

REFLECTION ARTICLES

CANCER SURVIVORSHIP: UNWRAPPING THIS REALITY

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ABSTRACT

This study was a reflection grounded in the report *From Cancer Patient to Cancer Survivor: Lost in Transition* and literature studies that deal with the subject. The objective was to describe cancer survivorship, its aspects and concepts, providing knowledge on the subject that has been little studied in Brazil. This reflection covered three topics: What is cancer survivorship?; Identity after the diagnosis of cancer; The need for health care in cancer survivorship. Survivorship is a subjective concept that represents the process of living after the diagnosis of cancer, through and beyond the disease, passing through the stages of the cancer process, remodeling and understanding the physical, social, psychological issues and the context in which the survivor is inserted to achieve balance in life. It is essential that the nursing field acquire knowledge on the subject and recognize the importance of the symbolic aspects that survivors attribute to the disease, treatment, and survivorship.

Keywords: Survivors. Neoplasms. Nursing care.

INTRODUCTION

Cancer is still a stigmatized disease, feared by society; it is the one that sentences the individual to suffering and death. In contrast, in the United States of America (USA) about 14.5 million Americans with a history of cancer were alive in 2014, with an estimated increase of 19 million survivors by 2024. This scenario is justified by the technological advances in diagnosis, treatment, and training of professionals in addition to population growth and aging⁽¹⁾.

Despite the lack of data on the incidence of cancer survivors in Brazil, we tend to converge to the same level of developed countries. Thus, how many Brazilians with a history of cancer are still alive? Estimates in Brazil are incipient and comprehensive; the main general estimate is of 576,000 new cases of cancer in 2014-2015 in addition to survival calculations related to types of cancer presented by cancer patients⁽²⁾.

Due to the significance achieved cancer survivorship reported by researchers from several countries, the discussions in this area resulted in a landmark publication of the report *From Cancer Patient to Cancer Survivor: Lost in Transition*, by Hewitt, Greenfield, and Stovall⁽³⁾.

This report⁽³⁾ was developed with three main objectives: awareness with respect to cancer survivors, their functional and psychosocial consequences and treatments; recommendations and strategies to improve health care and quality of life of survivors; besides proposing access to clinical and psychosocial services through public and private policies, emphasizing the need for a health care plan during the transition from active treatment to post-treatment in cancer patients.

The planning of health care is essential given that some survivors have unique experiences and complications to endure throughout their lives. Permanent and disabling symptoms hinder their return to routine life. Changes in lifestyle, disruption of social roles and family dynamics,

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cognitive and communication problems, psychological distress, sexual dysfunction, organ dysfunction, impaired organs, limiting in body movements, and fear of recurrence are some of the complications that a survivor may display depending on the type, stage, and location of cancer, its treatment, and the psychosocial and financial support received^(3,4).

The health problems of survivors are poorly explored in Brazil, misunderstood and often confused by the mistaken belief that once the treatment is finalized, the sick start to live life without complications. Health policies are present but do not extensively nor even occasionally support the needs of survivors. Health services do not put into practice a comprehensive care, which is still fragmented.

Thus, we will reflect on the following questions: what is cancer survivorship and who are cancer survivors? How do they live after diagnosis and treatment? Why do they deserve our attention? What is still needed in our country? What is the importance of the nursing care in the process of cancer survivorship?

Considering that research in this area is still new in our country, the interest in the subject is based on its innovative and transformative character. Therefore, this study was a reflection grounded in the report *From Cancer Patient to Cancer Survivor: Lost in Transition*⁽³⁾ and literature studies that deal with the issue.

The intention is to go beyond the answers and provide a reflection on cancer survivorship and transposition of this scenario into the Brazilian reality with a view on those who managed to pass through the barrier of the disease, however, carrying the consequences of a disease that transforms lives. The objective is, therefore, to describe cancer survivorship, its aspects and concepts.

What is cancer survivorship?

Survival comes from the verb to survive and is indiscriminately defined by various disciplines. However, it is much more than a concept because it is a general idea that applies to everyone diagnosed with cancer, regardless of the course of the disease⁽⁵⁾. It is understood as a phase that starts at diagnosis and continues until the end of life⁽⁶⁾.

The creation of the *National Coalition for a Cancer Survivorship* (NCCS) Foundation in the

US in 1986 scientifically intensified the discussions about cancer survivorship when the term has undergone several redefinitions. The current definition provided by the *National Cancer Institute* (NCI) states that survivorship focuses on the health and life of the individual with cancer, from the completion of the primary treatment to the end of life. Every individual with cancer should be considered a survivor based on the disease diagnosis, including their families⁽⁷⁾.

