



Selected Papers of William L. White

www.williamwhitepapers.com

Collected papers, interviews, video presentations, photos, and archival documents on the history of addiction treatment and recovery in America.

Citation: White, W. (2012). Addiction treatment and cancer treatment: Personal reflections of a long-tenured addiction professional. Posted at www.williamwhitepapers.com

Addiction Treatment and Cancer Treatment: Personal Reflections of a Long-tenured Addiction Professional

William L. White

Emeritus Senior Research Consultant
Chestnut Health Systems
bwhite@chestnut.org

More than a decade ago, Thomas McLellan and colleagues (2000) published a seminal article in the *Journal of the American Medical Association* comparing addiction to such chronic primary health disorders as cancer, diabetes, and hypertension. In their analysis of these conditions, they noted a similar mix of risk factors, recurrence patterns, and problems of patient adherence to recommended treatments and related lifestyle changes. The article defined addiction as a chronic health problem whose effective management should parallel proven approaches to other chronic medical disorders. The article, because of the prominence of the authors and the journal in which it was published, marked something of a “tipping point” in calls to extend addiction treatment from models of ever-briefer acute biopsychosocial stabilization to models that offered the option of sustained recovery management for those with the most severe, complex, and enduring substance use disorders.

In the years since the McLellan et al. publication, considerable progress has been made in conceptualizing this shift and

defining how clinical practices would change within various approaches to recovery management. I have been deeply involved in this movement, particularly in marshaling the scientific evidence to guide this redesign process (White, 2005, 2008a; White, Boyle, & Loveland, 2002), but in recent years, personal encounters with cancer have afforded me an unexpected source of new insights into the question, “How would we treat addiction if we really believed it was a chronic disorder?” This article draws from these personal experiences to compare the treatment of cancer and the treatment of addiction.

Personal Context

Like many people in recovery from addiction, I have long feared that cancer was stalking me. Cancer ran in my family history on par with alcohol and other drug problems, with two of my immediate family members and many extended family members experiencing cancer before my own diagnosis. Similarly, I was a very heavy smoker for more than two decades and,

even after adding nicotine to the list of drugs shed in my life, worried that I might not have escaped its long-term consequences. Cancer seemed always close to me, bringing devastation and death to family, friends, professional colleagues, and many of my peers in addiction recovery. In the early 1990s, I was diagnosed with a blood disorder that has been continuously monitored since then due to the risk that it could morph into leukemia. In 2010, a CT scan revealed a tumor on my right kidney that, due to its location and growth pattern, was suspected of being cancer (greater than 90% odds) but turned out to be benign when surgically removed. In 2012, I was diagnosed with prostate cancer and have undergone treatment over the past months. These experiences have afforded a platform of personal experience and research into cancer treatments that I wish to contrast with prevailing addiction treatment practices.

Early Communication of Risk Factors

When the PSA scores in my routine annual physical doubled within one year, I was sent to a urologist, who first retested my blood only to find that the PSA score had risen considerably further in a month's time. But even before I met the urologist, I filled out forms in his office quite different than those I was used to completing for my primary care physician. These forms elicited four areas of information rarely touched on in such depth in routine medical screening: my family history of cancer (which was extensive, including my father's death from prostate cancer), my history of exposure to alcohol and drugs and the duration and intensity of my smoking history (also extensive); my exposure to environmental toxins (higher than normal because of my work as a young man in the construction trades), and co-occurring conditions that could influence future cancer treatment options (in my case, several conditions of potential concern).

Anyone facing a potential cancer diagnosis is preoccupied with two questions: 1) "Do I have it?" and 2) "Why me?" The third question ("Is it going to kill me, and if so, how

quickly?") comes a bit later in the process. Before I met the urologist, several things happened as I filled out forms in his waiting room. First, my fear that I was at elevated risk for cancer was confirmed. Second, I knew a combination of family history, personal lifestyle, and environmental circumstances constituted the sources of that risk. Third, I knew that I had co-occurring medical conditions that would be factors in determining any needed treatment choices and my long-term treatment prognosis. Those conclusions were reinforced by the assessment forms, educational materials in the waiting room, and by my own preparatory Internet searches on prostate cancer. In short, I was psychologically prepared to enter this world of cancer treatment even before my cancer diagnosis was confirmed.

That state of readiness made me wonder: Are those sitting in the waiting rooms of addiction treatment programs similarly prepared?

