

It's All Semantics

Even though I've gone through and pulled apart the cancer lexicon, it's simply to promote awareness, dissect my own feelings on them, and explain some of the backlash.

March 18, 2019 By [Allison Ruddick](#)

I don't know anyone that hasn't been touched by cancer in some way. Even if you haven't, you're still aware that it exists and know the common phrases that accompany the subject. Lately, there's been some debate regarding various terminology that gets thrown around, so I decided to dissect and discuss some of them. Join me, won't you?

Fight/Battle

I admit, I've used these phrases myself and don't find much wrong with them. In fact, I still use "fight" because some days I literally feel like simply going through my everyday life is a fight against this overwhelming desire to retreat from society, lay in bed, pull the covers over my head and let the fatigue and anxiety consume me. So yeah, I do feel like I'm fighting in a way, just not in the physical sense, since I can't exactly go all Innerspace and battle the cells to the death with my own bare hands. The best I can do is choose a method of treating it that limits the casualties. After that, it's out of my control.

Warrior/Hero/Inspiration

Here's where it gets a little tricky for me. I personally don't like the idea that I'm being put on a pedestal simply because I got cancer and am trying to stay alive. It doesn't make much sense to me, and, admittedly, makes me uncomfortable (but don't get me wrong, I may get awkward about it, but I always appreciate the sentiment). Being called a "warrior," "hero" or "inspiration" for that reason seems to imply that I'm special because I got cancer. Nothing could be further from the truth, and I make it a point to state that outright whenever I can. I'm not special. None of us that have gotten cancer are special. If you think that we've got some power that you don't, it further perpetuates this idea that "it can't happen to me." Yes, it very well could happen to you, just like it happened to me and millions of other people. That's why it's so important to stay on top of your health. And if it does happen to you? You'll likely do the exact same things we're doing, because you find strength you never knew you had when your life is on the line.

However, there are instances when "hero/warrior/inspiration" can be warranted when referring to a cancer patient.

For example:

Hero — We're heroes when we tell our stories. We're heroes when we put all of the uncomfortable symptoms/side effects/struggles out there because we could very well be saving someone's life. Whether it's the person that decides to go to the doctor and get checked out, or the fellow patient that realizes they're not alone in the way they feel or react. We're heroes when we sign up for studies and trials that could advance treatment options, when we answer surveys that could help mitigate side effects, and when we pick up the phone for the friend of a friend that just got diagnosed. We're heroes when we help each other through it. Tell us we're your hero when we've convinced you to go for your own screenings. Knowing that something I said triggered your need to take care of your own health means more to me than anything else you could say.

Inspiration — We're an inspiration because of how we've chosen to handle a really difficult situation. We're inspirations when we choose to see the silver linings and turn it into something worthwhile. We're inspirations when we can hold our heads (bald or not, not all cancer patients lose their hair, guys) high and accept the cards we've been dealt. So if how we're doing it inspires you to move through your own difficulties, then yes, please tell us so.

Warrior — The word "warrior" does imply a certain amount of fortitude, and in the case of cancer, fortitude is definitely a prerequisite. It takes a lot of it to walk into that treatment center every time knowing how you're going to feel afterwards. It takes fortitude to live your life as well as you can while going through it (something I definitely struggle with). It also takes a certain amount of fortitude to accept that which you cannot change, and to plan for the worst case scenarios, which brings me to my next phrase...

Lost Their Battle

No. Nope. No. I hate this one and I hope no one uses it if I die from my cancer. It implies that the cancer was stronger than the individual, and while that may be true physically, in my opinion, mental strength is even more important. To me, there is no stronger person than the one that can accept their fate with grace and dignity. The cancer patient that chooses to let their life come to an end on their own terms—and make plans for their loved ones' lives after they're gone—is a hero to me. I know I'm not that strong yet. I know that if it comes down to it, I don't have it in me to stop searching for treatment because facing the fact that I would have to say goodbye to the people in my life is too much for me to bear. My strength, therefore, is limited. The patient that dies from cancer has never been as strong as they were at the end of their life, and please don't weaken that by saying that they "lost" in some way.

