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Patient Handout: The Healing Power of the "Survivor" Label

Dear Patient,

As a cancer patient, you will see and hear the word "survivor" a lot. That label triggers a wide variety of reactions among patients. Whatever your thoughts and feelings about the term, this handout offers insights and tips on helpful, hopeful ways to think about "survivor."

What is a "survivor"?

The original definition dates back to 1986, when the term was introduced: "From the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor." [National Coalition for Cancer Survivorship (NCCS)]. According to that definition, anyone alive who *ever* received a cancer diagnosis is a "survivor."

Since then, some cancer organizations (including the NCCS) have broadened the term to include patients' family, friends, and caregivers. In the oncology literature for researchers and clinicians, "survivor" almost always refers only to the patient—and not to others impacted by a patient's illness.

What if you don't like the label "survivor"?

That's totally fine. We encourage you to use whatever label works for you. Popular alternatives include thriver, fighter, and cancer veteran. It may help to try out a few different labels before you settle on the best one for you for now. We say "for now" because your preferred label may change over time as you or your situation changes. You are not alone if you want no label at all.

Here's a suggestion to help minimize your distress and for you to benefit fully from others' information and inspiration: When you come across "survivor," simply substitute in your mind whichever label helps you feel your best about yourself and your life. Think of "survivor" as a technical term for "cancer patient" (just as "analgesic" is the term for "pain reliever.")

Why bother learning about the original meaning of "survivor"?

A brief review of the original intent when the label was coined may help you tap into its strengths whenever you see or hear it. Rewind a few decades to when cancer patients were called "victims." Everyone—clinicians, patients, families, caregivers—seemed to expect the patient's last treatment to mark the end of that patient's cancer experience. Patients who faced physical or emotional problems after treatment, or who were living with metastatic disease, had trouble understanding what was going on or talking about it with anyone. Clinicians were not trained to recognize patients' post-treatment problems or deal with them.

The survivorship movement aimed to change all that. In 1986, two goals of the term "survivor" were to…

- Move the culture of cancer away from the shame and helplessness of victimhood. They chose "survivor" because back then it stirred connotations of empowerment and hope.
- Help clinicians and patients perceive life as a continuum *before-during-after* a cancer diagnosis. Learning about the varied ways cancer may impact patients' lives would help everyone continue responding in helpful, hopeful ways from the moment of diagnosis and for the rest of life.

Whether or not you call yourself a "survivor," we encourage you to link that label to the ideas of empowerment and hope. In affairs of health, use whatever language works for you and try to respond to others' use of the word "survivor" in ways that help you…

- Get high-quality care in keeping with your values.
- Live as fully as possible every day.

How has the label "survivor" improved patient care?

The label was instrumental in advancing the *survivorship movement* where people joined together to change the culture of cancer. "Survivor" was one element of a broad agenda that succeeded in encouraging clinicians and patients to address the whole person, and not just focus on the cancer.

Generally speaking, clinicians and support services today strive to address your cancer *and* how your cancer and its treatments …

- Are affecting your physical condition now.
- Might impact your physical condition in the future.
- Are affecting the other spheres of life now (e.g., your emotional, psychological, spiritual, financial, and social health).
- Might affect those other spheres of life after treatment or during chronic treatment.

When you hear or see "survivor," keep in mind the original intention of capturing all aspects of "living" after a cancer diagnosis. When professionals and support resources use "survivor" today, it's with the idea of addressing your cancer cells *and* your quality of life today. At the same time, they want to prevent or minimize future health issues, cancer-related and otherwise, whenever possible.

Why might some people feel uncomfortable with the label "survivor"?

The "survivor" label does nothing for some people. For others, it's unsettling or even offensive. Understandable reasons include…

- Negative experiences with the word "survivor."
- Negative associations of "survivor" unrelated to cancer.
- Objection to anyone identifying people by their disease.
- Fear of tempting "fate," as if "survivor" jinxes a recovery.
- If living with advanced disease, "survivor" seems unsuitable and/or stirs anger about the prognosis.

Discomfort with "survivor" may be related to the literal definition, which says nothing about your role in your care or your quality of life. After all, people are "survivors" whether pursuing high-quality oncology care or declining effective therapies in favor of "secret potions" ordered online. People are "survivors" whether embracing each day with gratitude or fretting in a pity party of hopelessness.

How can you use "survivor" in healing ways?

If you like the term, use it with pride. Find ways to strengthen the positive associations of empowerment and hope. If "survivor" does not work for you…

- Honor its historical contribution to improved cancer care.
- Substitute your preferred term whenever you read or hear it.
- Consider it a technical term for "cancer patient"—and not a label.

If you prefer a different label, explain that to those close to you, including your healthcare team. Be forewarned, you might have to help them remember. If they slip up, there's a good chance that they are thinking of "survivor" differently than you.

From the time of your diagnosis and for the rest of life, use and respond to "survivor" language in whatever ways help you live your best life today, tomorrow, and every day. OT