

Hope for the Person with Advanced Cancer in Palliative Care

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Esperança da Pessoa com Câncer Avançado em Cuidados Paliativos

Esperanza para la Persona con Cáncer Avanzado en Cuidados Paliativos

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INTRODUCTION

In science and in the practice of care, several areas of knowledge explore the theme of hope, each in their own specific approaches and theories. These investigations aim to understand the meaning and sense people attribute to it in different settings, from promoting health to coping with the challenges of chronic diseases. Salutogenesis, mental wellbeing and oncology are just a few of the fields where this theme of hope is explored, whether to understand or strengthen it as a clinical resource in coping with the disease and completeness¹.

Although hope is an essential coping mechanism for everyone regardless of the cancer stage people find themselves in, a systematic review shows that the study of hope is usually framed during an advanced stage of the disease and/or palliative care², as these are situations permeated by uncertainties, fears, denial and hopelessness¹. In this phase, patients experience an internal process that triggers psychoemotional and physical consequences due to their clinical conditions and therapeutic limitations³.

As symptoms grow heavier, so does psychic suffering and depression, which in turn diminishes hope. Thus, hope is negatively related to an increase in symptoms, psychic suffering, and depression. However, when such a situation is met with social support, spiritual and existential wellness, a positive relation between hope and health-related quality of life (HRQoL) is observed, despite the demographic and clinical variables²⁻⁴.

In the context of oncology, two theoretical models of hope are predominantly studied. One of them is proposed by nurse Kaye Herth⁵, based on a multidimensional theory (emotional, cognitive, behavioral, affiliative, temporal, and contextual dimensions). It is “a motivational and

cognitive attribute that is theoretically necessary for starting and maintaining the action towards reaching the goal”⁵. The other theoretical model, found in psychology, is Snyder’s theory of hope, which covers three inter-related components (goals, pathways, and agency) that consist in any event a person desires⁶. Both theoretical constructs present the sense of expectation focused on goals and in the future, supported by interconnection and relationships^{7,8}.

Nonetheless, this essay is justified by the need for caring not only about the challenges faced by people with advanced cancer, but also the elements that may strengthen and support hope, contributing for a broader understanding of the psychological and emotional impact of the construct.

Thus, the present study emerges from the opinion of professionals who have experienced the process of caring for these people, frequently assaulted by dichotomous hopes regarding the advanced cancer prognosis, even though not all of them can benefit from palliative care. This is an opinion article aimed at reflecting on the hope of people with advanced cancer in palliative care.

DEVELOPMENT

THE CONSTRUCT OF HOPE

Hope should be understood as an optimist coping mechanism; even when possibilities suggest otherwise, hope can intensify the individual’s capacity of achieving purposes as they develop resilience. Given the conceptual overlapping, optimism is associated to some results, such as hope, coping, reaching goals and wellness indicators^{4,9}.

People with limitations to their estimated lifespan find hope to be a driving force for survival or healing (desired, even with a limiting illness), which can be attributed to the

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optimistic bias. In advanced cancer, though the possibility of a favorable result is objectively limited, hope is the fuel that helps the patient continue the journey¹⁰.

The construct of hope may be considered a cognitive energy, that is, an individual's interior and/or mental ability of coping, the will to keep going. As such, it is part of the individual, always present in their daily life; its intensity varies and depends on the several aspects that cause positive or negative interference. At first, this energy seems to contain what the person can believe, related to the intrinsic issues of being, such as values, habits, beliefs, and life experiences⁸.

Moreover, hope can be related to a person's reflection-action towards life, highlighting the will to pursue alternatives and means for reaching goals. In this sense, hope is present in the human being's life, associated to the belief of fulfilling desires, which will stimulate new behaviors towards accomplishing them¹². Hope can also sustain the individual's relationship with their past and future, in the search for meaning in the situation they find themselves in.

Different adaptive control mechanisms are developed in the pursuit of satisfaction for one's own life. Self-esteem and engagement can be improved, with hope being a positive coping mechanism in the distinct phases of the illness. Associated to a positive attitude and keeping the spirits up, patients envision a more vigorous "path", without losing hope^{8,13}. Resilience is an important adaptation skill which is inter-related with spiritual well-being and hope¹⁴.

Figure 1 summarizes a schematic representation of the multidimensional and subjective construct of hope; it is a diagram with the purpose of clarifying the concepts, emerging from the reflection and discussion of the authors, based on literature findings about the construct.

ROLE OF HOPE IN ADVANCED CANCER

People with advanced cancer may be affected by different psychosocial factors, mainly after faults in

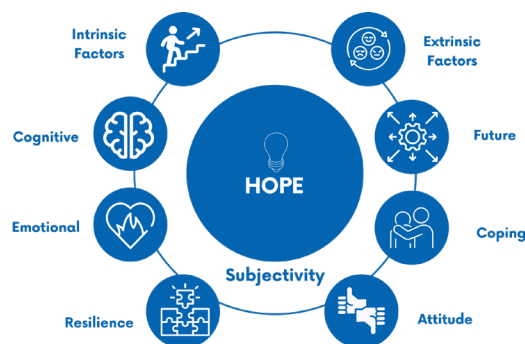


Figure 1. Representation of the multidimensional and subjective construct of hope

multiple systemic treatments. The therapeutic itinerary is permeated by a continued uncertainty, anxiety, and fear regarding the progression of the illness and death. In this context, hope emerges with the goal of prolonging life and mainly maintaining HRQoL. Loss in several aspects of existence and worries about the impact of the illness on their family members, as well as changes to social life, may become prominent psychosocial themes¹⁵.

