

When Trust in Doctors Erodes, Other Treatments Fill the Void

BENEDICT CAREY *nytimes.com*

A few moments before boarding a plane from Los Angeles to New York in January, Charlene Solomon performed her usual preflight ritual: she chewed a small tablet that contained trace amounts of several herbs, including extracts from daisy and chamomile plants.

Ms. Solomon, 56, said she had no way to know whether the tablet, an herb-based remedy for jet lag, worked as advertised. Researchers have found no evidence that such preparations are effective, and Ms. Solomon knows that most doctors would scoff that she was wasting her money.

Yet she swears by the tablets, as well as other alternative remedies, for reasons she acknowledges are partly psychological.

"I guess I do believe in the power of simply paying attention to your health, which in a way is what I'm doing," said Ms. Solomon, who runs a Web consulting business in Los Angeles. "But I also believe there are simply a lot of unknowns when it comes to staying healthy, and if there's a possibility something will help I'm willing to try it."

Besides, she added, "whatever I'm doing is working, so I'm going to keep doing it."

The most telling evidence of Americans' dissatisfaction with traditional health care is the more than \$27 billion they spend annually on alternative and complementary medicine, according to government estimates. In ways large and small, millions of people are taking active steps to venture outside the mainstream, whether by taking the herbal remedy echinacea for a cold or by placing their last hopes for cancer cure in alternative treatment, as did Coretta Scott King, who died this week at an alternative hospice clinic in Mexico. [Page A3.]

They do not appear to care that there is little, if any, evidence that many of the therapies work. Nor do they seem to mind that alternative therapy practitioners have a fraction of the training mainstream doctors do or that vitamin and herb makers are as profit-driven as drug makers.

This straying from conventional medicine is often rooted in a sense of disappointment, even betrayal, many patients and experts say. When patients see conventional medicine's inadequacies up close -- a misdiagnosis, an intolerable drug, failed surgery, even a dismissive doctor -- many find the experience profoundly disillusioning, or at least eye-opening.

Haggles with insurance providers, conflicting findings from medical studies and news reports of drug makers' covering up product side effects all feed their disaffection, to the point where many people begin to question not only the health care system but also the science behind it. Soon, intuition and the personal experience of friends and family may seem as trustworthy as advice from a doctor in diagnosing an illness or judging a treatment.

Experts say that people with serious medical problems like diabetes or cancer are least likely to take their chances with natural medicine, unless their illness is terminal. Consumers generally know that quackery is widespread in alternative practices, that there is virtually no government oversight of so-called natural remedies and that some treatments, like enemas, can be dangerous.

Still, 48 percent of American adults used at least one alternative or complementary therapy in 2004, up from 42 percent a decade ago, a figure that includes students and retirees, soccer moms and truckers, New Age seekers and religious conservatives. The numbers continue to grow, experts say, for reasons that have as much to do with increasing distrust of mainstream medicine and the psychological appeal of nontraditional approaches as with the therapeutic properties of herbs or other supplements.

"I think there is a powerful element of nostalgia at work for many people, for home remedies -- for what healing is supposed to be -- combined with an idealized vision of what is natural and whole and good," said Dr. Linda Barnes, a medical anthropologist at Boston University School of Medicine.

Dr. Barnes added, "People look around and feel that the conventional system does not measure up, and that something deeper about their well-being is not being addressed at all."

Healthy and Dabbling

Ms. Solomon's first small steps outside the mainstream came in 1991, after she watched her mother die of complications from a hysterectomy.

"I saw doctors struggling to save her," she said. "They were trying really hard, and I have great respect for what they do, but at that point I realized the doctors could only do so much."

She decided then that she needed to take more responsibility for her own health, by eating better, exercising more and seeking out health aids that she thought of as natural, meaning not prescribed by a doctor or developed by a pharmaceutical company.

"I usually stay away from drugs if I can, because the side effects even of cough and cold medicines can be pretty strong," she said.

The herbal preparations she uses, she said, "have no side effects, and the difference in my view is that they help support my own body's natural capability, to fight off disease" rather than treat symptoms.

