



CANCER SURVIVORSHIP: THE NEED FOR COMPREHENSIVE CARE AND THE IMPORTANCE OF ASSUMING AN ACTIVE ROLE

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Los avances en la detección temprana y en el tratamiento del cáncer han conllevado un incremento de las personas que han superado esta enfermedad, llegando a constituir en la actualidad el 5% de la población en nuestro país. Tal y como señala la Sociedad Española de Oncología Médica, esta situación plantea nuevos desafíos que requieren, entre otros, la identificación y atención a la calidad de vida y las necesidades psicosociales de esta creciente población. El objetivo de este artículo es reflexionar sobre la importancia de una atención integral, especializada y multidisciplinar y en la que el superviviente tenga una participación más activa; no obstante, previamente, se recoge el debate existente sobre el concepto de superviviente y se describe el impacto físico, psicológico y social del cáncer y su tratamiento.

Palabras clave: Cáncer. Superviviente. Malestar emocional. Calidad de vida. Automanejo.

Advances in the early detection and treatment of cancer have led to an increase in the number of people who have overcome the disease, reaching 5% of the current population in our country. As indicated by the Sociedad Española de Oncología Médica [Spanish Society of Medical Oncology], this situation involves new challenges that require, among other things, the identification of and attention to the quality of life and the psychosocial needs of this growing population. The objective of this article is to reflect on the importance of comprehensive, specialized, and multidisciplinary care, in which the survivor has a more active participation. However, previously, the debate on the concept of the survivor, and a description of the physical, psychological, and social impact of cancer and its treatment are described.

Key words: Cancer. Survivor. Emotional distress. Quality of life. Self-management.

The turn of the century has marked the beginning of a new era in cancer care, the hallmark of which is the interest in the health and psychosocial well-being of people who overcome this disease (Rowland et al., 2013). The significant advances in the treatment and early detection have enabled us to reach five-year survival rates that exceed 50% in the US and Europe (Verdecchia et al., 2007). More specifically, the data provided by the fourth report of the EUROpean Cancer REgistry (EUROCare-4) indicate that 68% of patients survive after a year and 49% survive after five. In its fourteenth National Congress held in 2013 and based on the data obtained in our country - similar to those of other European countries - the Sociedad Española de Oncología Médica [Spanish Society of Medical Oncology] (SEOM) estimates that the total population of cancer survivors stands at

1.5 million (range 1.3-1.7) and will reach 5% of the population in the coming years (SEOM, 2013).

The existence of this large and growing population of cancer survivors is the key to understanding the interest that has arisen in detecting, controlling and potentially preventing health consequences, not only physically but also from a psychosocial point of view, resulting from the diagnosis and treatment of the disease. Thus, the focus of medical, psychological and social care is extended to those patients who have successfully overcome the disease, but may have problems as a result of it or treatment side effects. As noted by the National Cancer Institute (NCI) of North America, cancer control constitutes a continuum that extends throughout the different phases in which it is necessary to address the disease. These phases do not end with diagnosis and treatment, but must also contemplate survival. In this framework and taking into account the state of affairs in our country, it is worth highlighting the Manifesto prepared by the SEOM on the care of long survivors (those who are free of disease after five years of diagnosis and treatment, even though this period varies depending on the type of tumor) (SEOM, 2018). The document defends the need to care for this population and to examine the quality of life and the psychosocial needs that it presents in a comprehensive and systematic way.

Received: 15 May 2018 - Accepted: 30 October 2018

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This work has been funded by the Ministry of Economy and Competitiveness. Government of Spain. (Project PSI2013-45905-R).



THE CONCEPT OF THE CANCER SURVIVOR

Two facts mark the beginning of attention to cancer survival and they explain, at least in part, the subsequent debate regarding who is considered a cancer survivor: (i) the use of the term for the first time by a young doctor to describe his experience with the disease (Mullan, 1985) and (ii) the creation the following year of the National Coalition for Cancer Survivorship (NCCS). This organization, which has the aim of increasing the patient's role in the decisions concerning his/her treatment, proposes that a person should be considered a survivor from the moment of diagnosis until the end of his/her life. It also considers family members, friends and non-professional caregivers as survivors, since they are also affected by the experience of the disease.

