

Chapter 7

Patients Who Use Unconventional Cancer Treatments and How They Find Out About Them

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INTRODUCTION

Whether or not they have cancer, most people know that unconventional cancer treatments exist. Most have heard of one or another treatment—from friends, neighbors, relatives, or through the media. A subset of cancer patients, their health care providers, friends, and family, however, actively seek information about these treatments in order to decide whether to try one. Federal agencies, advocacy groups, specialized information services, professional associations, various private sector societies, libraries, hotlines, and others offer an array of information for patients.

Information from a given source is generally either quite encouraging or quite discouraging about unconventional treatments. Advocacy groups and treatment proponents are positive about the treatments. The American Cancer Society (ACS) and the National Cancer Institute (NCI) try to discourage patients from using untested and unproven treatments. A few sources attempt to provide information in a neutral way.

This chapter presents the limited demographic information available about U.S. patients who use unconventional cancer treatments, and examines the ways in which people find out about and decide whether to try an unconventional treatment. Chapter 8 discusses the organizations that provide information on unconventional cancer treatments.

PATIENTS WHO USE UNCONVENTIONAL CANCER TREATMENTS

Patient Characteristics

The published literature on unconventional cancer treatments has often depicted users of these treatments as deviant, poor, marginal persons, hostile to mainstream medicine, mentally unstable, ignorant, gullible, “straw-graspers,” or as uninformed “miracle-seekers” (see, e.g., (104)). These stereotypes generally reflect the opinions of the writers and society, and are not backed by systematic observation. Though scanty, the studies that have

been carried out suggest that the stereotype should be discarded.

In the largest study to date of patients using unconventional cancer treatments, Cassileth and her colleagues at the University of Pennsylvania Cancer Center interviewed more than 600 cancer patients, approximately half of whom were selected because they used unconventional treatments; the other half were patients at the University of Pennsylvania Cancer Center. The patients using unconventional treatments were identified in a variety of ways: through lists of patients associated with clinics or practitioners across the country, direct contact by patients whose practitioners suggested they contact the researchers, referrals by other patients, and publicly available lists of patients associated with a national organization that supports alternative medicine.

In analyzing the results of the survey, Cassileth found that respondents could be sorted into three groups: those receiving conventional treatments exclusively, those who used both conventional and unconventional treatments, and a small group that used unconventional treatments only. Cassileth found that the majority of patients in the study who used unconventional treatments, either exclusively or in addition to conventional treatment, were well educated, and had accepted mainstream medical care before getting cancer (177). In another survey of 79 cancer patients who used a particular unconventional cancer treatment, Immuno-Augmentative Therapy (IAT), Cassileth reported that the patients were younger, better educated, and of higher socioeconomic status than are cancer patients in general (178).

NCI’s Cancer Information Service (CIS) runs a nationwide telephone hotline that provides information on the gamut of questions about cancer, including unconventional treatments. In an analysis of computerized data reporting on more than 10,000 CIS inquiries over a 4-year period, Freimuth found that callers inquiring about unconventional cancer treatments had a higher average level of education than the “average” of all CIS callers (306).

In 1986, Louis Harris & Associates, under contract to the Food and Drug Administration (FDA) and the Department of Health and Human Services (DHHS), surveyed attitudes toward “questionable treatments.” Questions were asked of a national cross-sectional sample of 1,514 adults, including a sample of 297 people who reported a diagnosis of cancer at some time. The survey found that among the surveyed population, including the subgroup with cancer, “college graduates seem more likely than those without a degree to use treatments that are questionable.” The researchers concluded that people who report using “questionable treatments” are generally similar demographically to the whole population of those seeking treatment for particular health reasons (566).

Users of unconventional cancer treatments in the United States cannot be characterized adequately because so little work has been done to find out about them. The few studies discussed here, however, suggest that patients interested in using unconventional cancer treatments are a heterogeneous group, not from one stratum of society.

