

A Father's Reflections on Windhorse and Mental Health Care

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Introduction and Acknowledgement

"I believe the greatest gift I can conceive of having from anyone is to be seen, heard, understood and touched by them. The greatest gift I can give is to see, hear, understand and touch another person. When this is done, I feel contact has been made."

Abbreviations used in this essay

BPD	borderline personality disorder
CTBE experts	community treatment by experts
DBT	dialectical behavior therapy
PBT	proton beam radiation therapy
RCT	randomized controlled trial

Virginia Satir

Fifty years ago, my professor of medicine, Dr. Miller (not his real name) taught by intimidation. He regularly humiliated students in front of their peers. He was on a high horse, appearing god-like and omniscient. Though well regarded in his time, Dr. Miller was the subject of adverse criticism in recent letters to my medical school alumni magazine. In retrospect, he was a dinosaur; compassionate teachers had come into favor.

Likewise, I believe that some psychotherapists have been on high horses with omniscient pretensions. What a refreshing idea it is to replace their airs and aloofness with therapy like that of Windhorse, in which compassion, trust and hopefulness prevail; friendship develops, and therapists even make home visits. In a bit of nostalgia, they remind me of Dr. Wagner (his real name), who made house calls in the 1940's for the likes of mumps and measles.

Windhorse therapy seems at once old-fashioned and revolutionary.

When my son Ben became seriously troubled at the age of 30, my researches suggested that Windhorse was made to order for his needs. The events that followed enabled me to formulate thoughts that draw not only on my recollections of Drs. Miller and Wagner but, more broadly, on my experiences as a physician, patient, father and 73-year inhabitant of planet earth.

I thank Don Haiman for the privilege of reading his master's thesis on Windhorse Treatment, which helped me greatly, and also for the friendship that he has shared with both Ben and me while a team

member and after. The opinions presented here, of course, are my own.

Evidence

"An expert is a man fifty miles from his home with a laptop."

Adapted from Will Rogers

How does one make a decision to enter a program like Windhorse? Decisions about treatments can be difficult at best but may be more so in the case of unconventional methods.

Consider aromatherapy, chiropractic medicine, reiki, yoga, St. John's wort, psychoanalysis—and Windhorse treatment. How can one know what is demonstrably effective, what is quackery, and what is somewhere in between? We decide such questions in many ways.

Sometimes, we respect the opinion of an authority. My daughter was in New York City on 9/11/01 and met two men who had been on a high floor of the second World Trade Center tower. After the first tower fell, an authoritative voice boomed, telling them to stay put. Instead, they ran down the stairs and saved their lives.

The voice of authority can be right—or wrong.

For about 20 years, in the field of medicine, there has been a demand for rigorous scientific substantiation of therapies, which in turn has led to the publication of guidelines for clinical practice that draw from the available evidence regarding many conditions. In these, a certain respect is given to expert opinion but more respect is given to research. The highest form of evidence for a treatment is considered to be a well-designed, randomized controlled trial (RCT), called the "gold standard," the features of which are intended to eliminate bias. An important refinement is blinding, meaning a lack of knowledge of who is in which of the two or more obligatory groups of subjects, e.g. receiving or not receiving the treatment under study. (A more agreeable term might be blindfolding.) Specifically, *double-blinding* refers to a situation in which neither the subject nor the researcher knows. Imagine yourself participating in research to determine which of two brands of coffee tastes better. Could you be objective if you knew that the cup you were drinking contained your favorite brand?

The study of an antidepressant medication is well suited to an RCT. The experimental group receives the drug in a particular dose. The control group receives a different but superficially indistinguishable medication or inactive substance (placebo), because knowing which group one is in may affect the results, based on

subjects' expectations. This, then, is an aspect of blinding. The placebo effect is well known—a benefit achieved simply by believing that one is receiving an effective medicine. Application of the placebo principle has even, at times, entailed a fake operation when the treatment under investigation was surgical!

To go into more detail about RCT's is beyond my scope. Among the articles that one can read on this subject, the on-line reference by Steven Bratman may be helpful, especially regarding blinding and placebos.

