The Politics of Medical Research

The Globe and Mail, January 14, 1993, carried a major story about a new treatment for thalassemia and possibly for sickle cell anemia. The story was based on a report published in the New England Journal of Medicine, dated January 14, 1993. It stated "The experimental medication has shown remarkable promise in the fight against the potentially fatal genetic blood disorder and also may prove effective against sickle-cell anemia." It described the response of a patient who had severe complications from thalassemia, including sores that would not heal and rapidly diminishing eyesight. After a few months treatment she was greatly improved and was no longer in any danger of dying. Dr. Nancy Olivieri, Hospital for Sick Children, Toronto, was very impressed and described it as a treatment with enormous potential. More than 180 million people worldwide suffer from this inherited condition. The drug was arginine butyrate. Arginine is an amino acid and butyrate is a short chain fatty acid found in fairly high amounts in butter. The new compound is an Orthomolecular substance and is non-toxic. It was remarkably free of side effects. But it had to be given intravenously. Five other patients in the USA were given the same compound, three with sickle cell anemia. They had not been on the compound very long and the response so far was not dramatic. This finding may, in fact, be extremely valuable. It was given massive public exposure even though it is highly unlikely it will become available for treating patients for many years, unless it is found that high doses of simple butyrates given by mouth are also effective. This discovery and the way it was dealt with, is in sharp contrast with another finding made in Canada which received different treatment.

Idiopathic thrombocytopenic purpura, ITP, is another common disease caused by the immune destruction of platelets. The treatments available for this condition include corticosteroids, splenectomy, immunosuppressive drugs, vinca alkaloids, danazol or intravenous gammaglobulin. They are all helpful for some patients but they are accompanied by peripheral neuropathy, cytopenia and immuno suppression (meaning they are now much more susceptible to infections, etc.). Only 12 percent of patients given hormones are successfully treated for long periods of time. Failures are usually given a splenectomy and about 80 percent of this group are helped. With failures the other treatments are used which achieve a 20 to 50% response rate. ITP is thus a very difficult disease to treat with a large number of failures even after heroic measures. About five years ago a group of physicians from the Royal Victoria Hospital, McGill University, found that ascorbic acid was much more therapeutic than any of these treatments. Their research followed a report from one of their treatment failures that she had been taking this vitamin, 1 gram per day, and her platelet count had remained normal. After eight patients were treated, the chief investigator prepared a paper which was submitted to the New England Journal of Medicine. But it was rejected. I suspect it was rejected because at that time the Journal was in the midst of a private battle with Linus Pauling over his claim that ascorbic acid was helpful to patients with cancer. I suspect their stated reason for rejecting was that it was not done double blind. In any event, since the paper was not published, it did not exist as a finding, for no finding can be considered research completed until it has been published and brought to the attention of the medical world. Eventually Borch, Howson-Jan, and Fauser (1988) had their findings published. There they reported that out of 11 patients studied who had been resistant to some or all of the usual therapeutic procedures, platelet counts improved in eight when placed upon vitamin C, 2 grams daily. A few months after I became aware of this finding I placed one patient with untreatable ITP on ascorbic acid. She has been well since except for a few months when she went off the ascorbic acid. On this vitamin her platelets are about 450, off the vitamin they decrease to under 100.

The British Journal of Haematology does not carry the clout of the New England Journal of Medicine and so far I have not seen any publicity given to this very important finding which can be enormously helpful to all the
patients now suffering from ITP. I would be very surprised, even astonished, if any of the major news media have science reporters who routinely scan this journal.

Let us examine these two events more carefully in the table below.

This brief history illustrates the enormous power held by establishment journals and their referees to disseminate and to withhold information that can be enormously helpful to sick people. Vitamin C is so safe that the publication in the New England Journal of Medicine could not have caused any difficulty for patients who might want to treat themselves by taking small amounts of vitamin C, i.e. 3 grams per day or less. The vast majority of patients with ITP would have been helped and a small number would not have been. But the latter group would have been given benefits from the therapeutic effects of ascorbic acid administration such as decreasing the frequency of colds, decreasing the possibility of coronary disease and so on. The N.E.J.M. and its referees may congratulate themselves for having held back a discovery they consider not well proven. What they have done is held back a treatment which meant life or death to many patients.

