Prostate Cancer, Month 161 – Crappy Development

It has been 19 months since my last radiation, Daniel Zeller writes, but something is now off with my bowels. Plus: anger and regret.

April 25, 2024 By Dan Zeller

If you've been reading this blog from the beginning, you already know that no detail is spared in the telling of this prostate cancer tale. If you haven't read some of the early, gory details, well, buckle up, Buttercup.

Let's talk bowels and crappy developments.

BIOLOGY AHEAD

LAST CHANCE. If you don't want to follow along, check out my travel website HERE or my photography website HERE.

One of the known possible long-term side effects of radiation when it comes to prostate cancer is issues with your rectum and bowels, and those side effects can manifest themselves years after the radiation was completed. (It's been 19 months since my last zapping session in August 2022.)

Something has changed with my bowels in the last few months, and I'm wondering if this is the beginning of those side effects.

The engineer in me is trying to evaluate different variables to see if these changes could be the result of something else.

As a baseline, I used to have one bowel movement a day in the morning and I was good for the day. Also, I'm a creature of habit, and my diet really hasn't changed at all, so that's likely not a contributing factor.

One other thing is the timing of the onset of my symptoms. It's about the same time that I started my daily walking regimen in earnest in February. I doubt they're related, but it is noteworthy.

So what's different? Well:

- About half the time, I'm now having two to three bowel movements a day. One recent day,

there were five over the course of the entire day.

- My stools have changed from well-formed “logs” to thin, soft “snakes” or “ropes” that tend to fall apart.

- I find myself having short periods where I’m quite gassy and flatulent without any likely dietary cause (e.g., not eating frijoles for breakfast, lunch and dinner).

The silver lining in this cloud is that I haven’t had any increases in bowel urgency, so this is quite manageable at the moment. I will admit, though, that there have been a few times when I’ve been on my daily walks when I felt the need to pass gas, and I felt I was on the edge of getting more than I bargained for if I did. Luckily, no accidents yet.

I haven’t done a ton of research on this yet, but a study out of Sweden, Salvage radiotherapy after radical prostatectomy: functional outcomes in the LAPPRO trial after 8-year follow-up, looked at the long-term side effects of salvage radiation therapy. The summary of their conclusions on bowel function:

> Fecal leakage was more common after radiotherapy as found in answers to question about ‘accidentally leaked liquid stool’ with 4.5% in Radiotherapy group versus 2.6% in Control group, ‘accidentally leaked liquid stool’ once a week or daily, Odds ratio (95% CI): 1.90 [1.38; 2.62]), ‘mucus from anus’, 6.8% versus 1.5% (4.14 [2.98; 5.76]), ‘leakage of feces in clothes’, 5.6% versus 2.4%, (2.18 [1.18; 4.04]), respectively in Radiotherapy and Control groups (Figures 2, 3A and 3B and Tables S2 and S3 in the Supplement). Bleeding from the anus was more common after salvage radiotherapy, 8.6% versus 1.2% in control (3.21 [2.32; 4.44]) as was flatulence, 25% versus 14% (1.82 [1.40; 2.37]), whereas distress due to bowel symptoms did not differ, 7.8% versus 6% (1.27 [0.90; 1.80]). Defecation urgency was more common in the group given salvage radiotherapy as reported in answers to questions about need ‘to rush to the toilet’, 14% versus 5% (3.22 [2.46; 4.21]), ‘open your bowels again within 1 hour’, 17% versus 9.4% (1.53 [1.18; 1.98]). There was no statistically significant difference in ‘how often do your open your bowels’, 3% versus 2.5% (1.23 [0.92; 1.64]).
>
> Carlsson, S., Bock, D., Lantz, A., Angenete, E., Koss Modig, K., Hugosson, J., Bjartell, A., Steineck, G., Wiklund, P., & Haglind, E. . (2023). Salvage radiotherapy after radical prostatectomy: functional outcomes in the LAPPRO trial after 8-year follow-up. Scandinavian Journal of Urology, 58, 11–19. https://doi.org/10.2340/sju.v58.7318

Another silver lining: no fecal leakage, mucus, or rectal bleeding so far. Woo-hoo!

Needless to say, this will be part of my conversation with my primary care physician on 9 May and

with the urologist on 14 May. I'll likely rope the radiation oncologist into the conversation, too.

I was reluctant to talk about this earlier because I wasn't sure if this was a temporary thing or something longer term. This has been pretty persistent for about two months now, so I thought it was time to talk about it. As long as things don't worsen, I can live with what's happening right now (although I would prefer that I didn't have to if I'm being perfectly honest).

I'll have to admit that I've been feeling a general sense of anger and perhaps regret about this whole situation.

The source of those emotions isn't from the side effects themselves, per se, but rather from this entire process that tends to move patients in the direction of what is considered to be overtreatment.

I may flesh this out in a longer, separate blog post one day, but when I see the likes of Dr. Scholz and others beginning to say, "Hmm. Maybe we should let the PSA rise so we can find out where the cancer is at before we start the treatments that could have life-long side effects adversely impacting the quality of life," I get annoyed. Annoyed because I'm beginning to agree with that line of thought more and more, instead of the old, "It's better to attack it while the PSA is low even though we don't know exactly what's going on."

It's frustrating because, my gut instinct all along was to delay until we knew where the cancer's location, and I let the more rapid increases in my PSA, my shortening PSA doubling time, and the current "industry" guidance to act sooner rather than later get the better of me.

The frustration will continue as I move into the next chapter. I've been looking for studies on the best time to start androgen deprivation therapy (ADT) for someone in my situation and, from what I've seen so far, the guidance seems to run the full spectrum of starting early or delaying for years. Throw in the decision of whether it's just ADT or ADT plus some sort of antiandrogen therapy, too.

I get that there are advances in research and technologies and that things are constantly changing. But at this point, I'd be happy for a clear path forward without adding additional side effects. (But I'm experienced and knowledgeable enough to know that's just a pipe dream at this point.)

Rant over. Time to invest in some toilet paper company stock.

What's next?

- 1 May – PSA test

- 9 May – Appointment with primary care (routine physical)

- 14 May – Appointment with urologist

- TBD – Another PSMA PET scan if my PSA warrants it OR wait another three months for the next PSA test.

This blog post was originally posted April 15, 2024, on DansJourney.com.