Many conventional treatments do not meet the "gold standard" for evidence of effectiveness and, according to Bratman, *most* alternative therapies do not. In the area of mental illness, it is difficult *but not impossible* to apply well-designed RCT's to therapies that entail personal interactions. I will illustrate with a research study of dialectical behavioral therapy (DBT, a special program of treatment that draws on the better-known methods of cognitive behavioral therapy). Marsha Linehan and her colleagues compared DBT with community treatment by experts (CTBE, more traditional psychotherapeutic approaches), in the treatment of borderline personality disorder (BPD) accompanied by suicidal behavior. One of the important outcomes was that, over a 2-year study period, the patients in the DBT group made significantly fewer suicide attempts than those in the CTBE group.

The study may have conformed as well as is possible with the concept of a well-designed RCT. It would have been impossible to achieve the double-blinding condition, because the patients inevitably knew which treatment group they were in, as did their therapists. As a result, the patients in the DBT group might have discerned that theirs was a new treatment with high expectations attached to it and therefore could have benefited from a belief that they would do especially well—the placebo effect. The researchers who assessed the outcomes of the research were blinded, however. Every subject was treated by one means or the other. This may have been partly for ethical reasons, given the hazards of leaving this serious condition untreated. However, in a critical review of clinical trials of treatment for personality disorders, Joel Paris noted that, in some other studies of BPD, the comparison group has consisted of *untreated* patients on a waiting list.

The problem of chronicity of psychiatric conditions like BPD is highlighted by Paris' critique of research by Linehan et al. He writes: "[A] limitation concerns long-term efficacy. Linehan...had suggested that a full course of treatment could take several years, but tested only the first stage...We...do not know whether treated samples maintain their gains and continue to improve or whether they might

relapse. Although the original cohort received therapy 15 years ago, there has been no follow up.”

I have discussed this research to illustrate both the potential and the problems. There are surely many other examples and much more to be said about the various kinds of evidence.

Decision

Everything that can be counted does not necessarily count; everything that counts cannot necessarily be counted

Albert Einstein

An RCT provides a quantitative result, i.e. something that can be counted, in Einstein’s terms. The group receiving an antidepressant, say, gets a higher average score on a test of depression than the placebo group, and the probability of that happening based on chance is calculated to be less than 5 percent. Therefore, there is a significant benefit, based on the numbers. RCT’s have special relevance to global matters like health policy and can also be applied on the individual level. One should not underestimate their importance.

Clearly, though, decisions are often made without the benefit of RCT’s, using what cannot be counted. Important individual factors may come into play and “gold standard” research may simply not be available to help. I can illustrate by the way Ben decided, with my guidance, to enter the Windhorse program in Boulder. He had been troubled since childhood, more so in his last 8 years, and had had many therapies and therapists, including participation in hometown partial hospitalization programs and a full year in the residential program of the renowned Menninger Clinic. He had lived with my wife (his mother) and me; elsewhere with one or another girlfriend or male roommate, and, as of the time in question, by himself. He was unable to earn a living. He had made progress in some ways, but had started to deteriorate, felt much distress and recognized that a change was desirable. It was time for an intensive therapeutic environment that did not entail hospitalization.

I had long had the role of exploring options, one of which was Windhorse. Ben had visited the Northampton program, but something didn’t click at the time, possibly because of an ongoing relationship.

He had a predilection for Eastern philosophy and religion and came to believe that his deterioration represented a spiritual emergency, warranting the approach of transpersonal psychology. One day, he said to me that if there were only a place for treatment that was in tune with his outlook, he would go there. So I set to work

intensifying my knowledge of the Windhorse program in Boulder, and ended up presenting my findings to him and suggesting that it was what he was looking for. After lengthy telephone discussion between Ben and Windhorse personnel, he agreed. There was the sense that it was a good fit.

Other factors had also contributed to a positive view of Windhorse: the fact that Menninger referred clients there and the testimonial of someone close to me, herself a former mental health professional, whose friend's son had undergone a remarkable transformation there. Unlike many families, we could afford to support Ben and his therapy expenses in this new step, as we had over the course of his illness in prior years.

