

# Who Is a Cancer Survivor? A Systematic Review of Published Definitions

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**Abstract** The term “cancer survivor” is commonly used by different persons, clinical institutions, academic bodies, and political organizations although it lacks of a unanimous and detailed definition. The objective of the study is to make a systematic review of published and proposed definitions of “cancer survivor.” Utilizing a systematic search strategy with different strings of “cancer survivor,” we searched the following databases: Medline (June 1975–June 2015), Scopus (all the years), Web of Science (all the years), Google Scholar (all the years), ERIC (all the years). This review suggests that there is not a unique definition of who is a “cancer survivor” and what is “cancer survivorship.” However, the most widely used definition sees cancer survivorship as a process that begins at the moment of diagnosis and continues through the balance of life. This definition highlights psychological and legal patient’s needs—as well as medical ones—to receive care and assistance from the beginning and, at the same time, it establishes valid criteria for making scientific and statistical sampling research. The extensive use of the term “cancer survivor” indicates that it is a significant term. This review has been written to outline the state of the art and it invites to reflect on a shared definition that could satisfy both clinical

and research aspects. Implication for cancer survivors: this compendium of proposed definitions may improve communication among the many patients and patient organizations that use and work with this term.

**Keywords** Cancer survivor · Cancer · Psychological aspects · Communication

## Background

Who is a “cancer survivor”? When a person could be defined a “cancer survivor”? What is “cancer survivorship”? These questions are the focus of numerous studies. Even if 30 years are passed from the first use of these terms in clinical oncology, there is still lack of consensus on what they mean. In fact, the term “cancer survivor” was coined and used for the first time by a pediatrician, Fitzhugh Mullan, who was diagnosed with cancer in 1975. In 1985, he published an article in *New England Journal of Medicine* theorizing the concept of “cancer survival” as a “time of life” that went from a phase of acute survivorship to a phase of extended survivorship. This idea has to counter the dichotomy “cured/not cured” and to highlight that, regardless of prognosis, there are experiences and characteristics shared by those who lived through the oncological disease and distinguish them from the general population. The increasing effectiveness of therapies and the increasing adherence to screening programs for early detection have greatly improved the prognosis of cancer, leading to the progressive and continuous reduction in mortality and the gradual increase in the number of people with a cancer. Today cancer survivor and cancer survivorship are the focus of numerous studies and behind a label there is a lot of questions and studies to define patients who have been diagnosed with cancer and who are still alive.

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The aim of this paper is to give an overview concerning this definition and to determine the contexts or settings in which the term has been used. We believe that to review different meanings of “who is a cancer survivor and what is cancer survivorship” could improve communication among the many individuals and organizations that use the term. For this reason, we collected, examined, and qualitatively analyzed the published proposed definitions of “cancer survivor” and “cancer survivorship.”

## Methods

We performed a systematic literature study to find unique definitions of “cancer survivorship” and identify and recurrent topics discussed in conjunction with this term.

### Search Strategy

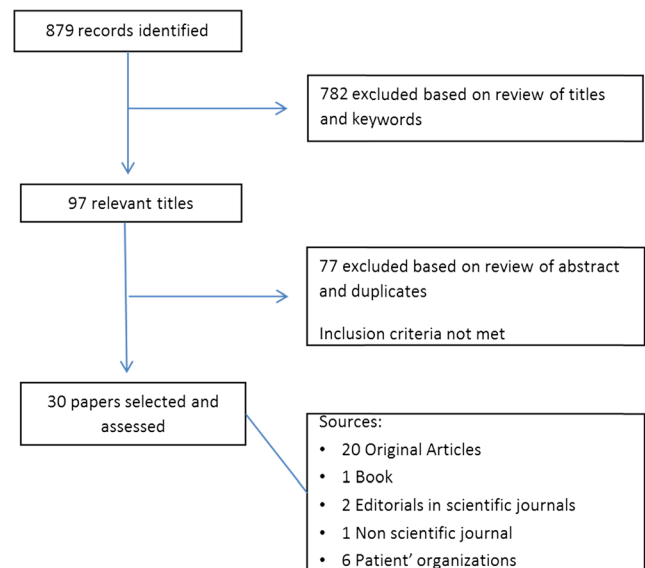
Four electronic databases were searched PubMed (June 1975–June 2015), Scopus (all the years), Web of Science (all the years), Google Scholar (all the years), and ERIC (all the years) using keywords “cancer survivor definition,” “cancer survivorship definition,” “cancer survivor label,” “cancer survivorship label,” “definition of cancer survivorship,” “definition of cancer survivor,” and “cancer survivor cancer survivorship definition” (Table 3). For each database, we searched all available years through June 2015. We included papers (1) written in English or Italian language, (2) published prior to June 2015, and (3) focused on cancer survivor/cancer survivorship definition (4) of adult patients. The initial search resulted in 879 articles. We also searched the reference lists of relevant articles to identify other articles.