Cancer survivorship is the state or process of living after the diagnosis of cancer, living with cancer, through and beyond it. It is a concept of the search for healthcare professionals, researchers, and patients themselves with cancer, extending to their families, not only to identify and understand the physical issues but also the social, spiritual, and psychological issues and the impact of cancer on the lives of those affected by the disease⁽⁸⁾.

The lack of an a consensual definition, along with the confusion and debates about who are survivors and who is part of cancer survivorship, prevents the understanding of needs involved in the process by health professionals, family members, and survivors. The tripod formed by professionals, families, and survivors remains for those who hold a mutual work on finding solutions to social, clinical, physical, and psychological problems existing along the lives of those diagnosed with the disease⁽⁹⁾.

Advances in treatment, early detection, less radical surgery strategies, and methods of combination therapy contributed to a decrease in the number of hospitalized patients. Without generalizing, we are moving to outpatient based treatments. Consequently, previously known punctual rehabilitation services became scarce. We turned the page, and a new reality is unwrapped, cancer survivorship⁽⁴⁾. Thus, this process was added as a phase of continuous cancer control (prevention, early detection, diagnosis, treatment, survivorship, and palliative care) encompassing the rehabilitation stage, which was once a specific phase focusing on the physical aspect, but which is now considered part of the treatment and survivorship⁽³⁾.

We believe that survivorship is a subjective concept, which goes beyond the state of liminality in the diagnosis-treatment that reports

to the human living process. That is, it is not a single moment or particular phase after treatment, and neither is a fixed concept, but a sequence of events (initial symptoms, diagnosis,

treatment, and disease control) in which understanding the situation, organizing the living experience, and if possible, alleviating pain, and surviving the disease are pursued (Figure 1).

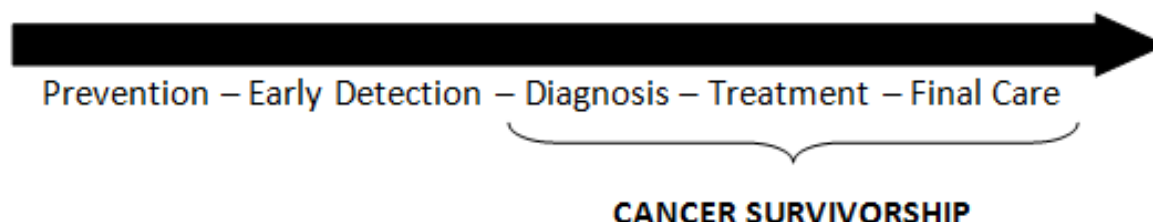


Figure 1. Process of cancer survivorship.
Source: authors of this article.

It is a process of continued actions and not punctual interventions, which can be understood as an additional and distinct step in cancer care that may, over time, enhance, aid, and impact the health and well-being of those who even after carrying out primary treatments suffer from complications from the disease. These patients continue to need support from health services and legal assistance to sustain their post-diagnostic needs. This context can favor and provide the opportunity to return to daily routines effectively and with less suffering for survivors and families.

Identity after cancer diagnosis

The lack of a consistent operational and conceptual definition of what is a cancer survivor, despite its widespread use, makes it questionable. The adoption of the term or which ones are to be used by survivors will depend on their experience with the disease. Most people can recognize different identities throughout its route as part of their experience, and thus, the endorsement of a determined noun is directly associated with the form of coping with the disease and how each one sees themselves as well as with their moment going through the process.

In the study⁽¹⁰⁾, the authors searched four different identities (victim, patient, survivor, and people with cancer) and their relationship with their physical and mental well-being. As a result, 83% of individuals endorsed the survivor term, 81% endorsed the identity of

the person who had cancer, 58% endorsed the classification as patients, and 18% as victims. The authors highlight the high self-esteem in individuals who considered themselves survivors of the disease. Therefore, they claim that the survivor identity can be associated with psychological well-being.

The qualitative study⁽¹¹⁾, a descriptive study conducted with 155 African-American women survivors of breast cancer, showed that some of them could define themselves as cancer survivors because they were alive and would be surviving for the rest of their lives, demonstrating that life was just starting over. In contrast, other women did not believe that being a survivor reflected their history with the disease or thought that the term was not familiar.