If Windhorse was in a sense a last resort, it seemed an inspired one and he was on his way to Boulder, in the spring of 2008.

The Team and I

"No man is an island, entire of itself; every man is a piece of the continent, a part of the main..."

John Donne

No sooner had Ben's Windhorse program taken shape than family involvement began. I participated in hour-long sessions with Ben and his team, about half of them including my wife. They occurred approximately monthly, in person or by telephone. I learned a great deal from the team and contributed what I could. My observations were always treated with respect, another hallmark of the Windhorse approach. I became virtually a team-member, even taking shifts (essentially a vigil) when I visited Boulder during a particular crisis in Ben's care. I came to consider team members to be my friends as well as his.

My son and I had a close and loving relationship, which was helpful overall, but it had a flip side, given that his problems included dependency and the need for separation. A team member observed that, unlike our situation, sometimes when clients and their parents met, there was a palpable tension in the air. I would not consider a tense relationship to preclude parental involvement; it might be a special reason to encourage it.

As a physician, I had a special role, all the more so because Ben had physical ailments. I was able to review his radiological images myself and to get expert opinions on them from colleagues, with the consequence that he was spared an unnecessary surgical procedure. I recognized that he was vulnerable to a vitamin deficiency and a

hormone deficiency, both of which could affect his mood, and saw to it that the appropriate tests were ordered.

The team could not have been expected to know about such matters. Even among physicians in the clinical medicine of physical ailments, there can be so much specialization that a key point is missed. My 26-year-old daughter consulted a gastroenterologist because of nausea and vomiting. He ordered many tests, but not the one to see if she was pregnant (she wasn't). It was outside his radar, although pregnancy could have caused her symptoms.

Isaac Asimov characterized all of science as an orchard within which each specialist "clings to his own well-known and well-loved clump of trees," hesitating to look beyond it. Asimov, both a scientist and a science-fiction writer, imagined himself in the privileged position of gaining an overview from a balloon floating over the orchard, a state that not many people can achieve.

In an age of burgeoning information, when no individual knows more than a tiny fraction, it is all too human to fail to see beyond one's area of specialization.

On the other hand, one walk of life sometimes enables insights into another. Once, I was explaining to a physician-in-training how I calculated the appropriate dose of radioactive iodine to treat a patient's overactive thyroid gland. The patient also listened and said afterwards that he was a heating contractor who determined the specifications of a furnace in a similar way. Where I inserted the mass of the thyroid gland in an equation, he inserted the volume of the house.

It is probably unusual for an involved family member to be a physician, but I believe that many people can contribute to a client's care, drawing from their special backgrounds, whatever they may be, and from their personal knowledge of the client, thus not only learning from the team but also expanding the team's horizons.

The more we can cross our boundaries of knowledge by sharing, the better. In all, I consider the involvement of family or significant others to be desirable. The form it takes may be somewhat individual.

A Sad Event

"...Never send to know for whom the bells tolls; it tolls for thee."

John Donne

When Ben died, part of me died.

In spite of his many innate strengths and the caring ministrations of his Windhorse team, after 10 months in Boulder, he took his life. Ben's was a difficult case. No fewer than 7 psychiatric diagnoses, including BPD and major depression (but not psychosis), had been applied. He had troublesome back pain, embarrassing obesity due to long-standing medication and, almost certainly, an as-yet-uncorrected hormone deficiency. As if that were not enough, he was diagnosed with cancer shortly after his arrival in Boulder. He received chemotherapy, the misery of which was mitigated by unstinting support from his team. As a matter of fact, the treatment was remarkably successful but it was nevertheless a grueling ordeal.

What were Ben's strengths? He was able-bodied, attractive, lively-minded, warm-hearted and spiritual. He had graduated from college magna cum laude and earned a masters degree in psychology. He had worked as both volunteer and employee at a drop-in center for the mentally ill, conducting groups and helping to produce a newsletter. After he died, his friends told how generously helpful he had been. The flavor of the message in the illustration was present in many others that we received.

