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# Concepts, theories and psychosocial factors in cancer adaptation

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se presentan las últimas revisiones del paradigma de es-

trés y afrontamiento aplicado a la psicooncología. A este

respecto se profundiza en los mecanismos psicológicos

que permiten manejar el sufrimiento emocional relacio-

nado con el cáncer y que determinan los distintos grados

The impact of psychological factors is increasingly taken into consideration in cancer patient care. In this review, we focus on the explicative models and the factors involved in psychosocial adaptation to cancer. Concerning the former, we present the latest reviews on stress and coping paradigm as applied to psycho-oncology. Specifically, we discuss the psychological mechanisms that make it possible to manage emotional distress related with cancer and that determine the different degrees of adaptation to the disease. This explanation is illustrated with two examples. On the other hand, the role of several variables that influence adaptation to cancer, grouped as sociocultural, psychological and medical variables, is discussed. Sociocultural variables make it possible to identify which patients have an increased risk of developing psychological distress symptoms. The psychological variables included the different coping strategies, psychiatric history, psychological distress and concerns and fears. The impact of sociocultural and psychological variables is illustrated with two case examples. The medical variables are associated with the disease stage, treatment and prognosis. Finally, we discuss in what way these models, concepts and factors allow for design interventions adapted to the specific needs of each patient.

Key words: Cancer. Psycho-oncology. Adaptation. Review.

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# Conceptos, teorías y factores psicosociales en la adaptación al cáncer

En la atención al paciente diagnosticado de cáncer se tienen en cuenta cada vez más el impacto de los factores psicológicos. En esta revisión nos centramos en los modelos explicativos y factores involucrados en la adaptación psicosociales al cáncer. En cuanto a los primeros,

Correspondence: Sergio Barroilhet Diez Escuela de Psicología Universidad de Los Andes Santiago de Chile E-mail: sbarroilhet@uandes.cl de adaptación a la enfermedad, complementándose esta explicación con ejemplos. Por otro lado, se discute la influencia de varias variables en la adaptación al cáncer, que hemos agrupado en variables socioculturales, psicológicas y médicas. Las variables socioculturales permiten identificar qué pacientes tienen un mayor riesgo de desarrollar síntomas de malestar psicológico. Entre las variables psicológicas encontramos las distintas estrategias de afrontamiento, la historia psiquiátrica, malestar psicológico y las preocupaciones y miedos. El impacto de las variables socioculturales y psicológicas se ilustra con dos casos ejemplo. Las variables médicas están relacionadas con el estadio de la enfermedad, tratamiento y pronóstico. Finalmente se discute de qué modo estos modelos, conceptos y factores permiten diseñar intervenciones adaptadas a las necesidades específicas de cada paciente. Palabras clave: Cáncer. Psicooncología. Adaptación. Revisión.

# INTRODUCTION

Cancer is a disease that requires important resources and needs optimization in efficacy and efficiency of the interventions. In this sense, consideration of the psychological and social aspects in integral and multidisciplinary management of the oncology phenomenon is gathering increasing importance<sup>1</sup>.

The systematized study regarding these two aspects is recent and constitutes one of the most prolific areas of investigation in medical psychiatry and psychology at present. Psycho-oncology, as this body of knowledge has been called, focuses on the knowledge of psychological, social and behavioral dimensions of cancer from two perspectives<sup>2</sup>: *a*) psychological, social and behavioral aspects that influence morbidity and mortality (psychobiological perspective), and *b*) psychological responses of the patients and their families to each one of the disease stages (psychosocial perspective). The first perspective is especially useful, since it studies the factors that predispose to the development of oncology disease in healthy persons and is related to behaviors, habits and life styles. It is of special interest to identify risk populations and design prevention or early detection strategies. However, in liaison care, we generally treat patients in process of diagnosis, already diagnosed, or with on-going disease, therefore we mostly refer to the second perspective in this review.

The way that an individual lives the experience associated to cancer is truly linked to psychobiography and personal and social context of the patient when the disease occurs. In addition, the experience associated to the cancer is conditioned by the possible treatments within those existing, and by the social beliefs regarding cancer in general and the type of cancer specifically. The experience of cancer is highly stressful since it forces the individual to cope with such immensurable issues as suffering, deterioration, death, transcendence, issues for which a personal sense must be found. Thus, the disease must be integrated into identity, and with others and with the setting, expectations regarding oneself and others, and finally the final sense of one's existence the patient must redefine. According to Spencer et al.<sup>3</sup>, more than being an isolated stressful event, having cancer implies suffering a series of interconnected stressful events.