Leaving aside the question of whether the person's environment should also be understood as a survivor, the definition of the person as such from the moment of the cancer diagnosis coexists with the traditional biomedical use of the term that designates the survivor as an individual who, after being diagnosed with and treated for a life-threatening disease, remains free of disease for a minimum of 5 years. From this view it is necessary to focus attention on this growing population of people who, after having been treated for cancer, are free of disease and are in the follow-up phase (regardless of the time elapsed since the diagnosis). The attempt to combine political, social, economic, etc. perspectives that come together in the definition of what is understood as a cancer survivor contributes to maintaining the existing confusion in the literature regarding the term. It is clear in the lack of consensus regarding the definitions of cancer survivor by the different organisms of relevance (e.g., NCI, NCCN, SEOM), and the fact that some of them will even have more than one definition. Thus, for example, in its dictionary of oncological terms, the National Cancer Institute (NCI, 2018) has the following entries: "the survivor includes a person from the time of diagnosis until the end of life" and "survivorship in cancer 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." Likewise, the National Comprehensive Cancer Network (NCCN, 2017), a group of American oncology centers of recognized worldwide prestige, supports the definition of survivor proposed by the NCI (the one that considers diagnosis and treatment within the survival period) and, in parallel, recommends the use of its guide for the post-treatment period (patients that have been cured, are in remission or have a chronic condition of their disease).

Regardless of the existing confusion, it is important not to distance the scientific work from the need to obtain a better understanding of the epidemiology, mechanisms and improvement in the handling of the challenges faced by people who are in the phase of survival. Consequently, we believe the defense made by Feuerstein (2007) in the initial prologue of the *Journal of Cancer Survivorship: Research and Practice* is accurate: people should be considered survivors if they are under treatment or supervision and have completed primary treatment or the main aspects of treatment and they wish to or need to resume their lives.

THE EFFECTS OF CANCER AND ITS TREATMENT

The same treatments that have helped improve cancer survival rates can also cause significant physical, psychological and/or social consequences. Several studies in recent years have tried to identify the most frequent problems in the cancer survivor population. Problems that encompass both long-term effects (symptoms that may remain present for a prolonged period of time after completing antineoplastic treatment) and late effects (symptoms or conditions that may not be present during active treatment of the disease, but appear months or years later). A review article suggests that at least 50% of the survivor population shows some late effect related to treatment, including physical, psychosocial, cognitive and/or sexual alterations, as well as concerns about recurrence and/or the development of a new cancer (Valdivieso, Kujawa, Jones, & Baker, 2012). In this same line, a systematic review focused on the four most common tumor sites (breast, gynecological, prostate and colorectal) reports the existence of a consistent pattern of symptoms, regardless of the tumor site and type of treatment received, which includes depressive symptoms, pain and fatigue as the most frequent problems in this population (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). Although the exact prevalence of late effects of cancer and its treatment is difficult to quantify, it is believed that it has generally increased over time, probably because antineoplastic treatments have become more complex and intense, with combinations of surgery, radiotherapy, chemotherapy, hormone therapy and specific biological treatments (Hewitt, Greenfield, & Stovall, 2006). Thus, achieving a better understanding of the consequences of cancer should be considered a priority study objective in this interdisciplinary field. Its results will allow all professionals to develop appropriate follow-up care plans, educate survivors in the prevention and early detection of healthcare needs and, ultimately, improve the quality of life of this population (Stein, Syrjala, & Andrykowski, 2008).



THE PHYSICAL CONSEQUENCES OF CANCER

The physical problems experienced by cancer survivors include, along with the two already mentioned, pain and fatigue, musculoskeletal problems, lack of energy, urinary/intestinal problems, lymphedema, infertility, cognitive deficits, and sexual dysfunction (Harrington et al., 2010; Stein et al., 2008). The effects of cancer treatments on the heart – cardiac toxicity (Lenihan & Cardinale, 2012) and on the bones (Lustberg, Reinbolt, & Shapiro, 2012) are also known.

Cancer-related fatigue is defined as the subjective and persistent feeling of fatigue or physical, emotional, and/or cognitive exhaustion related to the disease or its treatment; a feeling that is not proportional to the activity carried out by the person and that interferes with daily functioning (Berger et al., 2010). Studies show that between 17% and 29% of cancer survivors experience persistent fatigue years after the end of active treatment (Wang et al., 2014). These data are surpassed by those found in studies for chronic pain, since studies indicate that more than a third of survivors report this symptom (NCCN, 2017). Another of the most frequent problems in this population is sexual dysfunction. While the type of sexual dysfunction depends on the tumor site and the treatment modalities, the most frequent sexual problems among women include those related to sexual desire, activation, orgasm and dyspareunia, the most frequent problem in men is erectile dysfunction (NCCN, 2017). Also, sleep disorders (including insomnia, hypersomnia, those related to respiration and parasomnias) are present in 30% to 50% of patients and cancer survivors and often occur in combination with pain, fatigue, anxiety and/or depression (Ancoli-Israel, 2009; Berger & Mitchell, 2008; Forsythe, Helzlsouer, MacDonald, & Gallicchio, 2012). Finally, the incidence of (often subtle) cognitive deficits varies between 19% and 78%, the most frequent being the deficits that affect executive function, learning and memory, attention, and processing speed (Anderson-Hanley, Sherman, Riggs, Agocha, & Compas, 2003; Vardy, Rourke, Tannock, 2007).

