

LIVING WITH CANCER

Not a Cancer Survivor

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Susan Gubar writes about life with ovarian cancer.

I am not a cancer survivor, and neither are the women in my cancer support group.

Mary feels that cancer was a “blip” in her past that no longer defines her. Diane is a survivor, but not of cancer; she is “a survivor of treatments of cancer.”

Patricia and Judy are not survivors, because they are undergoing their first treatments and have no idea how effective they will be. Not a survivor either, Sarah braces herself for the time — not if, but when — the cancer will return. And there is Allison, who, like me, feels put off by the word “survivor”; somehow the term sounds too heroic to claim for ourselves.

In newspaper articles, on TV shows and Web sites, and at social gatherings, many people with cancer define themselves as cancer survivors. The term is meant to be optimistic, suggesting that such people have beaten cancer, defeated the disease. Through a valiant struggle to endure, they have managed to get through the trauma of cancer and emerge on the other side, perhaps sadder but wiser and possibly even better equipped for existence, for they are now attuned to the precious, precarious nature of human life.

While I can only congratulate such people, surely there are others (besides the members of my support group) who cringe at adopting such an identity — and for a number of reasons. Does the celebration of the triumphant cancer survivor cast those who died from the disease in the role of victims who somehow failed to attain the requisite resiliency to overcome it? An American propensity to circulate stories of valiant individuals triumphing over great odds must make people coping with recurrent, chronic or terminal illness feel like duds. And even for those patients with cancers that can be cured, claiming to be a survivor might feel dangerous — like a jinx, a sign of the sort of chutzpah or hubris that could bring about dire reprisals from the powers that be.

Despite all the hype surrounding the “war against cancer,” many cancers remain incurable, and the people coping with them need some other terms to describe their sense of themselves. Approximately 40 percent of the American population will get a form of cancer; half of them (roughly 20 percent) do not survive. There must be (and must have been) quite a few people who have known themselves not to be survivors. What should we call patients up against these numbers? If some of us are not cancer survivors before our dying, are we cancer contenders? Cancer lifers, cancer dealers, cancer mavens, grits? As I eagerly await any and all suggestions, I ponder the various lexicons that mystify or vex people trying to keep a sense of self intact after dire diagnoses and sometimes draconian treatments.

If commonly used words pose a problem, so do arcane, ugly and incomprehensible lexicons that may serve the needs of medical specialists, but prove trying for many patients who have no idea what “creatinine” or “platelets,” “neutrophil counts” or “ecog status” really mean. In the 2010 novel “The Sickness,” by the Venezuelan writer Alberto Barrera Tyszka, a physician whose father is dying of lung cancer “finds the clinical terms unbearable,” forming “part of a pretentious, useless dictionary”:

neoplasty, exeresis staphylococcal empyema
pleural empyema anastomosis iliocolostomy
biopsy haemostasis prothesis laparotomy
ischemia lithiasis.

Just as incomprehensible, the acronyms resounding in hospital halls and rooms – PIC, CT, BRAC, PSA, GOG, CA-125, NPO, PEG, NG, PTN, PK, HER2, DCIS, LCIS – need to be translated for the ordinary listener, or they degenerate into an unpalatable alphabet soup.

And then consider the sometimes hilariously inappropriate languages of friends and relatives responding to a diagnosis, which happily make the members of my support group laugh.

“What a tragedy for your children,” Diane reports one acquaintance exclaiming – an excellent example of what I would call predatory pre-grieving.

Or “You should have gone to M.D. Anderson,” which is a nice instance of the know-it-all with information after the fact.

Or “You look great. Just eat your flaxseeds, and you’ll be fine,” a rejoinder of indefatigable optimism that some of us find off-putting.

Even frequently used rubrics can mask complex realities. Take, for example, our usual categories of “remission” versus “recurrence.” Often patients who feel perfectly well believe they are in a remission until their physician informs them that some sort of blood test or body scan proves that the cancer has returned.

The language of remission and recurrence makes it seem as if the cancer is gone, then back. But the hide-and-seek in many case histories suggests that while a number of cancers recede, they do not disappear. Some people live during long periods of contestation in which treatments continue to exert their sway, but the cancer does too.

Perhaps we need a word for that murky in-between zone that a number of us inhabit daily.

Susan Gubar is a distinguished emerita professor of English at Indiana University and the author of “Memoir of a Debulked Woman,” which explores her experience with ovarian cancer and the need for better detection tools and treatments.

Suleika Jaouad, whose “Life, Interrupted” column usually appears on Thursdays, will return in two weeks.