During recent years, the growing knowledge about the influence of psychological and psychosocial factors in the oncology patient has contributed to generating an awareness regarding their importance in prevention, detection and treatment of the disease<sup>4</sup>, as well as including psychosocial interventions as an integral part of oncology treatment<sup>5</sup>. Thus, we propose to review the recent theoretical approaches and associated psychosocial factors related to psychosocial adaptation to cancer.

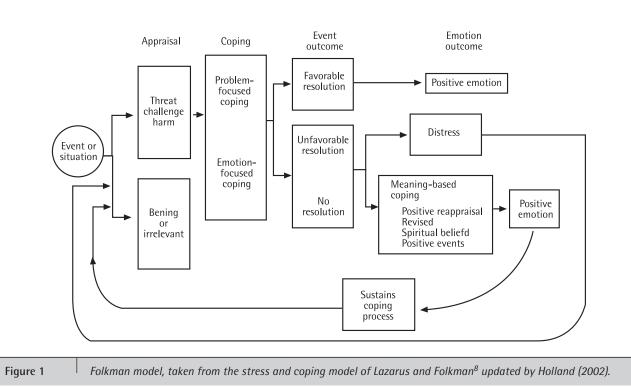
# Concepts and theories: present state

In the National Cancer Institute<sup>6</sup> guidelines, «adjustment» or «pyschosocial adaptation» to cancer is defined as a continuing process in which the individual patient attempts to manage emotional suffering, solves specific cancer related problems, and obtains command or control of life events related to this disease. Adaptation to cancer is not an isolated and unique event, but rather a series of constant responses that permit the subject to carry out the multiple tasks associated to living with cancer. Normal or successful adaptation occurs in patients capable of reducing the changes in the different functioning areas to a minimum, regulating emotional stress and remaining involved in the life aspects that still have meaning and importance for them. According to Holland<sup>7</sup>, psycho-oncology is focused on «suffering of the mind» that occurs with cancer and that incorporates psychological, social, spiritual and existential dimensions. Its goal is to help the patient finding a tolerable meaning to the presence of an intrusive and unwelcomed disease that is a threat for the future and life itself. However, presently there is no unifying model that incorporates all the factors that influence in this suffering associated to cancer. Recently, the «paradigm of stress and coping» originally applied to AIDS patients and their careguivers has gained acceptance<sup>8,9</sup>. This has been adapted to cancer, providing a conceptual framework that makes it possible to understand the coping processing of a fatal disease, «suffering of the mind» accompanying it, and the losses it entails. Folkman's model<sup>9</sup> updated by Holland<sup>8</sup> is shown in figure 1.

According to Folkman and Greer<sup>9</sup> the milestones of this model are two processes: «appraisal» and «coping». Appraisal is related with the individual evaluation of personal meaning of a given event and adaptation of the individual's resources to cope with it. The appraisal process is based on the hypothesis that individuals are constantly evaluating their relationship with the environment. Appraisal of a certain event influences subsequent emotions and coping.

The stress process begins when the person realizes that suffering cancer is a highly probable fact, or that it is already a certainty. At this time, the individual becomes aware of a change, or threat of change, in his/her goals and concerns conceived up to the that moment. Appraisal of this present or possible change due to the cancer includes an evaluation of its personal meaning (it may have a meaning of harm or real loss, of actual or possible harmor loss, or it will mean a personal challenge), which is called «primary appraisal», and evaluation of the coping options, which is called «secondary appraisal». The primary appraisal is influenced by the patient's personal beliefs and values. Secondary appraisals are related with the degree that the individual can control or change the situation generated by the cancer. For example, recurrence of colon cancer will lead to an appraisal of a combination of harm (to his/her mood, hope, trust, family), threat (to short term health, to short or middle term life, to independence, to economic well-being of his/her family) and losses (of control, physical health, future projects, etc.).

