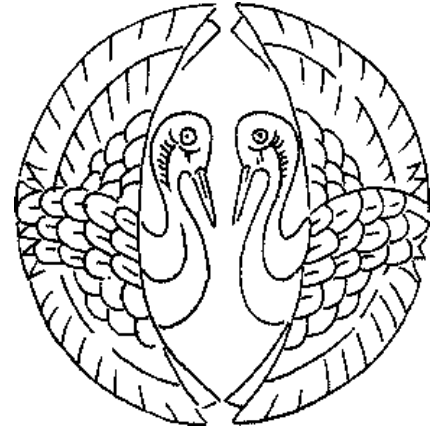




Commentaries

Political Correctness Is Unethical



I proposed a study to a national research group I belong to. I wished to collect reports from the study group members (doctors, nurses and associated personnel), on their Parkinson's patients' most interesting and educational descriptions of hallucinations, delusions and compulsions. These are quite fascinating to medical and non-medical people, particularly to people with personal experience with PD, both patients and subjects. They also help us to understand and care for patients. Finally, the reports provide opportunities for learning about the biochemistry or pharmacology of these phenomena.

So I asked to be allowed to send out an e-mail solicitation asking for these vignettes. My goal, stated in the mailing, was to compile the most illustrative and interesting reports, and publish them in both a medical journal and in the PD lay organization press. My research group agreed, but one administrator wisely asked if I had obtained **Institutional Review Board (IRB)** approval. Without it, she opined, the report may not be publishable. I was dumbstruck. Why didn't I think of something so ridiculous? Actually I thought that if the vignettes were not identified with the contributor, there would be no way to connect an anecdote with a location, let alone an individual, so that privacy could not possibly be an issue.

I contacted the editor of one of the journals I thought I might submit this article to and learned that the journal would indeed require an IRB approved exemption. That is, the journal would require an IRB to officially review my proposal and attest, in writing, that I did not need to obtain written informed consent to ask for this information.

I am not sure who would issue the consent if it was required. The patient or the informant? How this private health information could conceivably threaten the privacy of any individual is beyond me.

I am reminded of an issue of the *New England Journal of Medicine* many years ago when a case report was published and the person who was the subject of this anonymous report published a letter to the editor in the journal complaining about his privacy being violated, not noticing that his letter was the communication which unmasked his anonymity. Since the report came from Michigan, not a small place like Rhode Island where an unusual illness might be a source for identification, this made little sense, although one can argue that cases so unusual as to merit publication in the *New England Journal* may, in fact, allow easy identification.

In the case of journals, I think this type of policy is a disservice. It avoids taking responsibility for projects which are clearly ethical, and makes the pursuit of medical knowledge an almost adversarial enterprise, as if any project, no matter how removed from identifiable information, is a potential violation of HIPAA. It is a policy that extends our unmatched fervor for pursuing and defending against litigation to the research field.

If I think that a medicine causes a particular side effect I am bound to ask about it. Not to ask about it would constitute a form of malpractice. If, on the other hand, I wish to prove that this association is real, and keep track of how many of my patients who take this medication experience this side effect, I would not be able to publish the result in many national journals without getting approval from an IRB, an enterprise that takes both time and money. This is not simply silly, as in the true example I began this article with. It is unethical. It is malpractice to the larger community. Yet no one, so far as I am aware, has complained about it.

Medical journals belong to the medical societies they emanate from, or to the publishing houses which eke out their tiny profits. It is up to the readers

of the latter journals and the members of the societies to try to take back the journals from their mindless insistence on political correctness in the form of a mistaken belief that IRBs must provide an ethical seal of approval for any project. The only reason to think that an IRB provides any higher degree of ethical scrutiny than a journal's board of editors is that the lay public and religious organizations often have representatives on IRB panels. While these non-specialists provide a different point of view, there is little reason to think these views are required in many cases.

I propose that all medical journals only require IRB approval when there are privacy or ethical considerations. The reader will think this is obvious and merely constitutes common sense, because it does. Unfortunately, this is a dose of medicine that our academic journals appear to need.

— JOSEPH H. FRIEDMAN, MD

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