Presentation of the Diagnosis and Stage Information

My diagnosis of cancer unfolded in a series of five communications: 1) The latest elevation in your PSA calls for a biopsy (which was completed), 2) Your biopsy reveals the presence of cancer in 2 of 12 samples, 3) Your "Gleason Scores" for the positive cancer samples are 6 and 7 (of 10—indicating a pattern of more aggressive growth requiring treatment rather than just monitoring), 4) You will need various scans to determine whether the cancer has spread outside the prostate (which were done), and 5) You have prostate cancer that appears to be contained within the prostate (later confirmed in post-surgical pathology tests) and that is at an early to intermediate stage of development that will require treatment as soon as it can be conveniently scheduled. What was striking about this was that each step involved objective data that could be compared to norms of men with and without prostate cancer, and each step was accompanied by a teaching intervention. In short, I knew exactly the data the diagnosis

was based upon and was taught to understand the meaning of each piece of information. Rather than having a diagnosis thrust upon me, I was invited as a full participant into the diagnostic process. This raised for me the question of how frequently or infrequently the presentation of such objective data, companion teaching interventions, and full participation in the diagnostic process occurs in addiction treatment. I suspect that much of what is characterized as “denial” and “resistance” in addiction treatment flows from the omission of the steps I experienced in my cancer treatment.

Education on Treatment Options

At the time my cancer diagnosis was made, the specialist informed me that the next step was to educate myself on the treatment options. There was no attempt to induct me into a particular form of treatment. Instead, my urologist provided a very well-written educational booklet that outlined multiple (almost too many) options for treatment of prostate cancer with risks and benefits of each objectively outlined. At the next appointment, he reviewed these options with me and said that I would have to decide which would be best for me. When pushed by me for his recommendation, he recommended a particular type of surgery, explained why he recommended that treatment choice, but also insisted that I talk to other specialists about alternative treatment options (which his office helped arrange).

I cannot recall a similar process in my four decades of professional involvement in addiction treatment. It would be rare indeed in addiction treatment to ask a person seeking help to interview people offering different levels of care and different modalities before making a decision about the treatment he or she thought would be best.

Open Acknowledgement of Professional Bias / Second and Third Opinions

In discussing treatment options with the urologist, he explained what his role would be if I chose various surgical options and if I chose various radiation therapies, but he was very clear in stating his bias towards surgery in my particular case and insisted because of that bias that I see others who specialized in non-surgical alternatives. When I chose to compare reports and recommendations from the surgical and radiation specialists with the oncologist who had been monitoring my blood disorder for the past seven years, the urologist was delighted that I had this guide who would not be directly involved in delivering any treatment that I chose. That attitude of acceptance of second and third opinions on treatment options and linkage for such objective consultation are quite rare in the world of addiction treatment as I have observed it.

Objective Comparison of Recurrence and Survival Rates

There is a precision and candidness in discussing cancer treatments that I found quite refreshing. Probabilities were given for the outcomes of no treatment and the respective treatment choices available to me in exact percentages, e.g., five-year rates of cancer recurrence and five- and ten-year survival rates. Not only was I made aware of such rates for each treatment I was considering, but I was also given rates matched to my particular circumstances, which, in comparison to the general rates, quickly eliminated some treatment options and made my best choices clearer. This was a type of “treatment matching” I had not encountered in the addictions field. For example, what data is provided to persons seeking treatment for opioid addiction to help guide their decision of multiple treatment options? In my tenure working in addiction treatment, I have never seen such comparative information routinely provided to persons/families seeking assistance. Why

are such rates not available for addiction treatment? Why are the available limited data on long-term outcomes from no treatment and for various treatment interventions not routinely provided to patients and their families?

Candid Communication of Iatrogenic Risks

All of the providers—surgeons, radiologists, general oncologists—involved in my cancer treatment reviewed the potentially harmful effects of each treatment option I was considering. These spanned potential adverse effects during surgery (e.g., stroke, heart failure), risks resulting from hospitalization (e.g., blood clots, infection), and more prolonged post-surgical risks (e.g., incontinence, impotence). What was more remarkable was that they communicated the exact numerical probabilities of each of these risks and implemented specific procedures to reduce these risks, e.g., heparin injections and leg massages to prevent blood clots and stroke, antibiotics to prevent infection, and specific surgical techniques to reduce the risk of long-term incontinence and impotence.

There is a long tradition of iatrogenic effects (harm in the name of help) within the history of addiction treatment (White, 1998; White & Kleber, 2008), but patients entering addiction treatment are not routinely apprised of such risks or of their frequency of occurrence, even though some data related to such risks are available in the scientific literature (Ilgen & Moos, 2005; Moos, 2005).

Access to Experiential Knowledge

The sometimes clinical precision of information about the course of cancer, treatment options, and the outcomes of various cancer treatments was balanced by access to a very different type of knowledge—the experiential knowledge of patients in various stages of recovery who had experienced the exact treatments I was considering. This was made available through face-to-face and Internet-based

patient support groups and innumerable websites at which questions could be posed and answered by the broad experience of patients—both locally and from across the world. Imagine what it would mean to individuals and families considering addiction treatment to have access to that kind of experiential knowledge—before, during, and after the treatment process.