On one hand, coping refers to the specific thoughts and behaviors that a person uses in his/her efforts to adapt to the cancer. Patients can recur to three main coping strategies: emotion focused strategies; strategies focused on the problem, and strategies focused on meaning<sup>6</sup>. The first ones help oncology patients to regulate their degree of emotional suffering (e.g., avoidance, escape, seeking of social support, distancing); the second ones help them to manage specific problems, trying to directly modify the problematic situations that cause this suffering (e.g., through search for information, resolution of pending problems); and the last one helps to understand the reason for the disease and the



impact it will have on their lives. People vary their coping strategies, depending on the intensity of their emotional response and skill to regulate it, on the problem solving habilities for each situation, and on the changes in personsetting relationship as the situation unfolds.

On its part, the coping style refers to the most common, most frequent and longest term strategy, that the individual tends to use to cope with the different life situations, which is closely related with his/her general disposition and personality. Perspective studies regarding the different coping styles have been able to identify several categories that have been significantly associated to the future result of the disease. These categories were validated in patients with different types of cancer through the Mental Adaptation to Cancer (MAC) questionnaire, which defines five principal coping strategies: fighting spirit, avoidance/negation, stoic acceptance, anxious preoccupation and helplessness/hopelessness<sup>10,11</sup>. In a literature review, Watson and Greer<sup>12</sup> conclude that stoic acceptance, anxious preoccupation and helplessness/hopelessness are significantly related with obtaining worse results in the disease. The fighting spirit represents an active posture in which the patient accepts the diagnosis, maintains an optimistic attitude, and wants to participate in the medical decisions and fight against the disease. Avoidance/negation represents the patient's rejection to the cancer diagnosis, frequently minimizing the seriousness of the diagnosis and avoiding thinking about it. Patients with stoic acceptance assume the diagnosis with a resigned and fatalistic attitude. In anxious preoccupation, the patients frequently seek to be reassured since they feel constant anxiety due to the cancer and have a tendency to interpret physical distress as a sign that the disease is developing. Finally, helplessness/hopelessness describes patients that adopt a completely pessimistic attitude, overcome by the diagnosis and with the will to feel defeated. In a longitudinal study of 70 women with breast cancer in initial stages<sup>13</sup>, women who coped with the cancer through active acceptance showed better adaptation over time. On the other hand, coping by avoidance predicted greater fear of cancer recurrence.

Coping influences the result of the situation and the appraisal of it by the individual. The positive outcomes of a specific situation will lead to assessment of benefit, positive emotions, and end of specific coping for this situation. On the contrary, coping does not stop in situations with unsatisfactory outcomes.

We return to the example of the patient who experiences a recurrence of his colon cancer. This patient reappraised the reality he had. A secondary appraisal that leads to better control («I can do something») will be associated with coping mainly focused on the problem, as seeking information, use of problem solving strategies and use of direct actions towards this objective. On the contrary, a secondary appraisal that derives in less control («what I can do is very little») will be associated with the use of coping strategies focused on those that are predominantly emotion ones, such as avoidance, negation, social support seeking, or distancing.

The coping strategies used may not be efficient to control stress and the consequent emotional distress. This may occur because the situation is maintained or continues to worsen (as in the previous case), or because the coping strategy used was not sufficiently adequate, proportional, and/or persistent, to control the stress. This may be the case, for example, for head and neck cancer surgery, a situation in which aspects of different significance for the patients are affected, such as physical attractiveness, interaction and social acceptance, self-esteem, and in the case of some facial problems, emotional expression, with the patient having difficulties to speak, swallow, control saliva, etc. For most of the persons, this surgery has consequences difficult to cope with, independently of psychosocial resources<sup>14</sup>, since it is a cancer that cannot be hidden.

Finally, Folkman<sup>8</sup> suggests that each individual develops a «global meaning», influenced by beliefs, values, goals and self-image, which develops and persists over a lifetime. Global values are challenged by a catastrophic situation such as the diagnosis of cancer or loss of a loved one, which has a «situational meaning». Coping is directed toward reconciling «global (lifelong) meaning» with the situational meaning through appraisal and reappraisal where determined coping strategies are used, in order to arrive at a new balance that permits continued coping<sup>7</sup>. An example would be a guitarist who requires amputation of an arm for osteosarcoma. The guitarist must reconcile the loss to fit his lifelong goals or alter his global meaning to incorporate the loss.

# INFLUENCE OF PSYCHOSOCIAL FACTORS IN CANCER

When diagnosing cancer, it is very important to consider the psychological and social resources that the subject and his/her family have to cope with the disease and treatment. Efficacy of cancer treatments is measured not only in terms of the disease remission and survival time, but also in terms of the patient's quality of life, social and family functioning, degree of absence of physical and psychological distress. All this depends, in turn, on an adequate psychosocial adaptation to the oncological disease.