Patient or Survivor

Eeek. This one is tough because I feel like they flatten the cancer experience into black-and-white—you either have cancer and consider yourself a patient, or you don't and consider yourself a survivor. But if you've been through all of this time and time again, you know there's a whoooooole lot of gray area in between. I'm one of those people that live in the gray. Right now, there's evidence of disease in my body, but it's dormant. I'm on a break from treatment, but my scan next month could show growth, in which case I go back in. I'm essentially incurable through standard methods of surgery and radiation, but it seems at bay for the time being. So I'm not

exactly a “patient,” but I’m also not a “survivor.” So what do we call me? Telling people I’m “living with cancer” is just too clunky and always requires more of an explanation. “Cancer-afflicted”? “Cancer-ravaged” isn’t really pretty, but it’s definitely an accurate description for many of us. Even if those mutant cells are gone, they’ve left a whole lotta crap in their wake, no? Either way, there doesn’t seem to be a one-size-fits-all term.

Cancer-Free

I’ve learned my lesson with this one. I remember getting the results of my first scans after treatment and proclaiming myself “cancer-free” on social media. There was an influx of congratulatory messages, excited “YOU BEAT CANCER!!!” texts, and a feeling of relief that I could finally move on with my life because cancer was in my rear-view mirror. Oh, Allison, how naive you were. I didn’t really listen when my oncologist specifically used the phrase, “no evidence of disease.” What I heard was him telling me that I didn’t have cancer anymore, when in fact, it was just that they couldn’t detect any of the cancer at the moment. After two recurrences, I’ve discovered that these are two very different things. Cancer is a tricky, tricky little beast. It hides. It starts out so small that it can travel without being detected. It’s not always visible to the naked eye, so even when they’re looking directly at it during surgery, they can’t tell if they got it all. But because they can’t see it doesn’t mean it’s not there. So when my cancer came back, I was rightfully devastated, and now also embarrassed because I had enthusiastically declared myself “cancer-free.” I’ve since learned to try to manage my own expectations (and the expectations of others in regards to my condition) by remaining cautiously optimistic, understanding the limitations of medical diagnostics, and using the correct term, “no evidence of disease” or NED. Can we all collectively commit to try to replace the term “cancer-free” with NED in our vernacular? While we’re at it, let’s add “evidence of disease, but dormant” to the lexicon as well. That would really help a girl out here.

Cancer Journey

I know this one really fires people up. A “journey” seems to suggest a nice little trip. Cancer is definitely not a holiday in Tahiti. When this term is used, many cancer patients get upset because it seems to invalidate the gravity of what they’ve gone through. It also seems to imply that it’s a set period of time, which, for many of us, isn’t really true. It just becomes your life. But if we don’t use “journey” or “battle,” what should be used? I admit that I pulled up the ol’ thesaurus to try to settle this once and for all, but every synonym for “journey” just seems too positive and light. “Experience” kind of sounds like you’re talking about skydiving or parasailing. Maybe “tenure as a cancer patient”? I think I know a few people that would agree that sometimes, “in the throes of cancer hell” or “shitty situation” would be more accurate.

Finally...

New Normal

When I was on auto-pilot during the first few months of treatment, this term kept popping up. At that point, I was still naively under the impression that I would be one of the lucky ones that would finish treatment, be cancer-free and go back to my regularly-scheduled programming, so I refused

to wrap my head around what “new normal” meant. I was not prepared for how life-changing it all was, just starting with diagnosis. Once you’ve heard the words “you have cancer,” your life will never be the same. Every pain you feel tends to be met with terror. Every sympathetic look makes you feel self-conscious. Even attempting to plan for your future starts to be painful because you have no idea how much of that future you’ll have. To me, this idea of a “new normal” is a reminder that I’ll never be able to return to the old normal. As with anyone that goes through something profoundly traumatic, it takes a while to accept that. So forgive the cancer patient that bristles with the mention of their “new normal.” It’s a scary prospect that you’ll never be as carefree as you once were.

All of this having been said, I’m of the mindset that taking offense to general terms is a waste of energy. Even though I’ve gone through and pulled apart the cancer lexicon, it’s simply to promote awareness, dissect my own feelings on them, and explain some of the backlash. But if you call me a “hero,” I will always smile. If you ask me about my “cancer journey,” I will answer kindly without a second thought. I don’t believe in being picky about how people describe my situation. In the end, everyone just tries to do their best, and using the wrong word shouldn’t be held against them. I certainly don’t want the cancer laymen to feel that they have to walk on eggshells around me because they’re afraid of upsetting me (it’s bad enough that you feel somewhat isolated because no one wants to tell you of their own troubles since they “don’t compare to cancer.” Please, keep me up-to-date on your life. It gets lonely around here). I will also jump up and down screaming the next time I see one cancer patient shaming another cancer patient for a term that they used. The way you feel, talk and respond to your diagnosis and disease is one-hundred-and-a-million percent personal.

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