakening".

Six themes emerged from the data analysis, they are:

- a) expressed stress,
- b) taking control,
- c) social group association,
- d) cost considerations,
- e) mystical insights, and
- f) belief in a cure.

Stress was by far the dominant and pervasive theme in the informants' stories. Anger was the most usual emotion expressed. Most informants described angry confrontations. Arlene, the one native Indian informant, indicated her family encouraged her to keep her anger to herself, but other informants had angry encounters with their physicians. Fear, sadness and depressions were other negative emotions expressed by informants.

The remaining five themes can be understood best through their interconnection with stress. By leaving biomedicine and initiating alternate therapies, informants took **control** of their health care. However, taking control involved responsibility, and responsibility of a personal health care therapy for cancer is stressful. Most informants did not retain the responsibility of being in control. Most gave the responsibility to an alternate healer.

In most cases, the **social group** was instrumental and supportive of the informant's alternative choices; however, this was not the case for Pat, Tania and Helen. Each of these informant's husbands did not support their exit from biomedicine, nor their use of alternative therapies. (Each of these informants were biomedical professionals. They also received no support from biomedical peers.) In all cases, these informants found others who would be supportive.

**Cost** of the alternate therapy was most important for all informants. Informants chose a therapy they could afford. Members of the focus group (Pat, Sylvia, Tania and Helen) believed the Gerson Therapy was the treatment of choice; however, family disagreements about cost were a source of stress. Matt and Karen's alternates cost the most; \$20,000 not including travel. This cost was a hardship for Karen, widowed at age 44 with four children.

Informants sought **mystical insights** in Eastern religions, psychological and spiritual healing as a way of dealing with their stressful situation. Mysticism has a cushioning effect in dealing with the fear associated with the disease, cancer. However, the mysticism was often associated with the alternative system's "new age spirituality", heavily connected with the belief that psychological intervention cures the cancer.

Of interest, each informant chose a different therapy, yet each believed his or her therapy **cured** the cancer. The belief in a cure was sustaining and gave the informants feelings of power and control. However, in the one death, in Matt's case, the belief in cure presented a major difficulty. Karen was not prepared for him to die. Therefore, in review of each emergent theme, stress appeared as a major component.



## Post analysis through Lazarus' cognitive motivational-rational theory

The dominance of the stress variable in the emergent themes seemed to warrant a further investigation of the informants' experiences. After an intensive search, Lazarus' (1991) theory was chosen because of its powerful interpretation of stress as a multidimensional complex rubric. In other words, stress is a dynamic process of change, assessed through a reciprocal interaction between person and environment. An oversimplification of Lazarus' concept of stress is:

- a) each situation is experienced with its distinct meaning;
- b) an emotion is aroused;
- c) the emotion is assessed; ability to cope is assessed;
- d) coping strategy(ies) is(are) implemented;
- e) coping is reassessed.

All this is experienced against the individual's background of social group, resources, constraints, or demands. An emotion is **not** perceived as stress if the individual believes he or she has coped with it well. However, an emotion is perceived as stress when the coping was inadequate. Sometimes, realization that the coping is inadequate occurs much later.

In using Lazarus' (1991) theory, I acknowledge my own frames of reference are imbedded in the interpretation of the informants' stories, and this is only one possible way of interpretation. The emotions identified in the informants' stories were: anger, fear, anxiety, sadness, depression and hope. Of these, the first five are negative emotions. Hope is a positive emotion.

**Anger** was expressed by every informant and was the main reason for leaving biomedicine. An angry confrontation with an oncologist was the most usual situation, however Laura's confrontations were with an oncologist and a nurse. Arlene was an exception. Her family encouraged her not to show her anger and she did not. Informants coped with their anger by (a) leaving biomedicine and (b) searching for information about alternate therapies. Anger appeared to be coped with well and stress did not result. Alternate therapies became the source of help, replacing biomedicine.

However, when an informant had to return to biomedicine for something other than their cancer, it was clear that the anger had only been suppressed. The informant had to become secretive about their alternate therapy and sometimes secretive about their cancer. This happened in three cases:

- a) when Arlene returned to the hospital her herbs were in plain sight yet their names were kept secret. Arlene also kept her anger secret;
- b) when the unconscious Matt returned to hospital, Karen did not give an account of his therapies;
- c) Emma returned to hospital for an x-ray after a fall; she kept her breast cancer secret. While anger seemed to be resolved through leaving biomedicine, all informants spoke angrily about their experiences in biomedicine in their interviews. These interviews were conducted months and sometimes years after their experiences. Therefore, anger was not really coped with. It was kept secret.

According to Lazarus (1991), in highly-charged situations, individuals vacillate between the emotions of anger and fear, and between the coping strategies of attack and escape. Angry at first, the informants attacked or confronted their health professionals. Fearful, they wanted escape. They escaped from biomedicine.

**Anxiety**, according to Lazarus (1991), is vacillation between anger and fear. Anxiety was the emotion displayed most by Sylvia. She was ambivalent. She was cured by the faith healer. Yet, she was fearful about discontinuing the radiation therapy. She was also angry about her radical surgery and reports of no cancer cells. She resolved her anxiety shortly after the focus group by stopping her radiation.