Seventy-six papers were excluded based on review of titles, keywords, abstracts, and duplicates. Thirty articles were included in the final selection.

The flowchart for how articles were selected for this review is shown in Fig. 1.

## Results

Both in the USA and in Europe, the last 30 years have witnessed a growth of new cancer diagnoses due to two complementary phenomena [1, 2]. The first is the improvement of early detection and treatment of disease: primary prevention reduces important risk factors with the promotion of healthy lifestyles, such as avoiding tobacco, maintaining a healthy body weight, and being physically active throughout life. The second is the aging of the population [3, 4]. By 2030, it is estimated that 19.3 % of the population will be aged  $\geq 65$  years and by 2050, 19 million people will be aged  $\geq 85$ . At the same time, length of survival from cancer is steadily



**Fig. 1** Flow of study

increasing: an estimated 64 % of survivors had been diagnosed  $\geq 5$  years earlier, and roughly 15 % represented survivors whose cancer was diagnosed  $\geq 20$  years earlier [5]. The consequence is that by the year 2020, two thirds of all cancer survivors will be aged  $\geq 65$  years [6]. This growth in survival rates and an increased attention paid to the patient’s experience have led to a shift from defining cancer patients as victims to survivors [7, 8].

In order to describe a structured and exhaustive compendium of definitions, we have divided definition about “cancer survivor” (Table 1) from definitions about “cancer survivorship” (Tables 2 and 3).

### Biomedical Approach vs bioPSYCHomedical Approach of Cancer Survivorship

According to an evolutionary concept analysis, in the medical literature, the term survivorship first appeared in the 1960s, but only by the 1980s, it was related to cancer purview [9]. When cancer was considered incurable, the term “survivor” was used to describe family members who survived the loss of a loved one to cancer [10]. Then, in 1980, the term was associated directly to the patient and the survival acquired a double acceptance: a biomedical meaning in contrast with an experience that includes psychological aspects in addition to the medical ones [11].

Referring to the first, it means an individual who have had a cancer diagnosis in the past, but he has completed treatment [12]; so, survivorship refers to a period after therapy ends or, specifically, after 2, 3, 5, or 10 years after diagnosis without recurrence [9, 13–15]. However, this definition does not consider the individual’s perspective; thus, patients and organizations against cancer fight to reach a new concept of survivorship.