The factors that affect psychological impact of the cancer, that is, that influence the appraisals and shape coping strategies against the disease, can be divided into three large groups: variables referring to the sociocultural context, psychological variables and medical variables<sup>15</sup>. In the following, we review the contribution of some studies to the knowledge of the influence of these variables on the psychosocial adaptation to cancer, and their relationship with the disease course and outcome.

#### Variables relative to sociocultural context

Parle et al.<sup>16</sup> identified several factors concerning to the sociocultural setting that were associated to psychological distress in breast cancer patients, as, for example, lower age,

poor social support, family difficulties, relationship problems, children under 21 years old, economic difficulties and presence of other stressing life events. In another study, on 321 older persons who survived a cancer, Bowman et al.<sup>17</sup> observed that the younger persons and those with greater family distress considered the cancer diagnosis as a more stressing event in comparison with the other participants. On the other hand, in a heterogeneous sample of 351 oncology patients who came to a follow-up medical visit, Parker et al.<sup>18</sup> found that the older patients who had more social support presented less symptoms of anxiety and depression. In addition, older patients, married, with greater educational level and greater social support reported better quality of life in regards to mental health. According to this study, being married is a protective factor against depression, but not of anxiety. Patients with greater social support reported less anxiety and depression and better quality of life in regards to mental health, independently of the demographic and medical variables. However, specifically regarding sociodemographic variables, Denollet<sup>19</sup> stated that their relationship with emotional distress associated to cancer is still weak.

Another factor concerning to the sociocultural setting that must be considered is the patient is life cycle stage. This is a determining factor for the appraisal the subject will make of the cancer linked event in any of its stages and for the coping strategies that he/she will choose to control the cancer associated stress<sup>20</sup>. Even more, it has been demonstrated that the life cycle stage has a definite influence in the decision making patient and his/her family<sup>21</sup>. For example, the potential secondary effect of infertility associated to certain treatments is an important factor for a young woman of 20 years old, but not for a post-menopausal woman.

Appraisal of the cancer linked events is also influenced by the individual's culture<sup>22</sup>. In a study performed in 800 adults over 64 years, it was observed that most of the Afro-American and North-American individuals of European origin believed that the patients should be informed of the finding of a metastatic cancer, of the prognosis of terminal disease, and should be taken into account in the decisions in the final phases of the disease. On the contrary, Korean and Mexican North Americans were reluctant about this view, preferring that the family be told first and that they then guide the decision making process<sup>23</sup>. In addition, the Navajos in the USA understand that this discussion of negative information may enter into conflict with the sacred concepts in their culture<sup>24e</sup>.

The influence of the sociocultural factors becomes clear in the two illustrative examples presented in the following. These are two women who were recently diagnosed of breast cancer: Carmen and Blanca.

Carmen is a 35 year old woman who immigrated from Colombia to Spain two years ago with her husband and two children. She works cleaning houses, taking her younger 2 years old daughter with her since she says that a nursery school would be a difficult expense to pay. Her older 12 year old son goes to school and presented no difficulties until his father left home, 6 months ago. The couple is presently in process of divorce. When she has time Carmen likes to amuse herself writing to her family and friends in Colombia, since she feels a little lonely in Spain.

Blanca is 55 years old and lives with her husband and her younger daughter 23 year old, who is in the last year of medicine. Blanca is a housewife and her husband works in the family business. She has two other children, one married, who lives with his wife near his parents, and another one, a single daughter in who studies in another city. Blanca says that her family they are very close family and that they like to get together with their sibblings and family in laws, who also live in the same city. Furthermore, she says she greatly enjoys a yearly trip with her husband to a foreign country.

#### **Psychological variables**

According to Meyerowitz<sup>25</sup>, the psychological variables may be grouped, in turn, into three large groups: preoccupations/fears, changes in style of life and psychological distress. Furthermore, two other important variables can be considered in this section. These are the type of coping strategy used<sup>12</sup> and the history of previous psychiatric disorders.

During the diagnosis and treatment of cancer, concerns and fears vary according to the circumstances. In the beginning, the fears may be more related with the surgical intervention or with the change in the body image. Later, the patients are afraid of disease recurrence. However, fear of death may be present during all the disease stages.

