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Guest Editorial

The use and misuse of the concept of cancer survivor

As a cancer survivorship researcher, I have been wondering for two decades about the use and misuse of the concept of cancer survivor. “Controversies in defining cancer survivorship” have been raised before.¹⁻² This editorial is based on a recent experience after conducting a scoping review on the use of telehealth in cancer survivorship and struggling to find articles that distinguish between cancer patients in treatment and cancer survivors after treatment was completed.

The first definition of the concept of cancer survival was in 1985 by Mullan,³ a physician and cancer survivor, who presented the three “Seasons of survival” that included: acute survival (period after diagnosis, where the focus is on surviving treatment); extended survival (period after the end of treatment, often known as remission, where the focus is on dealing with short-term consequences of treatment); and permanent survival that refers to long-term survival (5 years after the end of treatment, when the patient is “cured” but needs to deal with late effects of treatment).³

Today, five-year survival for all patients with cancer has increased due to advances in cancer screening and effective cancer treatment, although differences exist between types of cancer and stage at diagnosis.⁴ Worldwide, there are more than 32 million cancer survivors, and this number is projected to increase in the following decades.⁴ Certainly,

we should acknowledge the survival statistics of cancer if health management is to be effective. However, we also should focus on the concept of cancer survival that is practical in the real-world setting.

Here is where the problem lies. Many researchers and institutions used interchangeably the term cancer survivor to refer to anyone who received a diagnosis of cancer no matter where they are in the course of the illness.⁵ I agree on the importance of having a holistic perspective of the cancer trajectory. However, this approach limits understanding of a cancer survivor as a person who has completed treatment, is disease free, and may be dealing with the challenges associated with cancer survivorship, including chronic pain, fatigue, chemobrain, organ toxicity, depression, fear of recurrence, financial toxicity, insurance problems, among others.³ Furthermore, it is important to distinguish between short-term and long-term cancer survivors to help ensure healthcare services are better tailored to suit their needs. “Short-term survivor” refers to the person who finished treatment 1 to 5 years ago and is in remission with no signs and symptoms of cancer (the extended survival according to Mullan). “Long-term survivor” refers to those who completed treatment 5 or more years ago (the permanent survival according to Mullan).⁶

Why is it important to make time distinction when referring to cancer survivors? The answer is both simple and complex: to enable practitioners, researchers, managers, and policymakers to meet the specific [physical, psychological, social, spiritual, financial] needs of survivors after completion of treatment. Since the pioneering report “*From cancer patient to cancer survivor: Lost in transition*” 17 years ago,² there appears to be agreement on the need for specific survivorship care from global institutions such as the Centers for Disease Control and Prevention (CDC), the American Society of Clinical Oncology, the European Organization of Research and Treatment of Cancer (EORTC)

Survivorship Task Force or the Livestrong Foundation. Essential components of survivorship care are 1) surveillance and detection of new cancers and recurrent cancer; 2) management of late and long-term effects of cancer and its treatment; 3) health promotion and quality of life (diet & nutrition, physical activity, effective coping, etc.); and 4) care coordination between specialists and primary care providers.² Today, these components are mostly operational through the Survivorship Care Plan (SCP) in which nurses actively participate in its design, delivery, monitoring, and coordination.⁷ However, the use of SCPs has not been extended to long-term cancer survivorship care and has been mainly implemented in acute and extended survival (hospital-based care) despite a growing population of long-term survivors.⁷ Therefore, it is urgent to extend SCPs to primary care to provide quality care to long-term cancer survivors, most of whom have been discharged from specialized care after 5 years of disease-free. Primary care nurses are excellent at assessing short-term effects of cancer (nausea, fatigue, etc.) but might be less prepared to care for survivors during long-term follow-up. Empowering cancer nurses to improve transitions following treatment and survivorship care has been recommended.⁸ Priorities about long-term cancer survivorship should comprise assessment and monitoring of late effects and toxic effects, life conditions (e.g., work or insurance issues), and health-related quality of life. Without forgetting family caregivers who also have unmet needs in long-term cancer survivorship.

To end, this editorial is not intended to be conclusive about a definition of cancer survivor but to provide a catalyst for a universally accepted definition to establish the most appropriate research and care delivery agenda. There is a need for consensus that a cancer survivor is a person who completed treatment and is disease-free for at least 1, 3, 5, or more than 5 years. In addition, there is a need to recognize the full spectrum of late

and long-term effects in cancer survivorship as well as to meet the challenges of those no longer cancer patients but survivors who may feel “lost in transition”.

My very best,

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