**Table 1** Title and definition of cancer survivor

Title	Definition of cancer survivor
National Coalition for Cancer Survivorship, (1986).	A cancer patient is a survivor from the moment of diagnosis and for the balance of his or her life, regardless of the ultimate cause of death.
Carter, B. J. (1993). Long-term survivors of breast cancer: A qualitative descriptive study. <i>Cancer Nursing</i> , 16(5), 354–361. ISO 690	Individuals who have survived breast cancer beyond 5 years without recurrence.
Marcus, A. D. (2004). Debate heats up on defining a cancer survivor. <i>Wall Street Journal</i> , D4.ISO 690	Who have had a cancer diagnosis in the past, but he had completed treatment and he was disease-free for a minimum of 5 years.
Office of Cancer Survivorship of the National Cancer Institute (1996–2014)	One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.
Little, M., Sayers, E. J., Paul, K., & Jordens, C. F. (2000). On surviving cancer. <i>Journal of the Royal Society of Medicine</i> , 93(10), 501.ISO 690	Those people who have had a cancer, and who are living, at any period after treatment, apparently free of recurrent or persistent cancer.
Hewitt, M., Greenfield, S., & Stovall, E. (2006). From Cancer Patient to Cancer Survivor: Lost in Transition. Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council.	An individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life, according to the National Coalition for Cancer Survivorship and the NCI Office of Cancer Survivorship.
Department of Health, Macmillan Cancer Support and NHS Improvement (2010) The National Cancer Survivorship Initiative Vision. London: Department of Health, Crown Copyright; 2010	Those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease.
Twombly, R. (2004). What's in a name: who is a cancer survivor?. <i>Journal of the National Cancer Institute</i> , 96(19), 1414–1415 Feuerstein, M. (2007). Defining cancer survivorship. <i>Journal of cancer survivorship: research and practice</i> , 1(1), 5–7.	The individual with the cancer diagnosis, not the family.
Simonelli, C., Annunziata, M. A., Chimienti, E., Berretta, M., & Tirelli, U. (2008). Cancer survivorship: a challenge for the European oncologists. <i>Annals of oncology</i> , 19(7), 1216–1217. Mattioli, V., Montanaro, R., & Romito, F. (2010). The Italian response to cancer survivorship research and practice: developing an evidence base for reform. <i>Journal of Cancer Survivorship</i> , 4(3), 284–289. IVEuropean conference on survivors and chronic cancer patients, Siracusa, Italy, June 8th 2012. Available at <a href="http://www.oncologicicronici.it">www.oncologicicronici.it</a> .	Patients without evidence of disease and free from specific treatment for a period of at least 5 years.
Giacalone, A., Lleshi, A., Zanet, E., & Tirelli, U. (2012). Symptom burden in cancer survivors 1 year after diagnosis. <i>Cancer</i> , 118(7), 1955–1955.	
Shi, Q., Smith, T. G., Michonski, J. D., Stein, K. D., Kaw, C., & Cleeland, C. S. (2011). Symptom burden in cancer survivors 1 year after diagnosis. <i>Cancer</i> , 117(12), 2779–2790.	A cancer patient is a survivor from the moment of diagnosis and for the balance of his or her life.
Surbone, A., Annunziata, M. A., Santoro, A., Tirelli, U., & Tralongo, P. (2013). Cancer patients and survivors: changing words or changing culture?. <i>Annals of oncology</i> , 24(10), 2468–2471.	Patients who have lived beyond 3–5 years from diagnosis, or end of treatment, with no evidence of disease.
Bell, K., & Ristovski-Slijepcevic, S. (2013). Cancer survivorship: Why labels matter. <i>Journal of clinical oncology</i> , 31(4), 409–411	Someone who has had a cancer.
<a href="http://www.tumori.net">www.tumori.net</a> (2015)	People who have had a diagnosis of cancer for more than 5 years.

