THE PROBLEMS WITH TESTIMONIALS

Patient stories can provide encouragement and sometimes important lessons.

Testimonials, on the other hand, are stories put forth as "evidence" that an action led to an outcome.

The intent is to persuade and promote a medical practice, often one that is not yet proven:

"I did this, and benefited. If you do this you can benefit too."

A testimonial can be a form of practicing medicine when the goal is to influence others on how to treat disease.

Testimonials cannot inform about:

- **Rates of benefit or risk in others** - if the outcome could be reproduced at all?

  Having no denominator (1/?) a testimonial cannot provide even an estimate of benefit or risk for others.

  Clinical studies have predefined study population, providing response and adverse event rates (such as 100/300).

- The **number** of persons who used an intervention and did not benefit, or were harmed.

  - Compare with peer-review clinical trial where outcomes are measured uniformly – and, prior to marketing approval must be reviewed independently by FDA.

- The **authenticity** of the report, and its accuracy

  Can we know if the person really has the condition? Is honest or knows the truth?

- The **biases** of the individual reporting his case as evidence

  Is there a financial conflict of interest? Do they also sell the product or charge a fee for dispensing the information?

  Is the testimonial a way of validating their personal decision process and theories?

- The **natural course of the disease**

  Can it, like indolent lymphoma, wax and wane without intervention?

  Did the intervention cause the outcome, or was it coincidental?

  Even for cancers with a very poor prognosis there are case reports in the literature of spontaneous remissions, independent of any intervention.

  People sometimes win the lottery, but this does not mean that playing the lottery is a good bet – particularly when betting your life.

- How the **outcomes** were measured

  Was it an objectively measured response, or a patient reported outcome? Was it subjective: that the patient felt better?

  Did the response lead to a lasting clinical benefit?

- What **other medical treatments** were given shortly before or after?

  A CT scan will often show lesions after standard treatment that is necrotic scar tissue. Credit might be given to an alternative practice used after this treatment, when it was merely the resolution of a scar tissue, a normal process.

- The **accuracy of the diagnosis**

  Was it a false diagnosis of a cancer?

Testimonials *do not deserve our trust –should instead be regarded with suspicion.*

Reproducibility *is the cornerstone of medical progress and sound decision-making.*

RED FLAGS

Signals that a promotion of a cancer treatment is not reputable:

- The treatment is for **ALL cancers**
- **CURES** cancer and other diseases
- No side effects
- **CONSPIRACY** is used to explain why it is not mainstream
- Doctor's **PRESCRIPTION NOT required**
- Relies on TESTIMONIALS
- There is **NO INDEPENDENT REVIEW** by FDA, or a similar independent regulatory agency
- The clinical data is **NOT PUBLISHED** IN RESPECTED JOURNALS
- There is only **ONE GROUP** promoting the product or service – the group that is selling it
- The scientific evidence is **PRECLINICAL** - does not involve human subjects
- It's ALL NATURAL. Natural does not mean non-toxic or better. The Natural Products Branch of NCI screens natural compounds searching for new cancer drugs. Taxol, Vincristine, and Etoposide, mainstream cancer drugs, are examples of drugs derived from plants.

CONSPIRACY THEORY?

That secret cures are hidden from the public because of a conspiracy is just not credible because

… scientists, regulators, politicians, medical doctors, and their loved ones also get cancer.

Are we to believe that all professionals around the globe are involved in a conspiracy – and

would not the diagnosis of cancer in the child of a "conspirator" not force the parent to relent and to go public? Would this not happen often?

LIMITATIONS OF PRECLINICAL EVIDENCE

ASK: Was the anti-cancer activity detected in a test tube (in-vitro) experiment?

The human body is infinitely more complex than a test tube.

- The tumor cells change rapidly when removed from the body; and may even die spontaneously.

Nevertheless, activity in a test tube can become the basis for inappropriate supplement claims.

You might ask if the dose which produced the in-vitro effect is possible to achieve in the body, or if it can it be achieved safely?

Further, is the active compound absorbed in the blood, or merely excreted? - Is it bioavailable?

The PROBLEMS with Testimonials

"For many centuries doctors used leeches and lancets to relieve patients of their blood. They KNEW bloodletting worked.

EVERYBODY said it did. When you had a fever and the doctor bled you, you got better.

EVERYONE knew of a friend or relative who had been at death's door until bloodletting cured him. Doctors could recount thousands of successful cases."