Take care when you use the word survivor

The Canadian Association of Nurses in Oncology is in the process of updating the Survivorship Resource Modules, which ought to be ready early in the new year. These modules were first developed in 2011, but much has happened since then within the domain of cancer survivorship and the resource needs to be aligned with those developments. We continue to see a growing cadre of individuals who are living after a cancer diagnosis and treatment with no clinical evidence of disease or with ongoing therapies that control the disease. For some, cancer has become a chronic illness. With the advent of new screening approaches and targeted therapies, we can expect this trend in cancer survivorship to continue and, hopefully, spread around the globe.

Despite these advances, there is one controversy that remains. That controversy is the definition of survivor and how we use the term. There are still several definitions of the word, none of which are universally accepted.

The National Coalition of Cancer Survivors (U.S. based) defines a person as a survivor from the time he or she is first diagnosed and throughout the balance of life. The U.S. National Cancer Institute extends this definition by also including family members, friends and caregivers. The argument to include them is that the cancer experience affects them, as well. The Canadian Cancer Society ascribes to this broad definition of survivor, and includes individuals who have experienced recurrence and require palliative care. Meanwhile, the European Organization of Research and Treatment of Cancer (EORTC) defines a cancer survivor as an individual who was diagnosed with cancer, finished primary cancer treatment and has no evidence of active disease—a circumscribed viewpoint.

So, depending upon the definition one embraces, the target audience differs, as well as the focus on the point of the cancer journey. If you are planning for service delivery, a support program or a research proposal, you will have a vastly different population (the individual versus both the individual and his or her social network) and focus (the interval after primary treatment to the diagnosis of recurrence versus the entire cancer experience) to be concerned about if you embrace one or other of the definitions.

The definitions should also influence your reading of the research literature on survivors. You always need to ask yourself which definition the investigators followed—especially if you want to use the evidence as a basis for your practice. And if you are trying to decide what standardized instrument to use to capture PROs, the definition comes into play there, as well. The PROs that have meaning for an individual during the interval of receiving treatment will be different (although there will be some overlap) than during the interval following the completion of primary treatment. And the PROs will definitely be different for the family and friends than for the patient (although this is an area that still needs a great deal of attention).

But perhaps most importantly, not all individuals who are living with a history of cancer embrace the word ‘survivor’ and feel it applies to them. The word itself likely grew out of the declaration of ‘the war on cancer’, and is connected with a notion of ‘winning a battle’. But for many individuals with cancer, this is not the case. For many so-called survivors, they are left with late and long-term effects with which they continue to struggle. Others just want to put the whole experience behind them, to ‘return to normal’ and carry on with their lives as before.

However, some do incorporate the identity of a survivor and feel empowered and connected to a community that has coped with adversity and difficult times. And some look beyond this vision and see their time following cancer as a time to make life changes and embrace the notion of becoming a ‘thriver’.

Thus, as oncology nurses, we needed to be careful how we apply and use the term ‘survivor’. We should not use it without careful consideration of the definition we embrace personally. And we need to check with those who are approaching the interval following their cancer treatment about what they would like to be called.

Margaret I Fitch, RN, PhD
Editor in Chief, CONJ