**Table 2** Title and survivorship definition

Title	Survivorship definition
Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer. <i>New England Journal of Medicine</i> , 313(4), 270–273.	Three phases of cancer survivorship: the period after diagnosis and during primary treatments is defined “acute survivorship” and it’s the time where there could be an existential crisis. The difficult time when patients are focused on dealing with the physical and psychological consequences after completion of treatment is called “extended survivorship”: individuals may experience other concerns like their health or the quality of received care. Finally, the “permanent survivorship” characterizes the period when patients are living with cancer as a chronic disease or when individuals are in remission thanks to ongoing treatment.
Dow, K. H. (1991). The growing phenomenon of cancer survivorship. <i>Journal of Professional Nursing</i> , 7(1), 54–60. ISO 690 Wallwork, L., & Richardson, A. (1994). Beyond cancer: changes, problems and needs expressed by adult lymphoma survivors attending an out-patients clinic. <i>European journal of cancer care</i> , 3(3), 122–132. ISO 690	Survivorship is a process without an endpoint.
Deimling, G. T., Sterns, S., Bowman, K. F., & Kahana, B. (2005). The health of older-adult, long-term cancer survivors. <i>Cancer nursing</i> , 28(6), 415–424. ISO 690	Survivorship is a lifelong journey.
Pelusi, J. (1997). The lived experience of surviving breast cancer. In <i>Oncology nursing forum</i> (Vol. 24, No. 8, pp. 1343–1353). ISO 690 LiveStrong Foundation (Centers for Disease Control and Prevention and the Lance Armstrong Foundation) (2004)	Cancer survivorship is the experience to live with, through and beyond cancer.
Office of Cancer Survivorship of the National Cancer Institute (1996–2014) and The National Plan (2004)	In cancer, survivorship focuses on the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.
Doyle, N. (2008). Cancer survivorship: evolutionary concept analysis. <i>Journal of Advanced Nursing</i> , 62(4), 499–509. ISO 690	It is a process life-changing experience that begins at diagnosis and involves uncertainty with a duality of positive and negative aspects and is unique to the individual while also having some universal features. The consequences of cancer survivorship may be divided into four main themes: physical health, psychological health, social health, and spiritual health.
Leigh, S. A. (2008). The changing legacy of cancer: issues of long-term survivorship. <i>Nursing Clinics of North America</i> , 43(2), 243–258.	Cancer survivorship could be viewed (1) as a time frame, so it could be developed on the basis of type and stage of the disease (i.e., after 2, 5, or 10 years); (2) as an outcome like no evidence of disease, complete remission, or cured; (3) as a stage or phase and, in this case, we must consider if primary treatment are ended or there are any recurrence; or finally (4) as a process where people live through different stages of illness.
Miller, K., Merry, B., & Miller, J. (2008). Seasons of survivorship revisited. <i>The Cancer Journal</i> , 14(6), 369–374.	Today, acute cancer survivorship is still a time of intense emotion and medical activity surrounding the diagnosis, staging, and actual treatment. We then propose that after the intense initial therapy is completed, the survivors enter a “season” that can be called “transitional cancer survivorship” reflecting the transition from active treatment to careful observation and the emotional, social, and medical adaptations that occur. Next, there are a growing number of cancer survivors who are (1) alive and “living with cancer” but requiring ongoing treatment for recurrent, active, and often advanced disease; (2) in a complete remission that requires ongoing therapy; or (3) in a complete remission and with a favorable prognosis. Collectively, this is a diverse group in “extended survivorship” and some later go on to obtain a permanent remission although others experience disease progression. Finally, there are millions of long-term or “permanent survivors.” This group is also very heterogeneous and is comprised of 4 subgroups including (1) survivors who are “cancer-free but not free of cancer,” (2) survivors who are cancer-free but continue to have significant “fall-out” from cancer and its treatment including psychosocial, medical, financial, or legal sequelae,

**Table 2** (continued)

Title	Survivorship definition
	(3) survivors who go on to develop second cancers which may be unrelated to the first cancer or its treatment, or may be more likely due to genetic or environmental factors, and also (4) survivors who later develop cancers that are secondary to the initial treatment.

The term “cancer survivor” begins to be used in clinical setting by Fitzhugh Mullan, a physician who, in an article about his own cancer, reported his illness experience as “to pass through the seasons of survival.” In 1985, Mullan described three phases of cancer survivorship in *The New England Journal of Medicine*: the period after diagnosis and during primary treatments is defined “acute survivorship” and it is the time where there could be an existential crisis. The difficult time when patients are focused on dealing with the physical and psychological consequences after completion of treatment is called “extended survivorship”: individuals may experience other concerns like their health or the quality of received care. Finally, the “permanent survivorship” characterizes the period when patients are living with cancer as a chronic disease or when individuals are in remission thanks to ongoing treatment [16].

This definition underlies that there are different phases of the disease. Each of these has specific cures and specific emotion to cope: the survivorship experience is the *trait d’union* among them.

One year later, Mullan and other organizations established the National Coalition for Cancer Survivorship (NCCS) in the USA to “advocate for quality cancer care for all individuals touched by cancer” and “to deal with the full spectrum of survivorship issues” [17]. According to NCCS, a person could call himself or herself a survivor “from the moment of diagnosis and for the balance of his or her life, regardless of the

ultimate cause of death.” This perspective aims to recognize the person and not only the patient, the needs and not only the treatments. This definition will be shared by several organizations that deal with cancer survivor’s experience [18, 19]. To witness the definition’s agreement of survivorship as a continuous process, from 1981 to 1985 (the 5 years period before the founding of the NCCS), a search of PubMed was conducted among research articles. Twenty-eight studies were identified using the terms cancer survivorship and between 2001 and 2006, they were about 7700 [20].