References

<table>
<thead>
<tr>
<th>Disease</th>
<th>Politically correct</th>
<th>Not politically correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thallassemia</td>
<td>Transfusions with red blood cells, monthly</td>
<td>Steroids, splenectomy, vinca alkaloids, immunosuppressants, gammaglobulin</td>
</tr>
<tr>
<td>Erratic, partial</td>
<td>Accumulation of iron and iron toxicity.</td>
<td>Erratic, partial</td>
</tr>
<tr>
<td>Arginine butyrate</td>
<td>In the future, probably as a patented drug, therefore expensive</td>
<td>Vitamin C</td>
</tr>
<tr>
<td>Yes, now, no patent.</td>
<td>No prescription needed.</td>
<td>British J. Haematology</td>
</tr>
<tr>
<td>New England J. Med.</td>
<td>Widespread</td>
<td>None</td>
</tr>
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Alternative Medicine Liberated in a Second State

In 1992 the State of Washington passed House Bill #1960 which states "The use of nontraditional treatment by itself shall not constitute unprofessional conduct, provided that it does not result in injury to a patient or create an unreasonable risk that a patient may be harmed." Perhaps we might see a counterclockwise move of similar legislation in the U.S.A., i.e. from Alaska to Washington, to Oregon, to California and so on. In the first two states physicians are free to treat their patients using their best judgement. No longer need they be afraid they will lose their license if they think the best treatment includes alternative treatment, or better still, complementary treatments such as vitamins, minerals in optimum amounts. They will be free to use intravenous vitamins if in their judgement it is indicated, and chelation treatment for these treatments are generally safer than all treatments using xenobiotics. They may practice Orthomolecular medicine, or Orthomolecular psychiatry, or clinical ecology.

Recently a friend wrote to the Minister of Health, for the Province of B.C. requesting that the Minister consider the introduction of similar legislation. He replied that in his view such legislation was not necessary for "It is the policy of the College of Physicians and Surgeons of British Columbia to not initiate disciplinary proceedings against a physician who is practicing
an alternate form of therapy if there is no evidence of harm suffered by the patient as a result of the alternative therapy and if the patient has been advised fully of the nature of the alternate therapy, the risks associated with such therapy and of the conventional methods of therapy available."

My friend informed the College of the Minister's statement and requested the College confirm that the Minister had correctly described their policy. In two replies to my friend this reassurance was carefully avoided.

Perhaps the Minister is correct even though the College refuses to confirm his interpretation. But physicians in B.C. do believe that this is their policy. Thus they believe that it is dangerous to step out of line, for example by giving patients intravenous vitamin C. The perception they will be exposed to College censure has been reinforced by a recent action of the College.

The College announced that it was going to investigate a couple of Vancouver physicians who were giving chelation therapy, a treatment which is helpful for several conditions and which is remarkably safe. The physicians fought back by suing the College of Physicians and Surgeons in the Supreme Court of British Columbia.

April 11, 1991 the College informed these two doctors that they would be investigated. The College had passed the following resolution:

"Resolved that Dr. xxxxxxx be summarily investigated under Section 50(4) of the Medical Practitioners Act with respect to the use of chelation therapy in his practice and that Dr. xxxxxxx and Mr. xxxxxxx be appointed to conduct such investigation." The letter to the doctors informed them that these investigators would visit their offices on April 18, 1991.

The doctor's claim was for general and punitive damages against the Defendants and each of them for defamation as a result of libel and slander and slander unlawfully committed by the Defendants and each of them in their intentional, deliberate and irresponsible acts which resulted in the passing of a Resolution on the 17th day of January, 1991, and from their subsequent embarking on a course of conduct in commencing investigatory procedures against the Plaintiffs and each of them; and for costs.

One doctor is quoted in the Vancouver Sun, Tuesday, April 23, 1991. "There is no law against doing chelation therapy. The College is coming to investigate us under a section which has to do with infamous conduct, and that essentially questions our professional calling. The charges are quite serious and it's not something that you want to have on your record or your reputation." One doctor said he had not been told of any patient complaints regarding the therapy. He said the College is trying to make an example of them as a warning to other physicians considering chelation. "We were concerned that they were coming on a general witch hunt to our offices and just looking for things that they might find that they might be able to criticize us for and might lever us into quitting chelation therapy." The College Registrar said the inquiry was called because of concerns about potential hazards.

I think the College should have initiated a scientific inquiry but not by attacking two doctors. A scientific committee could have been set up which would have reviewed the literature and which would have called as witnesses practitioners of chelation therapy. They could also have called critics of these treatments to tell them why they were opposed to it and upon what evidence, whether in the medical literature or from their own clinical experience, they had come to their negative conclusions.

It is clear that the College has not adopted the enlightened position of the Minister of Health and that was why they could not come forth with a straightforward answer to my friend. It is clear to me that the freedom of doctors to practise medicine as they see fit provided that they do not harm their patients must be enshrined in legislation here as it has been in Alaska and in Washington.

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