Patient Choice, Partnership, and Family Involvement

Cancer is such a terrifying diagnosis that one might well imagine the value of a medical superhero riding in on a white horse to take control and save the day, but cancer treatment is often quite different than that image. I had a specialist who insisted that the choice of treatments was mine, not his, and that his role was to educate me about those choices and to execute as best he could the decisions that I made. In fact, after reviewing all of my choices, I had to practically pry out of him what he thought would be the best choice for me. It was clear that what we were entering into was an extended partnership rather than my being the passive recipient of his knowledge and expertise.

One fears the “if you only have a hammer, everything looks like a nail” phenomenon when facing such a life-threatening crisis—the fear that all surgeons want to cut, all radiologists want to radiate, etc.—but I had the novel experience of a surgeon talking positively about radiology treatment and a radiologist affirming that I was a good surgery candidate. What was most striking was that each specialist I saw treated me as an intelligent person who was capable of evaluating choices and making a good decision. Also striking was their comfort, including my wife in every step of the decision-making process. They listened to both of us and responded fully to each of our questions.

In contrast to the above, people seeking specialized help for alcohol and other drug problems are less likely to be given a spectrum of treatment choices, more likely to be dictated a particular type of

treatment by a self-defined expert (usually the primary type of treatment provided by the organization conducting the assessment), more likely to be presented with a professional “my way or the highway” stance, and less likely to have their family involved in all aspects of their treatment (White, 2008a).

Education on Treatment Procedures

Once a decision had been made on the type of cancer treatment that would be best for me, the urologist provided further information on the procedure, including a DVD illustrating exactly how the procedure would be performed. He again went over risks and side effects and their prevalence both nationally, in his practice, and at the local hospital where my surgery would be conducted. Again, I understood why this procedure was one of the best choices for me, how it was to be done, the sequence of my care, and what I could realistically expect as an outcome. It isn't that in addiction treatment we don't do that kind of patient education; we do. It is that the depth of patient education in the cancer arena far exceeds anything I have seen in the addiction treatment field.

Management of Co-occurring Conditions (Whole Person)

Cancer, like addiction, often co-presents with related and unrelated health conditions that require concurrent or sequential treatment. For me, management of these co-occurring conditions was considered within my treatment choices and actually eliminated some possibilities. I did not have the feeling of being a machine being worked on by a mechanical expert—the surgeon as expert craftsman with little awareness of me as a whole person. That was exhibited in a number of ways—clear assessment of co-occurring conditions, openness to having other physicians involved in the decision-making process, respect for their opinions, help in sequencing needed medical procedures across multiple practitioners,

and respect for my decisions related to that sequencing.

As I went through this experience, I was struck by how rare those precise ingredients were in addiction treatment. For example, I did not want my treatment to interfere with the forthcoming “robing ceremony” related to my daughter's PhD completion. Information was provided on risks related to the timing of treatment initiation, and treatment was scheduled to begin right after this important event in my life. I suspect few addiction treatment programs would have been so accommodating.

Treatment Duration Based on Measurable Clinical Benchmarks

I am sure there were arbitrary insurance-influenced limits on the length of my hospitalization following surgery, but the timing of my discharge was linked to very clear clinical benchmarks. These benchmarks included both factors that were not present (e.g., fever and other signs of infections) and measurable markers of post-surgical recovery (e.g., kidney functioning, reductions in pain, mobility). In other words, my treatment was shaped by my personal response to treatment and not by an artificial length of stay. That made us wonder how that very clinical benchmarking process could be more widely applied to the treatment of addiction. In fact, my surgeon insisted I would be discharged as soon as possible because the risk of infection rose with the length of hospitalization.

Plan for Long-term Monitoring and, if Needed, Early Re-intervention

My diagnosis of cancer was accompanied by two communications consistently reinforced over the course of my treatment:

- 1) There is a risk of cancer recurrence even under the best of circumstances (e.g., risk of recurrence even with 100% compliance with all treatment protocols and follow-up

recommendations for preventive care).

- 2) The morbidity and mortality associated with cancer recurrence can be significantly lowered by sustained monitoring (for at least five years) and, if and when needed, early re-intervention.

Part of the partnership involved not just getting through acute treatment but participating in scheduled checkups, identifying at the earliest possible time any return of cancer, and in the face of any recurrence, assertively re-intervening with renewed and potentially different treatment. So I voluntarily entered and committed myself to a partnership that I knew at a minimum would last five years and probably all of my life. That did not mean that I would be undergoing active treatment forever; it did mean that the most important risk predictors (e.g., findings from lab tests) would be monitored on a set and sustained schedule. Like many cancer patients, I also received information that if I achieved five years of sustained remission, the risk of future recurrence would significantly decline after that critical milestone.