Even though several years have passed since the beginning of defining cancer survivorship and who is a cancer survivor, today there is still no a unique definition for these terms.

#### **A Definition Matter: Is Cancer Survivorship a Time Frame, an Outcome, a Stage or a Process?**

Surely, the time is the first obstacle to the achievement of an agreement: when does the cancer survivorship start? When a patient could be defined a cancer survivor?

During the 2007 San Antonio Breast Cancer Symposium, 516 respondents including physicians, oncology nurses, nurse practitioners, physician assistants, and other members of breast cancer care (e.g., advocates and patients) completed a survey that revealed a lack of consensus on the definition of cancer survivor [21]. Only 26 % of respondents selected the definition established by the National Coalition for Cancer

**Table 3** Search strategy for scientific literature

Search Engine:	Search String:	Hits	Relevant <sup>a</sup>	Included <sup>b</sup>
Pubmed	“Cancer survivor definition” or “cancer survivorship definition” or “cancer survivor label” or “cancer survivorship label” or “definition of cancer survivorship” or “definition of cancer survivor” or “cancer survivor cancer survivorship definition”	643	20	17
Google Scholar	“Cancer survivor definition” or “cancer survivorship definition” or “cancer survivor label” or “cancer survivorship label” or “definition of cancer survivorship” or “definition of cancer survivor” or “cancer survivor cancer survivorship definition”	236	77	30
Subtotal		879	97	47
Duplicates				17
Total		879	97	30

<sup>a</sup> Relevant: number of relevant articles based on title, abstract, and keywords

<sup>b</sup> Included: number of included articles based on full article

Survivorship (i.e., from the moment of cancer diagnosis and for the balance of life) while more than half (51 %) said a cancer survivor is a patient who has been disease-free for 5 years [22]. These percentages demonstrated how there is no clear agreement among health care professionals on a survivorship definition. The debate concerns the point at which a person becomes a cancer survivor and how cancer survivorship could be better defined.

Cancer survivorship could be viewed (1) as a time frame, so it could be developed on the basis of type and stage of the disease (i.e., after 2, 5, or 10 years); (2) as an outcome like no evidence of disease, complete remission, or cured; (3) as a stage or phase and, in this case, we must consider if primary treatment are ended or there are any recurrence; or finally (4) as a process where people live through different stages of illness [23].

Considering the first, Carter conducted a study in 1993 on long-term survivors of breast cancer and he refers to them as “women who have survived breast cancer beyond 5 years without recurrence” [24]. This approach refers to a dichotomous view of the experience of illness: having a cancer and being a survivor appear to be mutually exclusive conditions, as being a survivor is only for cured people [25]. The greater critique to this approach is that the survival rates vary between different types and phases of tumor. It is difficult to reach a unique definition because different types of cancers have various time of healing: in breast tumors, the majority of patients survive more than 5 years, while in lung ones only 30 % survives more than 1 year. This is why patients’ cancer could not be classified only for a time matter [26].

Taking into account the second and third options to define cancer survivorship, the absence or the presence of disease (as an outcome) or the end of active treatment (as a phase) may be used as arbitrary cutoffs, but they could be misleading if patients are included in long-term treatments. An individual with no evidence of disease but who is taking chemoprevention drugs can be considered a survivor? [8]. Another point highlighted by Mullan, Aziz, and Rowland is that many challenges that confront the cancer survivor are not simply a continuation of problems experienced during treatment but represent unique problems in the trajectory of the experience with this illness as the survivor transitions from the acute to the chronic dimensions of illness [27].

