

The Language of Cancer

Richard Wassersug, PhD

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The word string “language of cancer” gets over a million hits in Google!

- Clearly many people have thought about this language and have written about it.
- There are many words and phrases that one could comment on.
- Here I will focused on a small selection of terms that have psycho-social implications; how they are understood can variously help or hurt us.
- This is just a small fraction of the terms one could explore about.

Here are a few terms that can be problematic because of how people understand (or misunderstand) them

1. Cancer
2. Survivor (diagnosed, treated, cured...or not?)
3. Fighter, warrior (and the “war” on cancer)
4. Palliative care, hospice
5. “Patient & Partner” vs. “Patient & Caregiver”
6. “Patient-Centered Care”, “Person-Centered Care” vs. “Relationship-Centered Care”
7. Patient Representative, Patient Advisor, Patient Advocate

Cancer

- There is no single disease called “cancer”; rather there are many diseases called “cancer” and they are not all equally dangerous.
- We too often fail to distinguish dangerous cancers from curable cancers.
 - By not making this distinction, cancer societies help promote the idea that one should be equally anxious about all cancers. [High levels of anxiety help them raise money!]
 - But one could argue that such imprecise taxonomy is unethical.
 - If the *American Cancer Society* were more honest, it would be called *the American Cancersu Society*.

- How do we change the situation? How do we get people to start to use the term “cancers”.
- Several authors have blamed the healthcare providers for not doing enough to educate patients that not all cancers are the same.
- But a case can be made that the problem lies mostly with the media.
- We can start with pushing journalists to be more accurate when reporting on famous people diagnosed with or dying of “cancer”.

Survivor

- Some patients love this term, others hate it.
- For some patients surviving is trivial, for others it is a miracle.
- For many, the term implies that one is “cured”.
 - While treatment for some cancers are clustered together, other treatments are offered to patients in a more incremental fashion as the disease progresses. [This is equivalent to the distinction between acute and chronic care.]
 - Patients, who are treated with intense, multi-modal therapies given over a relatively short time and have no further disease progression, are going to be the ones who will most like the term “survivor”.
- Breast cancer patients generally like this term.
- Prostate cancer patients commonly do not.

War, Fighting and Military Metaphors

- Common things one hears —
 - “He lost his fight with cancer.”
 - “He is determined to fight his cancer.”
- There is no evidence that the military metaphor extends life or improves quality of life!
- Instead it is associated with fatalism. It is all encompassing and takes away from living one’s life.

Hauser D & R Wassersug Do we need to end the 'war' on cancer? The Guardian. [[Op-Ed article](#)] March 22, 2015.

WINNING THE WAR AGAINST PROSTATE CANCER



An image used to promote the dog tag campaign in Canada, designed to emphasize a commitment 'to fight cancer'. The soldier's facial expression is meant to convey the seriousness of the moment and thus the seriousness of the disease.



Images of dog tags from two different prostate cancer dog tag campaigns.

Palliative Care, Hospice

- Linked to the warrior-mind set; i.e., to accept hospice is seen by those who believe that cancer must be fought (!), as surrendering to the enemy.
- But we are all mortal and death is unavoidable. Hospice requires accepting mortality...and that is not the same as giving up on life.
- Palliation is simply symptom management, including pain management. The common drug treatment for prostate cancer is androgen deprivation therapy. It is technically a palliative treatment and patients can be on and off it for years.
- Hospice would be more acceptable, if it came with life goals. [My goals are....]

For terminal breast cancer patients...

“Patients with longer admissions to hospice (>3 days) reported higher quality of life, and their caregivers were significantly less likely to experience major depressive disorder after their loved one’s death...”

Accordino MK 2017. Association between survival time with metastatic breast cancer and aggressive end-of-life care. *Breast Cancer Res Treat.* 166(2): 549–558.

“Patient and Caregiver” vs. “Patient and Partner”

- To be a caregiver is honorable in our society as it demonstrates a willingness to sacrificing oneself for someone else.
- But the title “caregiver” can be much more of a burden than a blessing.
- Research shows that having a partner improves survival, and thus, patient-partner partnerships should be protected.
- The first step to protecting these relationships is to keep the partners as partners, and not let their relationship devolve into a patient-caregiver relationship.

Some further points on the concept of caregiver

- Sex between a patient and a caregiver is unethical!
- Thus, to label someone the “caregiver” of a cancer patient implies that their sexual relationship is over.
- Because of our mortality, it is admittedly unavoidable that many relationships will end up with a “patient and caregiver” dynamic.
- However, we should resist that and avoid the label “caregiver” until it is absolutely necessary; i.e., when the relationship can no longer be a co-supportive partnership.

The Need to Keep Partnerships Strong

For five cancers—prostate, breast, colorectal, esophageal, and head/neck cancers—the survival benefit associated with marriage has been reported to be larger than the survival benefit of chemotherapy!

Given that fact, cancer centers might improve their outcomes by offering a little less chemo and offering instead dating services and marriage counseling.

Aizer AA *et al.* 2013. Marital status and survival in patients with cancer. *Journal of Clinical Oncology* **31**: 3869-3876.

“Patient-Centered Care”, “Person-Centered Care” vs. “Relationship-Centered Care”

- These terms are not exactly the same. But does it matter?
- It is not clear what the opposite of **Person-centered** care is, so it also follows that it is not clear what person-centered care is itself.
- At a superficial level, one assumes that patient-centered care or person-centered care involves direct eye contact between the caregiver and the patient rather than for instance, the healthcare provider looking at a computer screen or lab report.

- The terms patient-centered care and person-centered care are somewhat “gendered”. By that I mean...
- Women are better at reading emotion from body language and facial expressions.
 - Female patients may expect more eye contact and attention to body language than male patients because it carries more meaning for them.
- Technological advances in medicine mean more quantitative data for doctors to interpret, and males tend to be more data-oriented.
- It would help everyone in the healthcare system if everyone understood the stereotypic areas where men and women are more likely to excel.

- **Person-centered care** is about considering the impact of an illness on not just the patients, but on the people around them.

However...

- **Relationship-centered** care is a better term.
- It implies a working relationship between the patient and the healthcare provider.
- The equality associated with this concept can make life better for both patients and their healthcare providers.

Patient Representative, Patient Advisor, Patient Advocate

- These terms do not necessarily mean the same thing.
- Health organizations increasingly include patients with these titles on their boards, panels, ethics committees.
- So how should we and they determine who is qualified to be an “advisor”, an “advocate”, or a “representative” for other cancer patients?

Some thoughts on how to make people with these titles most effective

- **Patient representatives** should not rely on their experiences alone.
- **Patient advisors** should be able to give useful advice (and not just their personal opinions).
- To say a **patient advocate** is necessary, is to say that the healthcare system is not good enough at taking care of patients.
 - Thus, the term is an implicitly aggressive and confrontational. That may undermine the ability of a person with this title to provide the best advice.

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Thank you

richard.wassersug@ubc.ca