At the time I was given this information, I had been researching an interesting question: When is present recovery from addiction predictive of lifetime recovery? What I had found consistently in my review of long-term treatment outcomes studies (see White, 2008b) was that the stability point of addiction recovery (the point at which risk of future relapse in one's life dropped below 15%) was on average 4-5 years of sustained remission—precisely the range I was being given for stability of my long-term recovery from cancer. In the world of cancer treatment, patients are assertively monitored for the five years following treatment, but patients in addiction treatment receive no such sustained system of monitoring, support, and early re-intervention. Expensive, cyclical episodes of acute addiction treatment are available but nothing resembling the assertive follow-up following cancer treatment is standard practice in addiction treatment.

Absence of Contempt or Condescension

One could easily build a case that prostate cancer was for me simply a bad roll of the genetic dice, but when one looks at the larger risks of cancer in my lifetime, there are clear areas of potential culpability. I was aware of my family history and yet chose to embark on a career of heavy nicotine, alcohol, and other drug use. My overall health management (e.g., diet, exercise, stress, etc.) was not one that could be expected to lower my cancer risks. And yet, my cancer treatment unfolded within service relationships completely free from judgment, contempt, or condescension. Nor did I face any threats of punishment for the sin of noncompliance with treatment protocol. In short, I was treated like a patient who could fully and responsibly participate in my own treatment. I was not treated like a morally culpable criminal or recalcitrant child who needed to be aggressively controlled by my moral superiors—attitudes that too often still permeate the milieu of addiction treatment.

Implications

If we really believed addiction was a chronic disorder on par with cancer (and other chronic primary health disorders), we would provide every person seeking assistance:

- Clear and consistent communications regarding the intrapersonal, interpersonal, and environmental factors that contribute to the development of a substance use disorder.
- An assessment process that is comprehensive, transparent, and continual.
- Objective data upon which a substance use disorder (SUD) diagnosis is based (with normative data for comparison to the general population and to other patients being treated for SUDs).
- Objective information on the severity (stage) of the SUD.

- Objective information on treatment options matched to the type and severity of the SUD.
- A declaration of potential professional/institutional biases related to diagnosis and treatment recommendations.
- A menu of treatment options before making a final decision on the course of treatment.
- Access to the experiential knowledge of former patients who have experienced a variety of SUD treatments and who represent diverse pathways and styles of long-term recovery management.
- Personalized refinements in treatment-based assessment data and individual responses to initial treatment.
- At least five years of monitoring and support following completion of primary treatment.
- Assertive re-intervention and recovery re-stabilization in response to any signs of clinical deterioration.
- A long-term, person- and family-centered recovery support relationship based on mutual respect that is free of contempt or condescension.

It really is that simple. If we believe that addiction in its most severe forms is a chronic disorder, then let's treat it like we really believed it.

References

- Ilggen, M., & Moos, R. (2005). Deterioration following alcohol-use disorder treatment in Project MATCH. *Journal of Studies on Alcohol*, 66, 517-525.
- McLellan, A. T., Lewis, D. C., O'Brien, C. P., & Kleber, H. D. (2000). Drug dependence, a chronic medical illness: Implications for treatment, insurance, and outcomes evaluation. *Journal of the American Medical Association* 284(13), 1689-1695. doi:10.1001/jama.284.13.1689
- Moos, R. H. (2005). Iatrogenic effects of psychosocial interventions for substance use disorders: Prevalence, predictors, prevention. *Addiction*, 100, 1240-1248. doi:10.1111/j.1360-0443.2005.01073.x
- White, W. L. (1998). *Slaying the dragon: The history of addiction treatment and recovery in America*. Bloomington, IL: Chestnut Health Systems.
- White, W. L. (2005). Recovery management: What if we really believed that addiction was a chronic disorder? *GLATTC Bulletin*, September, 1-8. Chicago, IL: Great Lakes Addiction Technology Transfer Center.
- White, W. L. (2008a). Toward a philosophy of choice: A new era of addiction treatment. *Counselor*, 9(1), 38-43.
- White, W. L. (2008b). *Recovery management and recovery-oriented systems of care: Scientific rationale and promising practices*. Pittsburgh, PA: Northeast Addiction Technology Transfer Center, Great Lakes Addiction Technology Transfer Center, Philadelphia Department of Behavioral Health & Mental Retardation Services
- White, W. L., Boyle, M., & Loveland, D. (2002). Alcoholism/addiction as a chronic disease: From rhetoric to clinical application. *Alcoholism Treatment Quarterly*, 20(3/4), 107-130. doi:10.1300/J020v20n03_06
- White, W. L., & Kleber, H. D. (2008). Preventing harm in the name of help: A guide for addiction professionals, *Counselor*, 9(6), 10-17.