Pursuing this line, in 1997, Lance Armstrong, founder of Lance Armstrong Foundation and of LIVESTRONG.org (an online resource for cancer survivors), declared himself and other people affected by cancer a “survivor” and not a “victim” and he defines the experience of cancer survivorship as living “with, through and beyond cancer.” This image recalls Mullan’s definition of survival: living with cancer indicates the moment of receiving a cancer diagnosis and any treatment that may follow, living through cancer refers to the extended phase following treatment, and living beyond cancer suggests

the time of post-treatment and long-term survivorship [28]. Breaden [25] in her study “Cancer and beyond: the question of survivorship” shows how six women live their struggle to beat tumor as a continuous process, living from the point of diagnosis for as long as each of them shall. This journey will include feeling whole again, the body as the house of suspicion, the future in question, changes in time, lucky to be alive, and sharing the journey. As said Christine Piff of Let’s Face It [29], survival is “taking each day at a time” and many other authors support follow the thought that cancer survivorship is a process [30, 31].

At the same time, the Office of Cancer Survivorship of the National Cancer Institute was founded and it expanded the definition of survivorship to caregivers and family members considering them impacted by this process [32]. As we can read in their website: “in cancer, survivorship focuses on the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience” [33]. This suggestion is also shared by the National Action Plan [34]. On the contrary, the term survivor does not incorporate family and friend figures into statistical reports, affirmed Julia H. Rowland, Ph.D., director of the Office of Cancer Survivorship [35].

Little et al. [36] agree with the idea that the term survival can achieve different meanings if we speak with patients with cancer or those who care for them or those who cure their illness, but only “those people who have had a cancer, and who are living, at any period after treatment, apparently free of recurrent or persistent cancer,” they are cancer survivor.

Shifting the focus from how *long* cancer patients have to live to how *well* they will live, cancer survivorship has been described as a journey that begins at the time of diagnosis and continues throughout life [37–39]. This more comprehensive definition and an increased attention on Quality of Life of cancer survivors [40] contributed to the evolution of cancer care programs and of cancer survivorship research. In 2005, the Institute of Medicine (IOM) and the National Research Council published a report entitled “From Cancer Patient to Cancer Survivor: Lost in Transition” where are reported the essential components of survivorship care. It includes prevention and surveillance of patient’s health status, intervention for consequences of cancer and its treatment and coordination of care between primary care providers and specialists to ensure that each cancer patient receives what he needs [18, 41].

Doyle [9] has done a report of a concept analysis of cancer survivorship in adults and it is based on literature published in English between 1994 and 2006 and seminal work in the field. What this paper adds to the definition of cancer survivorship is

that it is a process life-changing experience that begins at diagnosis, it involves uncertainty with a duality of positive and negative aspects and it is unique to the individual while also having some universal features.

### Different Meanings Among Different Countries

Despite in the last 10 years, we have taken decisive steps forward in developing supportive care needs for every phase of cancer disease, including survivorship, and despite a lot of organizations are born to protect cancer patient's rights, only in the USA the terms "cancer survivor" and "cancer survivorship" are widely used [42–44]. In many other countries, these terms are not always interpreted positively by patients: to someone they remind a high risk of death that did not reflect their experience. On the contrary, others make the association "survivor means cured" and they reject it as they continue to deal with fear of cancer recurrence [43, 45]. In these places, cancer survivors are defined as patients who have lived beyond 3–5 years from diagnosis, or end of treatment, with no evidence of disease [46]. Bellizzi et al. [47] conducted a study on 490 prostate cancer survivors 1 to 8 years after diagnosis and they showed how the majority of respondents preferred to be defined as "someone who has had a cancer." Bell [8] agrees that this last definition may be more appropriate than "survivor" because it refers to all cancer patients acknowledging their heterogeneity.

In Italy, many oncologists and patient advocacy organizations have declared that to overcome some of the problems related to the heterogeneity is better to distinguish the patients with active disease (persons living with cancer) from the disease and treatment-free patients from at least 5 years (cancer survivors) [14, 37, 48]. An Italian website that promotes the results of epidemiological research in oncology discerns between "long-survivors" and "cured": the former are people who have had a diagnosis of cancer for more than 5 years, the latter are patients who survived more than a certain period of diagnosis and have a life expectancy comparable to people without cancer [49].

Instead in UK, the concept of cancer survivorship has been defined by National Cancer Survivorship Initiative (established in 2008) as "those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease" [50].

### Is a Unique Definition Required?

Some authors are inclined to abandon the search for a universal definition of survivorship, they suggest that the better solution could be context-specific operational definitions [26].