Patient Attitudes and Motivations

Cancer patients may become interested in unconventional treatments for a variety of reasons. The available data suggest that patients most frequently add unconventional treatments to their mainstream treatment regimens well after their diagnosis and mainstream treatment, and then either continue both or continue only unconventional treatment (177).¹ The experience of CIS suggests that disease progression or recurrence may precipitate or intensify a patient’s interest in unconventional cancer treatments (174). One of the cancer patients who wrote to OTA described her family’s anguish and growing interest in identifying unconventional treatment as her condition worsened on mainstream treatment (733). OTA received a number of similar letters and telephone calls during the course of this assessment. However, many patients seek unconventional treatments after completing mainstream treatment, when they have no evidence of cancer remaining but cannot know whether the treatment was successful for the long term. This section will present factors that may motivate patients at various stages of their

disease to seek information about or use unconventional cancer treatments.

Many patients are motivated to seek unconventional treatments by their desire to live and their fear of death from cancer (395,445). One cancer patient wrote to OTA that she began looking into unconventional cancer treatments in “attempt to move beyond incapacitating fear and panic” (366). While these motivations may contribute significantly to decisions to seek treatment, there are no data to suggest that those who use unconventional cancer treatments are either more fearful or life-loving than other cancer patients. These two factors might equally motivate a cancer patient to seek out or accept mainstream treatment. The limited data available thus far suggest that overcoming fear of illness and death can be viewed as psychological challenges faced by most cancer patients (233,417,713). In this context, use of an unconventional cancer treatment is one of many possible responses.

The desire to mitigate feelings of helplessness and hopelessness may specifically motivate cancer patients to use unconventional treatments. Holland, a psychiatric oncologist, suggests that cancer patients may become vulnerable psychologically when they learn of metastasis or disease progression because it is so difficult to accept a worsened prognosis. She finds that many patients wrestle with the “uncontrollability” of their disease and may experience helplessness and hopelessness, manifested by symptoms of anxiety, depression, or both (408). In this context, Holland observes that exploring unconventional cancer treatments serves to both restore a degree of personal control and offer a perceived antidote to the cause of turmoil. Both the activity required to search for alternative treatments and the fact that most unconventional treatments represent some promise of cure may be irresistible (408).

Some cancer patients may be motivated to use unconventional treatments by their feelings of abandonment or rejection by mainstream physicians during the course of their cancer treatment (395). Both cancer patients and oncologists have commented on how poorly many physicians respond to the intense psychological needs of cancer patients and cope with their own limited success in this arena as healers. Some patients may begin to seek out

¹In Cassileth’s 1984 study of cancer patients, 60 percent of those using unconventional cancer treatments began their use of these at an average of 24 months after beginning conventional treatment.

unconventional treatments when, in the course of their mainstream treatment, they are made to feel like treatment failures, of little interest, or abandoned (410,802).

Patients who use unconventional cancer treatments have cited an undeniable need to “do something” to assure continued survival (366,733). This need was dramatized in the 1988 television movie, “Leap of Faith,” in which lymphoma patient Deborah Ogg sought out several unconventional cancer treatments during a time when she was asymptomatic, her cancer was stable, and no mainstream treatment was recommended. A patient with metastatic lymphoma who wrote to OTA about his use of several unconventional cancer treatments stated, “I felt I had nothing to lose and I just might get some help” (265). Another cancer patient who uses an unconventional cancer treatment wrote to OTA that she began her dedicated search for these treatments at the point when, although her disease was stable, she realized “the limitations of traditional medicine in the treatment of [her] type of cancer” (366).