If these sentiments are present in someone like Ms. Solomon, who regularly consults her internist and describes herself as "pretty mainstream," they run far deeper in millions of other people who use nontraditional therapies more often.

In interviews and surveys, these patients often described prescription drugs as poisons that mostly mask symptoms without improving their underlying cause.

Many extend their suspicions further. In a 2004 study, researchers at the University of Arizona conducted interviews with a group of men and women in Tucson who suffered from chronic arthritis, most of whom regularly used alternative therapies. Those who used alternative methods exclusively valued the treatments on the "rightness of fit" above other factors, and they were inherently skeptical of the health care system.

Distrust in the medical industrial complex, as some patients call it, stems in part from suspicions that insurers warp medical decision making, and in part from the belief that drug companies are out to sell as many drugs as possible, regardless of patients' needs, interviews show.

"I do partly blame the drug companies and the money they make" for the breakdown in trust in the medical system, said Joyce Newman, 74, of Lynnwood Wash., who sees a natural medicine specialist as her primary doctor. "The time when you would listen to your doctor and do whatever he said -- that time is long gone, in my opinion. You have to learn to use your own head."

From here it is a small step to begin doubting medical science. If Western medicine is imperfect and sometimes corrupt, then mainstream doctors may not be the best judge of treatments after all, many patients conclude. People's actual experience -- the personal testimony of friends and family, in particular -- feels more truthful.

To best way to validate this, said Ms. Newman and many others who regularly use nontraditional therapies, is simply to try a remedy "and listen to your own body."

Opting Out

Cynthia Riley effectively opted out of mainstream medicine when it seemed that doctors were not listening to her.

During a nine-year period that ended in 2004, Ms. Riley, 47, visited almost 20 doctors, for a variety of intermittent and strange health complaints: blurred vision, urinary difficulties, balance problems so severe that at times she wobbled like a drunk.

She felt unwell most of the time, but doctors could not figure out what she had.

Each specialist ordered different tests, depending on the symptom, Ms. Riley said, but they were usually rushed and seemed to solicit her views only as a formality.

Undeterred, Ms. Riley, an event planner who lives near New London, Conn., typed out a four-page description of her ordeal, including her suspicion that she suffered from lead poisoning. One neurologist waved the report away as if insulted; another barely skimmed it, she said.

"I remember sitting in one doctor's office and realizing, 'He thinks I'm crazy,' " Ms. Riley said. "I was getting absolutely nowhere in conventional medicine, and I was determined to get to the root of my problems."

Through word of mouth, Ms. Riley heard about Deirdre O'Connor, a naturopath with a thriving practice in nearby Mystic, Conn., and made an appointment.

In recent years, people searching for something outside of conventional medicine have increasingly turned to naturopaths, herbal specialists who must complete a degree that includes some standard medical training in order to be licensed, experts say. Fourteen states, including California and Connecticut, now license naturopaths to practice medicine. Natural medicine groups are pushing for similar legislation in other states, including New York.

Licensed naturopaths can prescribe drugs from an approved list in some states, but have no prescribing rights in others.

Right away, Ms. Riley said, she noticed a difference in the level of service. Before even visiting the office, she received a fat envelope in the mail containing a four-page questionnaire, she said. In addition to asking detailed questions about medical history -- standard information -- it asked about energy level, foods she craved, sensitivity to weather and self-image: "Please list adjectives that describe you," read one item.

"It felt right, from the beginning," Ms. Riley said.

Her first visit lasted an hour and a half, and Ms. O'Connor, the naturopath, agreed that metal exposure was a possible cause of her symptoms. It emerged in their interview that Ms. Riley had worked in the steel industry, and tests of her hair and urine showed elevated levels of both lead and mercury, Ms. O'Connor said.

After taking a combination of herbs, vitamins and regular doses of a drug called dimercaptosuccinic acid, or DMSA, to treat lead poisoning, Ms. Riley said, she began to feel better, and the symptoms subsided.