Behind cancer survivorship label, there are a lot of differences among patients concerning not only physical features

like their disease stage or what treatment they are doing, but also ethnicity, age, gender, culture, religion, educational and social status, and psychological aspects. Moreover, living beyond a cancer diagnosis can either mean being cured or having an active chronic disease and even the status of disease-free could include different plans of care (i.e., surgical resection, long treatments,...) [8, 46].

On the basis of these psychosocial, epidemiologic, and medical concerns, Miller et al. [51] propose a modified model of the Mullan's Seasons of survivorship [16] by underlining how the actual survivorship trajectory for individual cancer survivors is quite variable. After acute survivorship, they identify a season of "transitional cancer survivorship" where individuals move from active treatment to careful observation and the emotional, social, and medical adaptations that occur. Then, cancer survivors enter the "extended survivorship" stage, where they could be (1) alive and "living with cancer" but requiring ongoing treatment for recurrent, active, and often advanced disease; (2) in a complete remission that requires ongoing therapy; or (3) in a complete remission and with a favorable prognosis. If patients defeat cancer, they will be defined long-term survivors and enter the "permanent survivorship." This last stage includes (1) survivors who are "cancer-free but not free of cancer," (2) survivors who are cancer-free but continue to have significant "fall-out" from cancer and its treatment including psychosocial, medical, financial, or legal sequelae, (3) survivors who go on to develop second cancers which may be unrelated to the first cancer or its treatment, or may be more likely due to genetic or environmental factors, and also (4) survivors who later develop cancers that are secondary to the initial treatment. It is clear that heterogeneity is the base of complexity and words are often inadequate to describe the reality and identity.

Other authors believe that common aspects are far more important than any difference. From Mullan to Feurestein [16, 52], they argued that common problems among patients with various cancers are more than a simple distinction between "cured" or not. These commonalities separate all cancer survivors from those who have not developed a cancer in their life.

The definitions of cancer survivorship are subject to many interpretations depending on the object of the research, patient point of view, or the perspective of advocacy and policy organizations applying the term [26]. Survivorship is a constantly evolving concept with the aim to organize a body of knowledge that will improve over time and ideally impact the health and well-being of those diagnosed with and treated for cancer [52]. To clarify the concept, it is therefore important to understand how to assess differences between cancer patients; otherwise, any theoretical will also be unclear [9]. This is why the definitions previously viewed should be unified basing them on the latest progress.

Certainly, the complexity of this population makes it difficult to find a unique definition for all patients recovered from different types of cancer. One possible solution would be to establish criteria that help us to delineate who is a cancer survivor. Although each definition has its limitations, we could get help from a tool that already exists, but it has not been used yet for this category of patients: a key to an understanding of the cancer survivor can be the International Classification of Functioning, Disability and Health (ICF) [53]. The ICF model is a classification developed by the WHO that illustrates the health status of people using a unique framework where human functioning and disability are described as a dynamic interaction between various health conditions and environmental and personal factors [54]. Through this system, any changes that occur in the body, in the whole person, in person's ability to perform tasks, in his or her social roles, and in the environment that forms the context of a person's life could be described with a standardized language. General criteria may be established to describe cancer survivors who are facing care. Despite the obvious difficulties in finding a common line which satisfies needs of patients and physicians, healthcare professionals and caregivers, it is important to define the cancer survivorship to better determine the prognosis of the patient and to better assess "the back to life" after a cancer. The new "normal" is affected by emotional changes caused by the traumatic experience of cancer and may include the need to make changes in interpersonal relationships and physical habits and food. For these reasons, it is important to identify cancer survivors to educate them in a good way of life that allows them to stay healthy. In other words, to monitor their state of health, good nutrition and maintain a healthy weight, physical activity and reduce unhealthy behaviors (e.g., alcohol, smoking). Moreover, criteria that place the patient on a continuum from the disease until recovery would be helpful to provide precise indicators to those involved in survivorship's health policy, to measure and to compare data on survivorship in different groups of patients and, eventually, to draw up guidelines for patients and oncologists.