Little information exists about the attitudes towards mainstream medicine of patients using unconventional cancer treatments. An Australian study (which may or may not be generalizable to U.S. patients) reports that negative views of mainstream medicine are not key factors in most patients’ decisions to use alternative forms of care (260). Another study suggests that a constellation of attitudes, including an opposition to mainstream medicine and acceptance of officially condemned health beliefs, was important to the widespread use of one unconventional cancer treatment, laetrile, in the 1950s and 1960s (931). Holland suggests that patients who have previously relied exclusively on mainstream care may be willing to suspend their usual pattern of disbelief and accept unproven or unconventional treatments when it becomes clear to them that mainstream medical treatment can no longer control the cancer (408).

The belief that unconventional cancer treatments may be useful even if they may not cure cancer is common among users. In one study, 190 cancer patients with metastatic disease were interviewed about their beliefs; only 25 percent indicated that they thought laetrile, vitamins, or special diets could cure cancer, yet 70 percent stated that they would try these forms of treatment if they were available (272).

Similarly, in the 1986 Harris Poll described above, although 90 percent of U.S. cancer patients using questionable treatment methods did not consider it likely that unconventional treatment would “cure” them, a substantial number found them ‘effective.’

GATHERING INFORMATION ABOUT UNCONVENTIONAL CANCER TREATMENTS

Person-to-person contact—word of mouth—is an important way for cancer patients to find out about unconventional treatments, and is cited by many patients as the most persuasive source of information in treatment decisions (55,190,288,365). In an unpublished 1987 survey of cancer patients who use unconventional treatments, a sociology student working with an unconventional cancer treatment advocacy group (the International Association of Cancer Victors and Friends; IACVF) found that “friends” and “the media” were the two most frequent sources for learning about unconventional cancer treatments. Other sources included a large advocacy group (The Cancer Control Society; CCS), family members, physician referral, and incidental exposure to clinic advertisements or brochures (193).

Similarly, the Harris nationwide survey found “word of mouth” the most common method of introduction to unconventional treatments reported by U.S. adults. Although not asked specifically about unconventional cancer treatments, 3 out of 10 users of “questionable products” of all kinds reported that they learned of these from friends or neighbors, and 45 percent of users reported telling others of their experience (566). Cancer patients are likely to feel socially isolated and to some extent unique when they begin to consider alternatives to conventional treatment (365). Person-to-person contact appears to be especially compelling and persuasive in this situation, gaining camaraderie in what was previously seen as a unique problem.

Once the surface is scratched, there is a great deal of supportive information that would encourage patients looking into unconventional cancer treatments. Patients find specific leads from advertisements in the many journals and newsletters published by advocacy organizations (described in ch. 8); at conventions held by some of the larger advocacy groups; and through the anecdotes of clergy, fiends, family members, nurses, physicians, physical therapists, social workers, etc. Others may

get treatment advice and referrals from diverse sources such as fellow cancer patients at mutual aid group meetings, health food store workers (see below), or even wig store personnel. Information referrals may sometimes be obtained through social organizations, e.g., the Singles Club for Live Fooders, based in Hollywood. Some popular books on specific unconventional cancer treatments are available at commercial bookstores, health food stores, and specialized libraries, and these are often suggested to cancer patients.

Some patients take an analytical approach to researching unconventional cancer treatments. Many locate and interview patients already using unconventional treatments. Others may read widely, consult a professional research service, or take a special bus trip to visit unconventional cancer treatment facilities, and then compare features of available treatments.

Health Food Stores

Local health food stores are a major source of information about unconventional cancer treatment. In the 1970s and 1980s, health food stores became common fixtures in many communities. Having started as small businesses selling mostly vitamins and natural foods, health food stores gradually expanded in scope, variety, and number to become providers of a wide range of dietary, cosmetic, and household products. A common thread among many of the stores is an interest in "alternative" health care and its network of services and providers. They provide vitamins and natural foods promoted for general health maintenance, prevention of disease, and often treatment of disease; herbal products and homeopathic preparations for a variety of common ailments; and an array of written materials, including books, pamphlets, and popular health magazines. Health food stores also provide a link to unconventional health services by maintaining bulletin boards for notices about clinics, practitioners, and mail-order products and by referring customers directly to practitioners who use unconventional approaches, including physicians, herbalists, chiropractors, homeopaths, naturopaths, and acupuncturists.