Along the way, Ms. O'Connor explained the treatments to Ms. Riley, sometimes using drawings, and called her patient regularly to check in, especially during the first few months, Ms. Riley said.

Other doctors said they could not comment on Ms. Riley's case because they had not examined her. Researchers who specialize in lead poisoning say that it is rare in adults but that it can cause neurological symptoms and bladder problems and is often missed by primary care doctors.

Dr. Herbert Needleman, a psychiatrist who directs the lead research group at the University of Pittsburgh, said DMSA was the pharmaceutical treatment of choice for high blood lead levels.

Researchers say there is little or no evidence that vitamins or herbs can relieve symptoms like Ms. Riley's. Still, she said, "I look and feel better than I have in years."

Life and Death

Diane Paradise bet her life on the uncertain benefits of natural medicine, after being burned physically and emotionally by conventional doctors.

In 1995, doctors told Ms. Paradise, now 35, that she had Hodgkin's disease. After a six-month course of chemotherapy and radiation, she said, she was declared cancer free, and she remained healthy for five years.

But in 2001 the cancer reappeared, more advanced, and her doctors recommended a 10-month course of drugs and radiation, plus a marrow transplant, she said.

Ms. Paradise, a marketing consultant in Rochester, N.Y., balked.

"I was burned badly the first time around, third-degree burns, and now they were talking about 10 months," she said in an interview, "and they were giving me no guarantees; they said it was experimental. That's when I started looking around. I really had nothing to lose, and I was focused on quality of life at that point, not quantity."

When she told one of her doctors that she was considering an alternative treatment in Arizona, the man exploded, she said.

"His exact words were, 'That's not treatment, that's a vacation -- you're wasting your time!' " she said.

And so ended the relationship. With help from friends, Ms. Paradise raised about \$40,000 to pay for the Arizona clinic's treatment, plus living expenses while there.

"I had absolutely no scientific reason for choosing this route, none," she said. "I just think there are times in our life when we are asked to make decisions based on our intuition, on our gut instinct, not based on evidence put in front of us, and for me this was one of those moments."

Cancer researchers say that there is no evidence that vitamins, herbs or other alternative therapies can cure cancer, and they caution that some regimens may worsen the disease.

But Ms. Paradise said that her relationship with the natural medicine specialist in Arizona had been collaborative and that she had felt "more empowered, more involved" in the treatment plan, which included large doses of vitamins, as well as changes in diet and sleep routines. After four months on the regimen, she said, she felt much better.

But the cancer was not cured. It has resurfaced recently and spread, and this time Ms. Paradise has started an experimental treatment with an oncologist in New York.

She is complementing this treatment, she said, with another course of alternative therapy in Arizona. She moved in with friends near Phoenix and started the alternative regime in January.

"It's 79 degrees and beautiful here," she said by phone in mid-January. "Let's hope that's a good sign."

For all their suspicions and questions about conventional medicine, those who venture outside the mainstream tend to have one thing in abundance, experts say: hope. In a 1998 survey of more than 1,000 adults from around the country, researchers found that having an interest in "personal growth or spirituality" predicted alternative medicine use.

Nontraditional healers know this, and they often offer some spiritual element in their practice, if they think it is appropriate. David Wood, a naturopath who with his wife, Cheryl, runs a large, Christian-oriented practice in Lynnwood, Wash., said he treated patients of all faiths.

"We pray with patients, with their permission," said Mr. Wood, who also works with local medical doctors when necessary. "If patients would not like us to pray for them, we don't, but it's there if needed."

He added, "Our goal here is to help people get really well, not merely free of symptoms."

That is exactly the sentiment that many Americans say they feel is missing from conventional medicine. Whatever the benefits and risks of its many concoctions and methods, alternative medicine offers them at least the promise of affectionate care, unhurried service, freedom from prescription drug side effects and the potential for feeling not just better but also spiritually recharged.

"I don't hate doctors or anything," Ms. Newman said. "I just know they can make mistakes, and so often they refer you on to see another doctor, and another."

Seeing a naturopath, she said, "I feel I'm known, they see me as a whole person, they listen to what I say."