Cancer Health™

On Survivorship, From the Survivors

We are a community; how might we all learn together from our shared yet unique experiences?

September 17, 2018 By Adam Hayden

“Why does mommy have to work all the time?” Our three-year-old, Gideon, asked through broken sobs when I greeted him at his crib one recent morning.

“I’m sorry, buddy, we all miss her, don’t we,” I replied, my own eyes blurry and breath shortened, choking back tears of my own.

Later this same day, or the day after, rinsing dishes following breakfast I began sobbing.

“Are you sick, daddy?” Gideon asked.

“Yeah, bud, daddy is sick,” I say.

“Are you going to throw up?”

“No,” I chuckle.

Scenes like this play out frequently, swapping the subjects and settings, themes are similar.

Our family is slogging through a waste-deep sludge of survivorship, and like quick sand, we seem to sink more each day. The new experiences of active cancer care are behind us. The quick wins and short-lived milestones are long past. Setting our eyes to the horizon reveals more angst than anticipation.

We lug the bags of survivor’s guilt behind us, recognizing we have these moments together, moments that many families did not.

We lug the bags of insecurity, too, second guessing our decisions to work, to keep busy, to be productive, to send the kids off to daycare so that I may sit in an empty house to write in an effort to satisfy a life project—papers, books, or posts—at the cost to my family of lost wages and absent parenting.

Whitney experiences terrible guilt leaving the house each morning. I feel terrible guilt that she has to.

I sat across the coffee shop table from a close friend last week, a rare trip out of the house. I shared with him the idea I was trying to make sense of: when I search for meaning and purpose, in light of my predicament—uncertain life expectancy, a desire to live fully today, a desire to aid Whitney with financial stability, a desire to achieve future aims—I am motivated to say something helpful to others about what it is to grieve the loss of future possibilities that will likely never come to be.

"I've never thought about this before," said my friend, "but now that you say it, it seems so obvious! You're experiencing things we all experience in our lives, but your experience is more […] compressed."

I nodded.

I've alerted myself to this insight also. Several months following my diagnosis, when I was wrestling with acceptance of a terrible disease and what it amounted to for my life and the life of my family I expressed something similar, "my life is like everyone else's," I said, "but the volume has been turned up." I was trying to get at this notion that each of us gives some thought to our relationships, to goals and priorities, to what legacy we build, and to thinking of our own mortality. For me, these occasional considerations are amplified. Or, as my friend put it, "compressed." They become daily, high-pressure considerations and decision points.

"A lot of people work through the decisions you're making, and they take 20 or so years to do it." This was the response from a friend, a palliative care physician, when I rattled off the horizon of possibilities for my future direction, possibilities that narrow more each day. "But of course, you don't have 20 years, do you?"

I am a member of a loving brain tumor community including patients, care partners, loved ones, researchers, and clinicians. Struggling with survivorship, I set out to write this post—in fact, much of what you just finished reading was my first pass—in hopes it would meet others where they are, in their own struggles as a spouse, child, sibling, parent or guardian, also slogging through survivorship. Then I realized, we are a community, and if the sign posts I've been reading are correct to signal I speak in ways that amplify the experience of others, how might we all learn together from our shared yet unique experiences?

I posed the following question vis-a-vis Twitter (in the following quote, I spelled out the hashtag acronyms, with brackets):

> Drafting a blog post today about #survivorship. What issues do you find most challenging to navigate after the dust settles from the shock of diagnosis? #btsm [brain tumor social media]

> #btsmqol [brain tumor social media quality of life] #ptexp [patient experience]”

The community responded with thoughtful, vulnerable, and honest replies. My mood immediately lightened as I experienced the embrace of a community that stands shoulder to shoulder with each other as we experience our disease from our unique perspectives. In the following paragraphs, I report on many of the replies I received to my prompt. As a note of caution, I quote responsibly, but I also present these replies thematically through the lens of my own worldview. As we say on Twitter, retweets are not endorsements, and opinions are mine only!

I consider it an important observation that an inability to work and provide for one’s family is one of the most noted difficulties when navigating a brain tumor diagnosis. I ask rhetorically what does it suggest about our culture that in the face of serious illness it is employment and income with which we find our selves concerned? In my life I’ve sacrificed time on personal projects in order to fit in working hours to earn income. This is a perennial issue for me. My good friend @JBHarp82 put things most bluntly. She replies, “Guilt:feeling like a burden on others at times when unable to do things ie: not working full-time to contribute financially as before.” Another reply suggests the painful loss of productivity: “it’s disheartening that while I don’t feel less intelligent, I am much less productive” (@mcintose).

It seems addressing, defining, measuring, and evaluating value and productivity are possible gaps for people living in a period of survivorship. How might our goals of care better close this gap?

Our social life is impacted, and this theme shows up in many replies, “Dealing with family/friends who say, ‘you’ve changed’,” writes @PatientAdvocac4. A more direct critique comes from @Lahla42928400: “…being careful about who I let in- too many assholes out there…” Before you find that remark too harsh, here it is in softer language, Again, @JBHarp: “Loneliness:everyone comes out of the woodwork offering support but once the initial shock wears off & surgery/initial treatments & restrictions are lifted, you don’t hear from anyone anymore it seems.”

Our friends play such a vital role in helping to process our experiences, and we need those friends to match our tenor. @Emi_Livingston gives voice to this concern: “dealing with people who are still in the ‘shock’ phase, and/or who focus on the negative when we want to embrace what’s normal and focus on moving forward actively.”

How might we better revise our cultural and social norms to encourage friends of those with serious illness to remain engaged through all stages of care, not only the most acute and interventional stages following disease onset and diagnosis?

The anxiety of survivorship comes up again and again: worries about the next MRI (@JBHarp82); “Waiting for shoe to drop recurrence (already thinking of next one and just beating this time,” writes @RipsRant. With a reminder that patients are not only tuned to their disease, @inewsham offers this insight: “Hearing about others whose cancer has returned and trying to keep those fears at bay.” For example, the death of Senator John McCain rippled through the brain tumor community regardless of political, demographic, and socioeconomic lines, I do not only speak for myself when I say we collectively mourned for the Senator that day.

Another theme to emerge is the drive toward acceptance of the “new normal.” “You’re all brave amazing people,” cheers @ChloeDrew8. She continues, “The new ‘normal’/facing life so differently to before is not to be underestimated.” The tremendous resilience and effort toward acceptance is visceral in this comment from @NancyNHuang: “I’m 2 years out and can pass for normal, but have come to realize that I will never fully recover. That is hard.” Or imagine this experience reported by @Project2Program: “After two surgeries, double radiation treatments, clinical trials, multiple chemo treatments and recovery from adverse events our biggest challenge in terms of #QOL [quality of life] is fatigue.” Striking a chord with balancing factors, @Sabine_NJ writes, “now:parenting; balance between living life (traveling) and family life.”

How might our care teams come alongside the persons under their care to pursue aims in light of the “new normal”? What we call the new normal is this period many call survivorship, and the challenges exceed those I mentioned in this post, which were: value and productivity, social life, anxiety, and ultimately accepting a new phase of one’s life, one that is like everyone else’s, maybe, but amplified and compressed.

How might we all better learn from the experiences of the seriously ill?

I was not able to include all of the many replies to my prompt. I thank all who ‘liked’ and ‘retweeted’ the question. To follow all the incredible members of our community, please navigate to Twitter and search hashtag #BTSM.

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