We know that embracing the cancer survivor identity can allow the sick and those who like to be included in the concept, to deal with cancer and its consequences in a positive way reducing suffering, anxiety, and depression with improved self-esteem. It is important that we are not concerned with just writing something but to mobilizing patients, families, oncologists, nurses, researchers, and others affected by the experience of this disease⁽¹²⁾. We should reflect that the adoption of the survivor identity can be an important step in the process of transformation and readaptation of the individual in dealing with the circumstances of everyday life, even after the biographical rupture promoted by the disease diagnosis.

Is this discussion of identity really relevant? We think so. We emphasize that it is not a matter of labeling, but to know how survivors feel, and not only about how they live over time, but also in which way they survive and thrive, how do they know and define themselves from the experience, and what is historically important for them. It is the knowledge of self from the self, where we, health professionals along with clients, caregivers, and family members can directly or indirectly contribute to the construction of the survivorship process.

The type of cancer, resulting complications, support offered, history, and lived experience are directly related to the identity adopted by the sick. However, there are many associated factors, few studies developed, and a lot to be discussed; it is impossible to import an external reality into our context.

The need of health care in cancer survivorship

Survivors undergo constant challenges to achieve the balance to live life fully; they live new and unexpected experiences that culminate in new routes. They reassess and re-signify life seeking new directions, limits, controls, goals, and values. Conversely, even after completing the treatment, they live immobilized by the fear of recurrence and late complications from treatment, hindering them in making decisions to carry out plans and guide their future⁽³⁾. In the long term, the survivor may go through a cascade of diseases that affect areas of welfare, disrupting his quality of life. As an example, patients who undergo prostatectomy may suffer in the long run with urinary incontinence, sexual dysfunction, and altered body image among other late effects that are dependent on the type of treatment adopted and consequently the type of cancer⁽³⁻⁴⁾.

In contrast, in the study⁽⁹⁾ conducted with 337 cancer survivors with different diagnoses (breast, prostate, and melanoma among others), common concerns such as fear of recurrence, fatigue, and financial problems were highlighted. These issues were the most prevalent among survivors, which despite their different diagnoses had similar complications.

The quality of life of individuals is a matter of public health where it is imperative to improve results. The quality of life related to

health among Brazilian survivors of breast cancer was observed in the study⁽¹³⁾ conducted in Paraná with 202 breast cancer survivors to evaluate fatigue and quality of life, comparing women with no history of the disease and evaluating the relationship between fatigue and quality of life. The results showed that the significant presence of score for fatigue among survivors worsens the quality of life in the physical, psychological, and social domains compared to healthy women.

Faced with complications that can be suffered by patients and hence alterations in their quality of life, the need for a comprehensive and multidisciplinary care is essential. Survivorship programs should include strategies to manage the needs of survivors being developed and adapted to offer help and support to these patients and their families⁽⁹⁾.

Thus, as a result of the presence of long-term complications and low quality of life in this population, many researchers have made efforts to provide models and effective care strategies for this group. The cancer heterogeneity, as well as the individuality of each survivor, hinders this planning and its applicability. The integrative review⁽¹⁴⁾ combined studies that brought models of care for blood cancer patients, however, the authors concluded that there is a lack of focus on the evaluation of effectiveness in these models because there is no criterion to determine which is the most effective.

Building an ideal model of care is not an easy task. However, it should include a systematic and organized service with a proactive rather than reactive approach in an attempt to ensure the prevention of discomfort with an early and continuous evaluation⁽¹⁵⁾. The understanding of the survivorship process as a whole is necessary for the health team to ensure an effective approach, fully focused on the patient's life and his family, leading to adequate communication to meet their needs, encouraging them to a healthy life.

In Brazil, the National Policy for the Prevention and Cancer Control in the Health Care Network of People with Chronic Diseases within the National Health System⁽¹⁶⁾ is incipient to attend the needs of survivors, which limits the development of health care plans toward this group. Professionals and services are not always

able to meet the physical, emotional, and psychosocial needs of survivors and their families.

Therefore, the need of focusing on research in cancer survival arises focusing on the remaining health of the individual beyond the stage of diagnosis and acute treatment. Researches are a great first step to moving from theory to demonstrating its implementation in practice. It is through them that policies can be built with a focus on prevention, control, and changes in certain contexts because they are standards with regulatory powers.