Other than the most popular ones, books and articles about unconventional cancer treatments are relatively difficult to find in public places outside of health food stores. The selection of materials varies widely among different health food stores, however,

depending in part on the nature of the store and local interest in particular treatments.

Health food stores and their employees are thought to be influential in cancer patients' decisions about unconventional treatment, but the evidence in support of this contention is largely anecdotal or conjectural. One exception is a 1983 survey sponsored by the American Council on Science and Health (839), a group that describes its purpose as protecting consumers by providing them with valid scientific information. In that survey, researchers visited or telephoned health food stores in the New York, New Jersey, and Connecticut areas and either asked specific questions about products or presented a set of symptoms and asked for advice. In the one scenario that might relate to cancer treatment, a researcher called 17 stores, stating that, for no apparent reason, she had lost 15 pounds in the past month (a symptom that could result from cancer) and was concerned about losing more. Employees in seven stores recommended that the caller see a physician. Five tried to diagnose the problem, and in nine stores, employees recommended dietary products plus a variety of mineral, vitamin, and other supplements. Two other store employees referred the caller to an herbalist and a naturopath, while a third employee discouraged her from seeing a physician.

In an effort to understand more about the role of health food stores in patients' decisions about unconventional cancer treatments, OTA commissioned a small survey in three cities: Philadelphia, Tucson, and Berkeley (420). In that survey, the graduate student researchers noted the types of available printed material related to cancer treatment and asked for advice about treatment, giving the details of a friend or relative's cancer with which they were familiar. Responses to the researchers differed by store and by city, but in all three cities, health food stores provided links to the alternative cancer treatment network. A pro-alternative, rather than an anti-medicine, attitude prevailed. In general, salespeople were willing to give advice, which included do-it-yourself practices, specific clinics and practitioners, further sources of advice, including referral networks or organizations favorable to alternative medicine, and books, magazines, and pamphlets. No single book, product, or treatment was brought up consistently, however. In addition to literature and products for sale, and the advice of salespeople, informal contact with other patrons and

bulletin board postings offer health food store customers entry into the alternative network.

The OTA survey is in general agreement with the American Council on Science and Health study and the anecdotal information pointing to health food stores as relatively easy places of entry for seeking out alternative cancer treatments. The growth in numbers of health food stores over the past decade suggests that a large portion of the population has easy access to such stores, but we still do not know the number of cancer patients for whom health food stores play an important role.

Mass Media and Books

According to the 1987 Harris poll described previously, most American adults are generally aware that "questionable" or unconventional treatments for cancer and other chronic diseases exist. The media are important sources of information about cancer in general, as was found by a 1978 ACS survey in which the overwhelming majority of respondents described television, newspapers, and radio as their primary sources of information about cancer (548). The airing of a single 15-minute segment of the television show "20/20" in October 1987, entitled "Promise Them Anything," which examined the promotion of unconventional cancer treatments at conventions held by advocacy groups, undoubtedly increased general awareness of unconventional cancer treatments among the estimated viewing audience of 18 million people (670). An example of "unintended publicity" by the media was the press coverage of actor Steve McQueen's use of unconventional treatments before his death from cancer. The total number of inquiries to NCI's Cancer Information Service concerning unconventional treatments—which is a useful marker of public awareness of unconventional cancer treatments—increased substantially during that time (305).

Over the last 3 years, in addition to the "20/20" episode cited above, a major network aired several shows on this topic, concerning individual patients' search for unconventional cancer treatment options, nutritional approaches to cancer treatment, the role of positive thinking in curing cancer, and the phenomena of underground medical cults and health fraud. These shows reached estimated audiences of 7 million, 20 million, 24 million, and 16 million respectively (670).

