DEFINING CANCER SURVIVOR AND CANCER SURVIVORSHIP: THE WHO, WHAT, AND WHEN

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Abstract

Over the past three decades various definitions of cancer survivor and cancer survivorship have been proposed. These definitions frequently describe (1) who is considered a cancer survivor and who is experiencing cancer survivorship, (2) what it means to be a survivor and experience survivorship, and (3) when someone is considered a survivor and when survivorship begins. Descriptive epidemiology indicates that certain individuals diagnosed and treated for cancer describe the presence of specific unmet needs following diagnosis and treatment for cancer. Evidence also points to an increased likelihood of cancer recurrence or a new cancer in many cancer patients. These observations should be reflected in the case definitions of cancer survivor and cancer survivorship. This paper reviews the literature for evidence to validate existing definitions of cancer survivor and cancer survivorship and proposes updated definitions for each. Based on this evidence, a cancer survivor is defined as an individual diagnosed with cancer. The period following primary treatment, which is characterized by transitions in care and a need to address the late effects of cancer and its treatment, may be a particularly critical time for the cancer survivor. The definition does not preclude the major involvement of family, friends, caregivers, and providers, but does place the focus on the individual who received the diagnosis.

Resumen

Durante las últimas tres décadas se han propuesto diversas definiciones del superviviente de cáncer y la supervivencia del cáncer. Estas definiciones describen con frecuencia (1) quién se considera un superviviente de cáncer y quién experimenta la supervivencia del cáncer, (2) lo que significa ser superviviente y la experiencia de sobrevivir, y (3) cuándo se considera que alguien es un superviviente y cuándo comienza a ser un superviviente. La epidemiología descriptiva indica que ciertos individuos diagnosticados y tratados de cáncer describen la presencia de necesidades específicas insatisfechas tras el diagnóstico y tratamiento para el cáncer. Los datos disponibles apuntan a un aumento de la probabilidad de recurrencia del cáncer o un nuevo cáncer en muchos pacientes con cáncer. Estas observaciones deben reflejarse en las definiciones de caso del superviviente de cáncer y la supervivencia del cáncer. Este artículo revisa los datos relativos a la validez de las definiciones existentes de superviviente de cáncer y supervivencia del cáncer y propone definiciones actualizadas para cada uno. Con base en estos hallazgos, se define como superviviente de cáncer a un individuo diagnosticado con cáncer. El periodo que sigue al tratamiento primario, que se caracteriza por las transiciones en el cuidado y la necesidad de abordar los efectos tardíos del cáncer y su tratamiento, puede ser un momen-
of cancer. Children and young adult cancer survivors should be housed in subgroups under the “cancer survivor” umbrella. In addition, cancer survivorship is defined as the period of time beginning at cancer diagnosis where attention by the survivor and his or her care team is directed at addressing needs related to health, symptoms, function, lifestyle, and well-being; these needs may change through the care trajectory. Coordination of care between oncologist specialists involved in the early phases of cancer diagnosis and treatment and primary care physicians involved in long-term follow-up is critical. As new knowledge is acquired regarding cancer survival and the cancer experience, modifications to these proposed definitions will be imperative.

**Keywords:** Cancer, oncology, cancer survivor, cancer survivors, cancer survivorship, definition, definitions.

**OVERVIEW**

While the incidence of cancer continues to increase, improvements in detection, diagnosis, and treatment\(^1\) have led to steady declines in mortality over the past four decades\(^2\). Internationally, an estimated 32.6 million cancer survivors were living within five years of diagnosis in 2012\(^2\). This statistic is based exclusively on a definition of cancer survivor that only considers 5-year prevalent cancer cases. However, other definitions of “cancer survivor” have been considered over the past several decades\(^3\). There is also a lack of consensus surrounding the definition of “cancer survivorship,” a term often used in tandem with “cancer survivor.” Though authors of recent reviews have provided excellent summaries on key concepts related to cancer survivors and cancer survivorship\(^3,4\), they have not clearly proposed updated definitions of cancer survivor and cancer survivorship based on the literature. In order to move forward in our understanding and ability to determine meaningful intervention targets and outcomes for cancer survivorship care, global consensus should be reached regarding evidence-based definitions of cancer survivor and cancer survivorship. As the definitions will guide resource allocation, it will be important that they capture the subset of individuals most affected by cancer and its treatment.

Tables 1 and 2 provide the range of definitions for cancer survivor and cancer survivorship that have been proposed over the last three decades. These definitions...