**Sadness and depression** were coped with through withdrawal (again withdrawal from biomedicine). All of the informants spoke of addressing their loss of health or body image through what I called "mystical insights", a main theme in the ethnography. Each one of the informants expressed their ways of coping with all of these negative emotions (anger, fear, anxiety, sadness and depression) through spiritual and mystical insights, many of these are closely associated with the "new age spirituality" part of the alternative system of health care. This again appeared to be an adequate way of coping. In a time of great emotional reaction, such as learning about and dealing with cancer, individuals often feel they need spirituality as a "cushioning" against the blow, and often need spirituality (whether it is an Eastern religion, psychological therapy, or Christianity) to be in touch with their soul. In this sense, mystical insights were positive ways of coping.

Informants also seemed to cope with their negative emotions by replacing them with a positive emotion, **hope**. My initial assessment of this was probably swayed because informants often made statements such as this: "Once I started my (alternate) therapy, I became hopeful". However, my search into theory made me understand that hope is distinguishable from a similar emotion, **optimism**. Hope is more realistic than optimism (Lazarus, 1991; Werbolowsky, 1983). Hope realizes the possible losses but yearns for the best. Optimism ignores possible losses and sees only the best.

Informants dwelt on the favourable odds offered by their alternate therapists and compared them with the much lower odds offered in biomedicine for cancer therapies. I soon realized informants were describing optimism (not hope). I also know from my experience with alternate systems literature and commentaries on it from other professionals (Butler, 1992; Cassileth, 1989), optimism is used extensively to endorse alternate systems. You will recall, one of the main themes for the ethnography was the belief in a cure. Informants sincerely believed they were cured by their alternate therapy. Optimism was the central emotion that sustained this belief of cure. While this coping appeared adequate for most of the informants, in the one case, where death occurred, the coping disintegrated. Matt and Karen did not appear to be prepared for death; as you will recall, Karen "panicked", returned to biomedicine and was abandoned at the end by her alternate healer. It is my impression that the coping strategy used in leaving biomedicine and engaging in alternate therapies was adequate, but only temporarily adequate, and the stress of these individuals' cancer experiences was postponed (in Karen and Matt's case to the time of death).

## Insights for clinical practice

The value of this analysis lies in its similarities to past research and its information for clinicians. First, let me remind you that this ethnography was initiated during a larger study with oncology patients in hospital who used alternate therapy along with their biomedicine.

## Certification exam writing centres

*The following writing centres have been identified for the first Canadian oncology nursing certification exam.*

Edmonton, Calgary, Vancouver, Victoria, Prince George, Winnipeg, Saskatoon, Regina, Yellowknife, Whitehorse, Toronto (east), Toronto (centre), Toronto (West), Hamilton, Ottawa, Barrie, Kitchener, London, Windsor, Oshawa, Kingston, Sudbury, Sault Ste. Marie, Thunder Bay, Cornwall, Belleville, St. Catharines, Montreal, Fredericton, Moncton, Halifax, Sydney, New Glasgow, Charlottetown, St. John's, Corner Brook, Gander.



Themes presented in this ethnography echo the significant variables ( $p < 0.05$  Chi Square) from the larger study (Montbriand, 1993a). These are social group suggestion, desire to be in control, belief in a cure, perceived stress, and cost considerations. Even the use of secrecy as a coping strategy, in this ethnography was found to be statistically significant for participants in the hospital based study (75% of 300 informants did not tell their doctors they were using alternatives [Montbriand, 1993a]). Searching for an alternate therapy was a major strategy for the hospital oncology patients, particularly if they were younger and had attained higher education. The estranged group in this ethnography tended to be younger, had attained education beyond high school and were searching for alternate therapies.

What is the importance of these similarities? Certainly this needs further investigations. More immediately, I see, and I hope you do as well, there is little difference between hospital and estranged patients' experiences. I tend to see patients' experiences on a continuum. In my past research there have been between 80 to 89% of hospital patients using an alternate therapy along with biomedicine. This estranged group represents the extreme end of the continuum; some writers have estimated this group at five per cent (McGinnis, 1990). My belief is that the use of alternate therapies signals a problem for a patient. Something is amiss. In light of this analysis, my first guess would be the problem is unresolved stress. My second guess would be that problems in communication are occurring.


First question to ask yourself: Could improved communication between health professionals and this estranged group have prevented the abandonment? In every situation there was an angry confrontation. Informants described highly-charged emotions, anger, fear to the point of nausea, anxiety, sadness, depression. They also remembered clearly the careless words spoken by health professionals.

The second question to ask yourself: If one of these estranged patients returns to my clinical setting, can I get past the secrecy? How can I restore or repair some of this mistrust? It may be a second chance for you as a nurse to help this individual see biomedicine in a different light.

Another question: How are you as clinical practitioners dealing with iatrogenic and nosocomial experiences of your patients? These were often the underlying resentments that distanced the informants of this ethnography. These informants lost faith in biomedicine.

On a similar note to the last question: Notice again, three of the informants in the ethnography were health professionals. They not only abandoned treatment, but also abandoned their professions because of lack of faith. Do clinicians need a chance to express their mistrust of oncology regimens?

I give you these questions because I have no answers. I also offer them as a challenge. Perhaps the stories of these estranged patients have also prompted questions or issues in your own minds.

I have introduced you to eight oncology patients who have abandoned biomedicine. The main themes of their experiences have been laid before you, with recognition that stress was a predominant theme. Their stories told of desire to be in control, social group influence, cost consideration, mystical insights, and a firm belief in an alternative cure. However, stress analysis showed their emotional attachment to cure through an alternative left informants poorly prepared for possible death. The informants told me their stories, expressing the hope I would tell their experiences to biomedicine practitioners. I hope their stories have given you food for thought. In my mind, the stories are thought-provoking. 

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