Occasionally, popular books and movies, such as *Death Be Not Proud*, may contribute to the public's general awareness of unconventional cancer treatments. In some cases, it is not the treatments, but rather the political issues surrounding the availability and evaluation of unconventional cancer treatments that have been the specific subject of both movies and television shows, such as in the AMA Department of Investigation's *Medicine Man* in 1958, the film *Hoxsey: Quacks Who Cure Cancer?* and various radio and television talk shows in 1988 and 1989 (e.g., Morton Downey, Oprah Winfrey, Sally Jesse Raphael, Robert Atkins). As described in the discussion on health food stores, a number of popular books publicize unconventional cancer treatments and are frequently cited by users as their initial source of information.

Although mass media may be the most powerful conduit of cancer information to the public, there are few data to assess their impact or how they may differentially portray mainstream and unconventional cancer treatments. One review suggests media's general handling of cancer to be fairly accurate in content and neutral in tone (307), but others raise concerns about undue sensationalism in reporting on cancer treatments (642). For example, in a recent nationally broadcast television talk show, Stanislaw Burzynski, M. D., developer of "Antineoplastons," and his patient-advocates were both encouraged and applauded by the hostess, with little opportunity allowed for the hastily invited expert in mainstream oncology to discuss her concerns about the treatment's safety and efficacy (729).

Some popular books, such as Glassman's *The Cancer Survivors and How They Did It* (341), and Kushner's *Alternatives: New Developments in the War Against Breast Cancer* (510) make mention of unconventional treatments though not focusing on them. A chapter on unconventional treatments is included in the *Consumer Reports Book, Charting the Journey: The Cancer Survivors' Almanac of Resources* (651). Others, such as Moss' *The Cancer Industry: Unraveling the Politics* (648), and Lerner's *Integral Cancer Therapies* (531), focus on unconventional treatments and place them in a positive light.

DECIDING ABOUT UNCONVENTIONAL CANCER TREATMENTS

As patients obtain information and begin to identify one or more unconventional treatments or approaches with which they feel comfortable, a single, pivotal experience may serve to focus and intensify the decisionmaking process. Several IAT patients, for example, have cited viewing a 1980 television show, "The Establishment Versus Dr. Lawrence Burton" (782), (which reached an estimated audience of 30 million viewers) as pivotal in their decision to investigate and ultimately use IAT. At some point in each cancer patient's research on unconventional treatments, he or she determines that sufficient verbal or written information has been obtained to either accept or reject specific treatments. However, as discussed elsewhere in this report, it is impossible to find published, scientifically valid information on most unconventional cancer treatments.

A cancer patient's personal and financial resources, belief system, and personal style of seeking health care all help to determine which sources of information are used, how information is interpreted, and how treatment decisions are made. As one author points out, patients considering unconventional cancer treatments may use the same lay referral network and go through much the same process of selecting information sources to rely on as they have in their previous health care decisions (54).

In response to written or telephone inquiries, many clinics or proponents send free brochures, published or unpublished articles, newsletters, issues of advocacy journals, or lists of suggested readings, and may offer to send books or more detailed audio-visual materials for a fee. A few clinics also send free audio cassettes or videotapes, lists of treated patients available for contact, or printed patient testimonials. Some clinics do not reply substantively to written or telephone inquiries or may send vaguely worded materials. Some encourage patients to pursue supplemental readings or ask their primary physician to contact the clinic before treatment information is made available (365).

Upon arrival at treatment centers, patients may obtain additional information from their contacts with practitioners and sometimes through informed consent documents. Nonetheless, the written materials sent by proponents and clinics to potential patients early in the information gathering process remain an important source of primary treatment information, often relied upon by patients in assessing and selecting among treatments.

Some factors that patients may consider in deliberating about the use of unconventional cancer treatments are: the nature of the treatment, the testimonies of other patients, claimed benefits, possible risks, expenses, associated discomfort, potential side-effects, philosophy of the provider, required travel, and anticipated difficulties in complying with the regimen (365).