Nurses, along with other professionals, are essential members of the professional group accompanying the survivor and playing an important role in the development, implementation, and evaluation of health care plans to be implemented. Nurses are those who evaluate and document the difficulties and anguish of survivors and their families, their way of dealing with the disease, fatigue, lymphedema, and sleep disorders, among other complications, encouraging the acquisition of a healthy lifestyle. The commitment of nurses to their profession is what guarantees success in any health care in cancer survivorship⁽¹⁷⁻¹⁸⁾.

As nurses, we have the responsibility to maintain our knowledge current and provide proper care to the sick based on evidence, innovating and adapting our assistance⁽¹⁹⁾ through the enlightenment of the concept of focus, regardless of our presence in the different levels of health care provided to cancer patients.

FINAL CONSIDERATIONS

The process of surviving a chronic disease leads to changes in life plans and brings uncertainty, losses, reflections, alterations in identity, and a life of dualities between positive and negative aspects. In a moment, survivors may feel well and rejoice at the end of a primary treatment, and in other moments, they may find themselves depressed with complications that they will have to live with. The unwrapping of cancer survivorship shows that it as a process that begins in the diagnosis and remains until the end of life. Adequate care must be offered during this process including symptom control and comprehensive assistance considering the patient's context by means of a multidisciplinary team that jointly respects the maintenance of the quality of life of survivors.

The need for consistency in their clinical practice is implied to the nursing care because it is essential that these professionals acquire knowledge on the topic, recognizing the importance of the symbolic aspects that survivors attribute to the disease, treatment, and survival, as well as their needs and possible complications.

We do not intend to exhaust this discussion; this topic is broad, and this study was limited to bringing up the points that we consider essential for the basic understanding of the subject. Conversely, we encourage further reflection to strengthen the process of survivorship, optimization of quality of life, and longevity in cancer survivors, which are characterized as a group that requires a new perspective extrapolating the physical complications.

SOBREVIVÊNCIA AO CÂNCER: O DESEMBRULHAR DESSA REALIDADE

RESUMO

Esse estudo consiste numa reflexão embasada no relatório *From Cancer Patient to Cancer Survivor: Lost in Transition* e em estudos da literatura que versam sobre o tema. Objetivou-se, portanto, descrever sobre a sobrevivência ao câncer, seus aspectos e conceitos, para proporcionar conhecimento do tema que ainda é pouco estudado no Brasil. Essa reflexão percorreu três tópicos: O que é a sobrevivência ao câncer?; A identidade pós-diagnóstico do câncer. A necessidade de cuidados na sobrevivência ao câncer. A sobrevivência é um conceito subjetivo que representa o processo de viver após o diagnóstico do câncer, com, através e além da doença, perpassando pelas etapas do processo do câncer, remodelando e compreendendo as questões físicas, sociais, psicológicas e o contexto em que o sobrevivente está inserido até alcançar o equilíbrio da vida. É fundamental que a enfermagem adquira o conhecimento da temática e reconheça a importância dos aspectos simbólicos que os sobreviventes atribuem à doença, aos tratamentos e à sobrevivência.

Palavras-chave: Sobreviventes. Neoplasia. Cuidados de enfermagem.

SOBREVIVENCIA DEL CÁNCER: LA ACLARACIÓN DE ESTA REALIDAD

RESUMEN

Este estudio es una reflexión acerca del informe *From Cancer Patient to Cancer Survivor: Lost in Transition* y estudios de literatura que se ocupan de lo tema. El objetivo fue describir diferentes aspectos y conceptos sobre la sobrevivencia al cáncer, proporcionando una aproximación a la realidad de la población brasileña. Esta reflexión abordó tres tópicos: ¿Cuál es la supervivencia al cáncer?; La identidad después del diagnóstico del cáncer; La necesidad de cuidado en la sobrevivencia al cáncer. La sobrevivencia es un concepto subjetivo que representa el proceso de vivir después del diagnóstico de cáncer, con, a través e a pesar de la enfermedad, pasando por las diferentes etapas posteriores al diagnóstico, comprendiendo las implicaciones físicas, sociales, psicológicas y el contexto en el que se inserta el sobreviviente hasta alcanzar el equilibrio de la vida. Es esencial que las enfermeras adquieran el conocimiento de lo tema y reconozcan la importancia de los aspectos simbólicos que atribuyen a los sobrevivientes a la enfermedad, el tratamiento y la supervivencia.

Palabras clave: Sobrevivientes. Neoplasias. Atención de enfermería.

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