## Discussion

Even if length of survival from cancer is steadily increasing, this review suggests that there is not a unique definition of who is a "cancer survivor" and what is "cancer survivorship." Both organizations and patients have not shared response to this question because everyone gives a definition based on personal life experience and it is so difficult to find a common idea. Consequently, the definition varies among countries and in each of these countries, there are people who prefer to split the fight against cancer in different periods, each with its own name, and who, instead, see illness experience as a continuous

process, without precise categories. Cancer survivors often have specific medical and non-medical needs related to their cancer experience. The experience of meeting the oncological disease marks a break in people's lives: outlook, sense of time, relationships, values, and priorities change. Problems with survivorship concern toxicity, pain, fatigue, disease and secondary tumors, functional limitations, concerns about a possible relapse and the onset of a new cancer, mood disorders, sexual and relational sphere, cognitive disorders, labor and social issues, recognizing the uncertainty of the future, and the limit of life; these issues may persist over time or occur even many years after the end of treatment. Today, the most widely used definition sees cancer survivorship as a process that begins at the moment of diagnosis and continues through the balance of life. In this case, we will focus on psychological and legal patient's needs—as well as medical ones—to receive care and assistance from the beginning and, at the same time, it establishes valid criteria for making scientific and statistical sampling research. When physical, psychological, social, and spiritual health of patients are dealt with in a constructive manner, cancer survivorship is seen as a continuum that begins with a state of illness and goes to a state of health. Consequently, the disease begins a meaningful aspect of health.

The International Classification of Functioning, Disability and Health (ICF) may be a good tool to achieve a definition of a cancer survivor, because it does not contain links to the disease, but refers to the complete human functioning. It evaluates people as a whole, without forcing them under a strict label. This method would allow to create a profile, which could be different according to patient's type and degree of the disease exceeded and, at the same time, could give minimum general criteria to identify who is a cancer survivor and who could use care or benefits needed for its condition.

Defining cancer survivorship, we could evaluate when the getting back to "normal" lifestyle starts and consequently, we could know if survivors feel themselves productive as they were before treatment or if they are treated differently or unfairly, compared to their status before cancer treatment. Moreover, if literature could find a clearer definition of cancer survivor and cancer survivorship, then the clinical oncological practice will benefit.

This approach could satisfy the personalized medicine model and ICF could be a useful tool to define better the complex interaction between individual health and environmental and personal factors, considering them as a dynamic interplay.

An understandable definition will give more precise information on the prognosis of patients and will better describe the characteristics of the survivors. In addition, it will evaluate treatment protocols and monitoring of health status over time and will be able to accurately identify the group of survivors to "use" them in research or in clinical trials.



This review has been written to outline the state of the art and it invites to reflect on a shared definition that could satisfy both clinical and research aspects. In addition, it could help to select a sample of patients with certain characteristics for future studies or to identify patients' characteristics to be included in possible guidelines of care programs.

### Limitations

There were some limitations in this review. First of all, this review was current at the time of its submission, but it is possible that additional relevant studies have been published and, even if a comprehensive literature search was performed, it is possible that eligible studies were missed.

There were also methodological limitations because in this review, we have included “minor” literature like theoretical articles or websites commentaries of recognized organizations and not only randomized trials. This decision was taken because there are few articles speaking on this topic and it was so difficult to find them on search engines.

### Future Directions

This review encourages researchers to:

- Clarify the definition of “cancer survivor” before sampling to standardize measures and to allow for cross-study comparisons.
- Find and develop a consistent timeframe to define “cancer survivorship” and “cancer survivor”

In addition, it will be useful for physicians involved in palliative medicine, statisticians who will “measure” better this part of population or researchers for their future studies.

### Conclusion

The current systematic review of the definitions represents only a first stage in research on the development of “cancer survivor.” To our knowledge, this is the first attempt from literature review. It is an important first stage because it helps us to understand how the existing literature defines the term. We are confident that this compendium of current definitions can be a valuable resource to enhance communication, dialog among researchers, and stimulate further investigations.

Issues persist about how all these different definitions can affect different interlocutors and impact on stakeholders. *What do patients imagine from survivorship? Do patients fully understand the phase of survivorship?* Studies, perseverance, and further data collection will offer at least more exhaustive answers to these questions, and they will contribute to direct the meaning of survivor/survivorship in a more agreed direction.

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