Despite the frequency with which the problems described in cancer survivors are presented, they are not treated effectively. Some of the general barriers that hinder their handling are the lack of training and/or time for health professionals to address them during follow-up visits (NCCN, 2017). There are also specific reasons for particular symptoms: for example, and as regards pain, we find the fear of side effects, addiction to some treatments or even difficulties related to their cost (Sun, Borneman, Piper, Koczywas, & Ferrell, 2008); regarding sexual problems, the discomfort that can arise from asking about this area of functioning is relevant (Bober & Varela, 2012). Since effective strategies are available to alleviate many of the

symptoms, the assessment and intervention in these areas should constitute an essential part of the care for the cancer survivor. The care of the physical symptoms will result in a better quality of life since the presence of any of them leads to greater emotional distress and a significant interference in daily life (lower level of activity, motivation, social interactions, etc.).

PSYCHOSOCIAL CONSEQUENCES OF CANCER

The completion of primary medical treatment may accentuate the distress response due, in part, to the loss of safety provided by the treatment, to the persistence of symptoms after the treatment and to the decrease in continued medical surveillance. Thus, at this time reactions of emotional distress, uncertainty and fear of a possible relapse are frequent. Although still scarce, the research that has analyzed the psychosocial consequences of cancer after completing primary medical treatment shows the existence of positive effects in a significant percentage of survivors as a result of the cancer experience, including greater appreciation for life, personal growth and strengthened interpersonal relationships. However, a considerable percentage also indicates clinically significant levels of emotional distress in the post-treatment (Andreu et al., 2012, Bower et al., 2005). Difficulties of a social and practical nature, such as issues related to the employment situation, the economic situation, and aspects related to the coverage of health and life insurance are also problems that exist among cancer survivors (Bradley, 2012; Vargo, 2006).

There is a lack of robust data on the prevalence of clinical distress in cancer off-primary treatment survivorship (Holland & Rednik, 2005). The reported prevalence ranges from 5 to 43% (Baker, Zabora, Pollard, & Wingard, 1999; Kornblith et al., 2003; Martínez, Andreu, Martínez, & Galdón, 2018). Fear of recurrence - persistent worry and distress that sometimes reaches clinical levels - is a common problem that occurs in up to 80% of cancer survivors (Syrjala & Yi, 2017). In addition, and even if the previous levels are recovered after receiving good news, this worry and distress may be increased at different times, such as, for example, the days prior to routine medical check-ups, while waiting for the results of the tests or when a physical symptom appears. About 29% of survivors manifest anxiety and/or depression (Mitchell, Ferguson, Gil, Paul, & Symonds, 2013; Watts, Prescott, Mason, McLeod, & Lewith, 2015), from 17% to 38% show symptoms of post-traumatic stress and a considerably lower percentage (from 5% to 12%) meet the criteria for this disorder (Syrjala & Yi, 2017). It is obvious that the presence of anxiety, depression or other reactions of emotional distress may also be the result of physical, work, economic, practical and/or social problems



(Hoffman, McCarthy, Recklitis, & Andrea, 2009). Moreover, it will be accentuated by the inevitable decrease in medical and interpersonal support after the end of treatment and the transition to the follow-up/check-up stage.

To achieve an adequate management of psychological reactions in this population, the NCCN (2017) recommends carrying out a routine screening of the emotional distress response, especially in moments of disease transition, survival, significant losses, relevant life events and/or social isolation, as well as in those cases in which multiple somatic complaints are presented by the survivor as part of their general evaluation. To guarantee the safety of the survivor, those who present these needs should be referred to specialized services (mental health, social services, community support resources). The presence of clinically significant untreated or uncontrolled distress leads to significant negative consequences that not only affect the survivor's quality of life; unfortunately, it also affects their physical health, by decreasing the likelihood of adherence to medical recommendations and participation in health-promoting activities (Carmack, Basen-Engquist, & Gritz, 2011).

UNMET NEEDS IN CANCER SURVIVORS

The spectrum of concerns or needs experienced by cancer survivors is quite extensive: side effects of treatments, changes in body image, infertility, sexuality, fear of recurrence, vulnerability or uncertainty about the future, feelings of personal inadequacy, difficulties in resuming family, work and social roles, etc. (Kornblith, 1998). It is a spectrum that suggests that rehabilitation efforts aimed at this population should begin with the identification of the specific problems or needs that exist in each case and should be implemented as soon as possible after the completion of primary medical treatment (Holland & Rednik, 2005).