Message

I KNOW YOU HEAR ME FROM WHERE EVER YOU ARE AND I KNOW YOU'RE NOW AT EASE BLESS YOUR HEART THAT WAS ALWAYS THERE TO HELP ME THROUGH THROUGH THE 8 YEARS THAT IVE KNOWN YOU, YOU ALWAYS HELPED ME ALONE TALKED TO ME AND SHOWED ME WAYS THROUGH STRUGGLES BUT SO MODESTLY HELD BACK THE PAIN YOU FELT. I WISH THAT TIME STOOD STILL FOR IF SO YOUR PAIN WOULD NOT HAVE GROWN UNBAREABLY. YOU SPENT A LOT OF TIME SAVING OTHERS AND BRINGING LIGHT TO OTHERS INSTALLING UNDERSTANDING AND HOPEFULNESS. I WISH I'D KNOWN YOU LONGER SEEMING OUR TIME FOR ME WAS NOT ENOUGH. I WILL GO ON AND STRIVE TO PROSPER BUT YOU MUST KNOW I BECAME DEPENDED ON YOUR LEAD. SO LONG FRIEND. BROTHER, TEACHER "LOVE"

From Ben's book of remembrances

Another friend wrote, "...I had the pleasure of studying several Buddhist concepts with Ben...Ben brought his sharp intellect with him to our study meetings...I remember several extended discussions with him in comparing Buddhist and Western concepts, ideas, and ideals. He challenged me to go further than textbook questions and answers-- he often tried to get to the heart of matter..."

There was much in him to support the emergence of "islands of clarity," which, in the Windhorse approach, as explained by Edward Podvoll, can be a basis for recovery. I am proud of Ben. It took great

courage to struggle against his ultimately unbearable pain. Unfortunately, his strengths could not prevail over his anguish.

Moving On

"Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek".

Barack Obama

It would be desirable for the best possible clinical research to be brought to bear to test the effectiveness of Windhorse therapy. Perhaps a good case could then be made for widespread adoption of the techniques and for a high level of third-party reimbursement. Such research could elucidate both merits and limitations. Apart from general applicability, special groups might be targeted for future help, such as troubled prisoners undergoing rehabilitation and veterans with traumatic stress disorder.

The health care climate is rapidly changing. Importantly, mental health parity legislation has been passed, countering long-standing discrimination against Americans with mental health and substance-use conditions, with regard to insurance coverage. Otherwise, as plans emerge to overhaul the health care system, there is increased emphasis on the need to validate treatment methods and to establish their cost-effectiveness. At the June, 2009, meeting of my professional organization, the Society of Nuclear Medicine, there was much discussion of the need for our specialty to respond to these imperatives. One flier deplored the insufficiency of evidence-based practice guidelines and proclaimed, "First, we must recognize that the driving force for all health-care reform is money."

The mental health field will also be under pressure to respond. Windhorse therapy might show cost-effectiveness if it is found to restore patients to productive lives better than other treatments do.

In the treatment of mental illness, as with other medical conditions, not only is the method that is applied of importance; so is the ability of the therapist. A well-informed prostate cancer patient knows that if he has chosen to aim for a cure through surgery, he should choose his surgeon on the basis of skill, as well as it can be assessed. If Windhorse therapy were to become more widespread, it would be important for its practitioners to have the compassion and skill of those now practicing it, as in Boulder.

I myself developed prostate cancer and chose to be treated by a novel method, proton beam radiation therapy (PBT), in spite of the

fact that there had been no RCT's comparing it with other treatments such as conventional radiation. I was persuaded by powerful theoretical arguments. Since the treatment, I have done well and have also continued to read papers about PBT. Although I still consider the theory to be strong, I have come to realize that, in addition to the continuing lack of RCT's, there are technical shortcomings in the way the theory is applied. It is also relatively expensive. Because of such considerations, reimbursement for PBT has been jeopardized. In my interactions with the organized group of largely satisfied "alumni" of this method, I have come to be both a fan of PBT and a gadfly. I can imagine myself in a similar role vis-à-vis Windhorse.

My well-loved, much-missed son, whose fondest wish was to help others, is best memorialized by renewed dedication to understanding mental illness and treating it in the best way possible.

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