Changes in life style appear as a consequence of adaptation to new routines and time schedules imposed by the treatment and hospital visits. In addition, the patient must adapt to a reduced functional level and lower capacity to perform usual tasks. Finally, the disease may entail changes in the in married life and sexual relationships. In fact, psychological distress of oncology patients is inversely associated to degree of marital satisfaction<sup>26</sup>.

Distress in cancer is defined as «an unpleasant experience of an emotional, psychological (cognitive, behavioral, emotional), social or spiritual nature that may interfere with ability to cope with cancer physical symptoms and treatment»<sup>27</sup>. Distress associated to cancer may occur on several levels going from absence of distress to extreme distress, with spiritual crisis and presence of psychopathological syndromes as depression, anxiety, anxiety attacks, having normal feelings of vulnerability, sadness or fear. All patients with cancer report having a certain distress level; however, extreme distress levels are less frequent. Prevalence of high levels of psychological distress is 35.1 % in heterogeneous samples of cancer patients<sup>28</sup>. In a study on depression in cancer, Bukberg et al.<sup>29</sup> found that 42 % of the patients had severe or moderate major depression, 14 % of the hospitalized oncology patients had mild depressive symptoms and 44 % of the patients did not have depressive symptoms. In a more recent study, with 89 women diagnosed of breast cancer and assessed after completing their treatments, it was observed that 75 % of the patients had no psychiatric symptoms, 10 % of the participants fulfilled diagnostic criteria of major depression, 8 % of anxiety disorder<sup>30</sup>.

Psychosocial risk factors of depression in cancer patients, poor coping skills, limited social support and presence of anxious preoccupation are found<sup>31</sup>. Depression in cancer is generally associated to negative intrusive thoughts related with disease and death subjects, which, in turn, contribute to the patient having unadaptive coping strategies and a negative view of the future<sup>32</sup>. According to the Parker et al.<sup>18</sup> study, evaluation of the social support level may help to identify patients with distress risk.

The degree of distress also depends on the personality of the cancer patient<sup>19</sup> and who surround them<sup>33</sup>. This determines the possible appraisals, affects coping skills, influences in social support and conditions social comparison<sup>19</sup>. Three traits, negative affectiveness, neuroticism and trait anxiety, are common to personalities with tendency to experience negative emotions and somatizations to identify the symptoms as threats to health and worry more about the disease<sup>34</sup>. Patients with high negative affectivity are more sensitive to physical symptoms and may be affected when seeing others who are worse then they are or feel frustrated in presence of persons that have had a better reaction than they have<sup>35</sup>, a phenomenon called «social comparison»<sup>19</sup>.

On the other hand, perception of quality of life is influenced by the individual differences of personality, as Yamaoka et al.<sup>36</sup> demonstrated when observing that patients who had more negative affectivity and more introversion perceived a worse quality of life in comparison to patients with other traits, which, in turn, has been associated to lower survival<sup>37</sup>. This is added to other findings that support the role in the progression of cancer of other variables related with personality, such as dysphoria, isolation, introversion<sup>19</sup>, and variables related with emotional response, such as emotional distress and emotional repression<sup>38,39</sup>.

Preoccupations fears, changes in style of life and psychological distress are the result of certain coping strategies used by the patient and share new strategies in turn<sup>9</sup>. Using the two previous examples, we can see how the two women, according to their primary and secondary appraisals, use very different coping strategies at the time of diagnosis:

Carmen, the 35 year old woman with two small children, seeks information on her diagnosis in her city's regional center of the Cancer Association. She asks her physician to please explain what she has to do to «win the cancer» and sees the disease as one more difficulty in her life that she will overcome.

Blanca, the 55 year old woman with three adult children told her physician that she prefers to think about it a before being operated. She says nothing to her family «not to worry them» and decides to postpone her next visit to the physician since «it is not convenient» at this time. When she feels the lump in her breast, she tells herself that the physician must be mistaken and that it is surely a benign tumor. However, she tries not to think about it very much, remaining as occupied as possible.

# Medical variables

The variables refering to the medical setting also play a fundamental role in psychosocial adaptation to cancer. The cancer site, disease stage at time of diagnosis, treatment, prognosis or rehabilitation opportunities certainly influence appraisals, copings and subsequent outcomes.