Different demographic, medical and psychosocial characteristics act as risk/protection factors for the presence of unmet needs in this population. Being younger (Constanzo, Ryff, & Singer, 2009) or having received systemic treatments (e.g., chemotherapy) (Thornton, Carson, Shapiro, Farrar, & Andersen, 2008) are variables that increase the probability of experiencing problems in the survival phase. On the other hand, social support, optimism, and the implementation of active coping strategies -problem solving, identification of benefits, expression of emotions related to cancer- act as protectors (Bloom, Petersen, & Kang, 2007; Smith, Petronis, & Antoni, 2006; Michael, Berkman, Colditz, Holmes, & Kawachi, 2002).

Unfortunately, we currently have few valid resources for the evaluation of the psychosocial needs and quality of life of this population. A review published by Pearce, Sanson-Fischer and

Campbell (2008) identifies a total of 42 instruments of which, however, only 9 address the needs of survivors. Furthermore, two scales stand out: the Quality of Life in Adult Cancer Survivors scale -QLACS- (Avis et al., 2005) and the Impact of Cancer scale -IOC- (Zebrack et al., 2006), for their adequate development based on representative samples of this heterogeneous population (including different types of cancer, both genders and a wide range of ages); however, the authors also point out that data are still needed regarding their acceptability, viability and usefulness in cross-cultural studies. In our context, we currently have only the data published by Escobar et al. (2015) on the psychometric quality of the adaptation to Spanish of the QLACS, so more research is necessary in this regard.

THE CARE OF THE CANCER SURVIVOR

In our country, the *Plan Integral de Atención a los Largos Supervivientes de Cáncer* [Comprehensive Care Plan for Long-Term Survivors of Cancer] presented by SEOM (2018) includes an action plan for health professionals. This plan identifies the need for a special and coordinated follow-up and the need for an intervention on the physical and psychosocial consequences of cancer and its treatment. Moreover, the text also identifies the main organizational, resource, research, training and awareness-raising needs so that the comprehensive care of survivors and their surroundings attain the highest possible levels of quality.

Likewise the plan indicates that our current care model based on multidisciplinary hospital care (sometimes redundant, not always coordinated, and with multiple visits and interventions and the consequent overuse of hospital resources) could be improved by a more active participation of the patient. In this sense, a study on interventions to enhance the self-care of survivors by the National Health Service (NHS) of the United Kingdom concludes that it is necessary to move from a system based on scheduled visits to a patient-activated follow-up (Davies & Bateup, 2010).

Although there is no standard definition of self-management, Barlow, Wright, Sheasby, Turner and Hainsworth (2002) define it as the "individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition". Self-management usually incorporates basic skills for problem solving, decision-making, resource utilization, communication with health professionals, and action planning or goal setting (Loring & Holman, 2003). Currently, effective self-management of the physical and psychosocial aspects of chronic diseases is considered key to reducing the gap between the needs of cancer



survivors and the ability of the health services to meet them (McCorkle et al., 2011).

In recent years, several review studies have been published on interventions focusing on self-management in cancer survivors (Boland, Bennett, & Connolly, 2018; Coffey et al., 2016; Howell, Harth, Brown, Bennett, & Boyko, 2017). The most recent of all of them, based exclusively on randomized clinical trials, includes six studies. Two of the three psychosocial intervention programs included in the review found significant differences in variables such as fatigue, physical functioning, emotional distress, fear of recurrence, and self-efficacy. As the authors themselves acknowledge, the rigor of the work required in this review may have been the cause not only of the small number of selected studies but also of their bias in terms of involving health personnel and, therefore, of the difficulty of drawing conclusions for genuine self-management programs. While the results are encouraging, much more research is needed in this regard.

CONCLUSIONS

The above describes a scenario in which the attention given to the psychosocial care of the survivor with cancer (i) is incipient; (ii) must necessarily be specialized, comprehensive and multidisciplinary, and (iii) seems to point to self-management, if it is to be sustainable. The role of the psychologist or psycho-oncologist in this care is more than evident, both in terms of comprehensive care and in the promotion of health. Psychosocial care should be focused on facilitating the reincorporation of the person to daily life, to work and to resume their previous roles in different life areas or, even, to enhance their personal growth after having experienced a life event such as being diagnosed with and treated for cancer. In addition, and given that the active participation of the patient during this phase is fundamental, the psychologist and/or psycho-oncologist should also enhance the autonomy of the person, facilitating self-management.

CONFLICT OF INTERESTS

There is no conflict of interest.

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