Social support is then viewed as one of the elements that nourish hope, invaluable for fostering the will to live, as it can provide courage and strength. The presence of family members is essential and may spark hope during the process of coping with the illness in a more positive way¹⁶. And, in the transition towards the end of life, this coping may be viewed as a demonstration of strength and courage by future generations⁸.

The quantification of hope levels in patients with advanced cancer depends on physiopathological, emotional, social, affective issues, uncontrolled symptoms, and mood variations; the sense of belonging to the family circle also plays a significant role^{5,16}. Hope can also offer physiological benefits, encourage adhesion to aggressive treatments, the extensive use of health care and the pursuit for prolonging survival¹⁷.

Another highlight in this construct is pain management; as pain increases, hope diminishes. On the other hand, a high score of hope may increase a patient's tolerance to pain and foresee a better HRQoL. It is worth noting that pain intensity does not reflect a person's hope score, but the experiences caused by the presence of pain, such as the limitations to social relations, performing daily tasks, self-care, among others^{8,12,18-20}.

Such reflection is that hope results from the essential dimensions of sense and human existence and not only as a foreshadowing of healing. Quality survival enables people to accomplish attainable goals (for instance, participating in festive occasions, visiting a desired place), and the degree of achievement of these goals interferes directly in the hope level. As these people realize they have achieved the proposed goals, new goals are set, which increases the levels of hope, optimism and will to live, so hope is redefined^{8,9,12}.

Hope can minimize the fear of advanced cancer so patients can continue their journey. In face of the fear of dying, hope enables people to keep a strong spirit; it acts as some kind of energy, spark, or inner strength; a dynamic mechanism that can awaken the ability to cope and pursue the "self", to go beyond, overcoming the present situation^{1,7,16}.

In this process, hope is related to spirituality (dynamic and internal aspect that searches for meaning, purpose and transcendence, connection with the self, others, nature,

and the Divine) and presents physical and psychological results^{5,19}. Regardless of religion, people keep looking for strength in the Divine, not to find a cure, but the absence of suffering and the meaning of life⁸.

The evaluation and development of strategies to foster hope in patients that cope with advanced cancer is based on the principles of palliative care that aim not only for the effective symptom control, but also improving HRQoL, allowing patients to perform their daily activities independently, preserving autonomy. This is crucial, including during transition to a dignified death, ensuring that each moment is lived with quality and, after grief, a continuous follow-up of care²¹.

The multidimensional construct of hope in the person with advanced cancer in palliative care is represented in Figure 2, in the diagram developed from the author's reflection about the main currents of thought described. Multiple variables interfere in the construct of hope (Figure 1) in a positive or negative view in the (im)balance maintenance, permeated by subjectivity and spiritually.

Notwithstanding, the construct of hope presents itself dynamically and suffers constant interference of different variables. According to the authors, hope gives the person with advanced cancer "energy" to go on their journey and is part of their vital "mechanism". Hope is not about cure, but helping people reach their goals and objectives in the search for balance.

In summary, hope is a complex and multifaceted construct²². It is an adaptive^{8,13,14} dynamic^{1,7,16} emotional state essential for transcendence²². Clinically, hope has been associated to psychoneuroimmunology¹², statistically significant for diminishing inflammation, depression, fatigue²³ and improving survival^{17,12}. Patients with advanced cancer and high levels of hope demand more health care. Though they follow different treatment lines¹⁷, hope should be considered in the care plans for better management of advanced cancer^{1,17,22}.

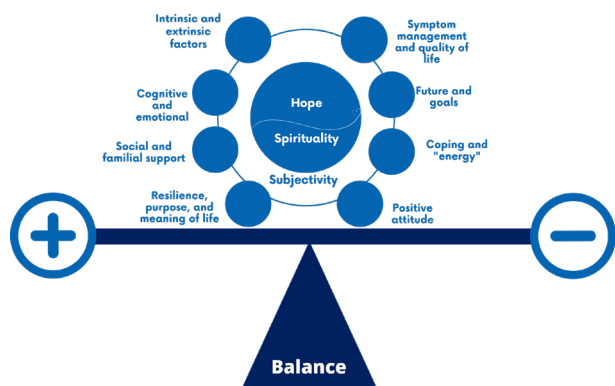


Figure 2. Representation of variables that interfere in the balance of the construct of hope

CONCLUSION

Hope appears as a multidetermined construct, it is part of a dynamic "mechanism" of biopsychosocialspiritual well-being capable of supporting the response to a clinical condition, providing quality of life as well as transcending existence. It is determined by multivariables, whose balance is the focus of the person with advanced cancer.

Reflecting on the density and deepness of all the dimensions intertwined in the construct of hope is a limitation of this opinion essay, and the authors' opinions cannot be generalized. What matters is the reflection, learning, and advances based on the exposed and on the available literature, so that the impact of hope in the treatment of people in palliative care due to advanced cancer is fully understood, and that care is planned to help balance the variables that interfere in these people's hope.

CONTRIBUTIONS

Tangriane Hainiski Ramos and Leonel dos Santos Silva contributed to the study design, acquisition, analysis, and interpretation of the data. Telma Pelaez de Carvalho and Luciana de Alcantara Nogueira contributed intellectually and to critical review. All the authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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