Although recovery indexes of many cancer types have noticeably increased in recent years, the medical context of the oncology treatment process continues to be highly stressing for the patients. Regarding the different therapeutic alternatives, the patients should face the uncertainty of their result, the multiple and uncomfortable side effects, and the feelings of isolation, stigmatization and guilt<sup>40</sup>. They frequently seek second opinions and collect a large amount of information on the different treatments, obtained from not always adequate sources and ones that are sometimes difficult to put into context as some Internet pages, or from more or less close persons with different experiences and beliefs.

The cancer site affects quality of life and psychological well being differently. For example, breast, gynecological and urological cancers have a greater impact on anxiety and depression symptoms and on quality of life than gastrointestinal cancer<sup>18</sup>. On the other hand, the Zabora et al.<sup>28</sup> study that included 4,496 oncology patients and contemplated 14 types of diagnoses observed that patients with pancreatic cancer had higher values of anxiety and depression while those suffering Hodgkin's Disease, had higher values of hostility.

On its part, the effectiveness of the different types of treatment is conditioned to the previous recognition of the psychological factors that influence the skill of understanding the procedure proposed, admitting its need, and tolerating the associated stress and discomfort, in order to be able to assess their benefits. In this sense, the relationship between the medical team and patient over the different disease phases is factor with increasing importance<sup>41</sup>. The patient deposits his/her trust in the medical team regarding

optimum health care and is sensitive to the degree of emotional involvement. This is because the medical team participates in very relevant specific experiences for the patient as the medical controls, examinations, procedures, planning, family advise, orientations, management of secondary symptoms, etc. and is the «carrier» of bad or good news. That is why after the diagnosis, the patients and their family not only expect medical care but also psychological care by the physician, attention for which the latter does not always have sufficient skills or knowledge<sup>42</sup>. The medical figure is frequently idealized and made a father figure, with all that this means in regards to the attribution of authority and ancestors, but also in regards to emotional, unconditionality and high availability demands. As the attributions towards the physician may be extreme, the reactions of gratitude and admiration, or hostility and rage of the patients or their families in the presence of the different results may also be extreme. Faced with this situation, some physicians choose to define the limits early, expressing an interest in solving the specific problem without becoming personally involved, and maintaining an emotional distance. This may be perceived with distress by the patient and his/her family. These facts generally give rise to a difficult physicianpatient relationship that may prevent good cooperation and harm the optimum therapeutic result<sup>42</sup>. On the contrary, a good quality interaction probably favors a more satisfactory experience of the disease and a better degree of comfort and security with which the patients will cope with the future<sup>43</sup>. According to Mager and Andrykowski<sup>44</sup>, patients with breast cancer who consider that their physicians are more concerned for them and that they offer more emotional support when informing them of the diagnosis have fewer cancer related post-traumatic stress symptoms, less depression and less general distress.

#### CONCLUSION

The degree of psychosocial adaptation in presence of the oncology phenomenon is inversely correlated with the stress level<sup>6</sup>, which seems to be the common pathway of biological repercussion for all the psychosocial variables involved. Both in animals and humans, chronic stress has been associated to the presence of DNA damage, faulty DNA repair, faulty apoptosis and decrease in the immune system vigilance, which may predispose to the genesis of cancer or favor its progression<sup>45</sup>, although in a complex context in which many other factors participate. In cancer, stress generally has a chronic course with episodic worsening and generally increases when advancing towards the disease's final phases. In addition, the process of adequate psychosocial adaptation to cancer requires continuity and permanent adjustment and correction mechanisms, for which care with psychosocial approach is essential. This approach requires paradigms that make it possible to understand the different phases and components of this adaptation process, to be able to pay attention to the multiple factors that affect it.

According to Turk et al.<sup>46</sup> inferences on psychosocial adaptation to cancer must not only be based on the state of the disease but also require a specific psychological evaluation. On the other hand, the psychosocial interventions performed by skilled professionals have already demonstrated greater effects in reducing the emotional distress, improving quality of life, decreasing oncological pain, reducing nausea and anticipatory vomiting related with chemotherapy, improving immune parameters and facilitating family adjustment to the cancer diagnosis and treatment<sup>5</sup>.

In view of all this evidence, it is reasonable to state that psychosocial aspects should be considered and be used as an integral part of the medical care in the evaluation of the oncology patient. Adequate interventions that favor a better psychosocial adaptation to cancer may be translated into not only a better quality of life and better well being but also a better disease prognosis.

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