Patient Empowerment and Sticking to a Treatment Regimen

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November 5, 2016 By Adam Hayden

Recently I have been talking about patient-centered healthcare, and I offered a philosophical take on patient empowerment, drawing from my own experience. One important suggestion I advanced is that both patients and medical teams share common ground: asking why? In this post I focus on the patient experience. In the future we will see this question framed for researchers.

Patients are often frustrated, disgruntled, and disengaged when they are not enabled to speak competently to their own treatment. I suggested a medical team is accountable to empowering patients by facilitating understanding of what to expect from treatment, therapy, or a special procedure. Most importantly, the onus is on the medical provider to illuminate why an order is an important component of a person's plan of care. Empowered patients are more likely to take an active role in their care, treatment, and recovery. Recall a recent medical intervention, and answer the following questions: Why has my doctor ordered this test? Why have I been prescribed this medication? Why is this therapy recommended for my particular diagnosis? This is a nice litmus test for the health of the dialogue with your primary care provider. I also hope this activity reinforces the notion that patients knowledgeable about their provider's decision-making are more engaged and diligent when sticking to a treatment regimen.

Speaking of sticking to treatment regimens…

Deserving of its own post, I am contemplating discontinuing use of the Optune device (tumor treatment fields (TTF)). This recently FDA-approved (for glioblastoma) durable medical equipment (DME) slows the growth of tumor cells by emitting an alternating electric field targeting the site of tumor growth, disrupting the process of cellular division (mitosis). A full description of the therapy quickly becomes complicated, and to wrap our minds around the mechanism of treatment, we would need to get into the weeds with theory and terms, including mitotic spindles, apoptosis, and the molecular dipole moment. Of course, I would have great fun blogging on this topic, but my fun may not leap off the page (screen). You can let me know in the comments, if you want to hear more. Regardless, as I consider continuing TTF therapy I seek answers to the contrastive (why?) questions I asked you to consider from your most recent medical intervention.

The Optune is inconvenient, requiring changing the equipment, shaving my head, and cleaning

with alcohol. It is adhered to my shaved scalp with medical-grade adhesive, generating heat, like wearing a beanie all day, with a bulky braid of wires running from my head to a two-and-a-half-plus pound battery backpack. It is neither fashionable nor kid-friendly, and midnight bathroom breaks are more cumbersome when you are plugged into the wall socket like a floor lamp.

Levity aside, wearing the equipment complicates transferring my one year old to his crib for bed; it frightens my three year old who has taken to yelling "no, daddy!" when I walk in his room; it impedes my ability to grab impromptu dinner with my wife and walk the Cultural Trail, without first thinking through stowing an extra battery or two and working out a jacket-and-hat combo to complement my three-pound backpack and headgear. Psychologically, wearing such equipment constantly reminds the wearer: you are ill; different; set apart.

An important question remains unanswered: Why is this particular therapy recommended for my particular diagnosis? The fact of the matter is this. Nothing else has stopped GBM. There is not empirical data to support alternatives to TTF therapy–at least, not empirical data that is FDA-sanctioned. Optune is an exciting, non-invasive therapy that has extended overall patient survival during clinical trial.

Discontinuing treatment offers a reprieve from inconvenience, maybe improved connection with my wife and kids, and a return to some normalcy during an unsettled time. Is this trade off worth sacrificing a statistically significant improvement in overall survival time?

The importance of answering this question cannot be overstated. My reality may diverge in severity from the medical decisions you face today. To put it in rather stark terms: every eight weeks I endure a 40-minute brain scan followed by an appointment with my neuro-oncologist (NO) to hear whether my cancer is growing. There is obviously much at stake, and imagine my state of mind should I discontinue TTF therapy, and subsequently discover tumor progression on an upcoming scan.

I encourage us all, not as a gloomy reminder, but for your thoughtful consideration as spouses and family, to entertain the types of treatments you are willing to endure, what side effects are tolerable, and when you would decide to discontinue treatment. The answers to these questions may inform your healthcare power of attorney.

Notice what is central to the preceding paragraph? These decisions are within your control. The decisions are yours to make. Decisions are to be made with the support of your medical team, and as I have already suggested, medical teams share in the responsibility of educating (hence, empowering) patients under their care.

Sticking to a Controversial Treatment Regimen: What Changes?

In the coming posts I will introduce the vitally important role nutrition plays in the prevention and treatment of cardiovascular disease, neurodegenerative diseases, diabetes, and, yes, cancer. Nutritional resolutions are difficult (for a myriad of reasons, proving their efficacy in a clinical setting among the most challenging) because for their success, nutritional resolutions require

strict adherence. This remark is not terribly insightful, anyone who has tried out a new diet or New Year's resolution already knows this. All aspects of food: our American cultural associations with the wholesome farm, rooted in our identity as an agrarian pilgrims, surviving on corn, and preserving in the root cellar, the happy cows from California©, our governments' farm bill and subsidies, Mark Bittman, Katie Couric, the paleo diet, kosher delis, meatless Mondays, Weight Watchers, and Ramadan, and let us not forget Holy Communion. Table fellowship is central to physical, emotional, and for many, spiritual lives. Messing with eating practices is calling into question childhood memories, emotional coping mechanisms, religious practices, and evolutionarily-signaled cravings.

Calling into question eating practices is just what I plan to do. We will explore the ketogenic diet as a resolution for cancer and neurodegenerative diseases. Keto's efficacy is contingent on the metebolic theory of cancer, so you know we will need to get that theory on the table. Keto is about our body metabolism; metabolic theory of cancer is about cellular metabolism. Be on the lookout for my next post: Our Cells; Our Bodies.

Cheers —AH

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