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# End of life of the cancer patient: patient, family and physician perceptions

## *Fin de vida del paciente oncológico: percepciones de pacientes, familiares y médicos*

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### Abstract

Chronic diseases such as cancer have imposed challenges on health systems. Colombia has worked on the construction and implementation of a legal framework for palliative care, but a comprehensive approach to the care provided to cancer patients at the end of their lives is still lacking. Such an approach should be based on understanding of the perceptions of its different actors in order to allow for adequate decision-making and improved support during this stage.

Currently, the infrastructure to provide adequate oncological support is insufficient, the administrative procedures that patients and families have to go through to get authorization for treatments and medications for symptom relief are overwhelming and, many times, costs must be paid out of pocket.

On the other hand, it is important to train healthcare personnel to develop communication skills to approach patients from a place of compassion, personal development and reflection, creating spaces in which patients can speak openly about their wishes, fears and worries, even if they come together with the desire to accelerate the end of life. In addition, healthcare staff should support and initiate conversations about life and the end of life between patients and their families if this communication is complicated, given its importance for healthcare, quality of life and death.

This article seeks to reflect on the end of life of the cancer patient from the perceptions of the actors involved, namely, patients, caregivers and healthcare professionals.

**Keywords:** Perception; Terminal care; Palliative care; Cancer; End of life; Anesthesiology.

### Resumen

Las enfermedades crónicas, como el cáncer, han impuesto retos a los sistemas de salud; Colombia ha trabajado en la construcción e implementación de un marco legal de los cuidados paliativos, pero la atención brindada en el fin de vida del paciente oncológico aún carece de un abordaje integral basado en la comprensión de las percepciones de sus diferentes actores, que permita una adecuada toma de decisiones y mejor acompañamiento en esta etapa.

Actualmente, la infraestructura para brindar un adecuado soporte oncológico es insuficiente, los trámites que debe realizar el paciente y su familia en la autorización de tratamientos o medicamentos para el alivio de síntomas se vuelven desgastantes y en muchas ocasiones los costos deben ser asumidos por ellos mismos.

Por otra parte, es importante fortalecer la formación del personal de salud en comunicación hacia el paciente y su familia, la cual debe ser compasiva, fundamentada en el desarrollo personal y la reflexión, mediante espacios en los que el paciente pueda hablar abiertamente de sus deseos, miedos y preocupaciones, incluso si estos acompañan el deseo de acelerar el fin de vida. Además, el personal de salud deberá apoyar e iniciar conversaciones sobre la vida y el fin de vida entre pacientes y sus familiares si esta comunicación es complicada, dada su importancia para la atención en salud, calidad de vida y muerte.

Este artículo busca reflexionar sobre el fin de vida del paciente oncológico desde las percepciones de los actores involucrados: pacientes, cuidadores y el personal de salud.

**Palabras clave:** Percepciones; Cuidado terminal; Cuidados paliativos; Cáncer; Fin de vida; Anestesiología.

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## INTRODUCTION

Population aging, together with exposure to risk factors, have resulted in an increased incidence of cancer. It is estimated that the number of new cases in the world will reach 30 million by 2040, a number to which Colombia will contribute with 191,631 new cases, as compared to 113,221 in 2020 (1).

Patients who die from chronic diseases like cancer often go through a protracted end-of-life period, sometimes due to prolongation of life through the use of futile treatments which end up making the process more painful for patients and families alike. Palliative care emerges as a multidisciplinary management strategy focused on symptom control, support in coping with the end of life, and the best management of the environment in order to enhance quality of life and death.

Despite the efforts at improving end-of-life experience and gaining deeper insight into the experience during this stage, advances and, in particular, offerings in this regard in Colombia are still limited. In order to expand knowledge in this area and create greater awareness regarding the care provided to cancer patients, we conducted a search of studies that approached this topic, starting with perceptions identified in studies carried out in Colombia and comparison with the findings in other countries.

## END-OF-LIFE OF THE CANCER PATIENT: PHYSICIAN PERSPECTIVES

Support during this stage poses important dilemmas to the healthcare professional, one of them being decision-making regarding the initiation or discontinuation of specific treatments for the disease (2,3). This scenario goes hand in hand with the challenge of dealing with difficult conversations with the patient and the family.

Some physicians express concerns about undermining patient and family expectations if they bring up the subject

of prognosis. It may also happen that these conversations are avoided in situations in which treatment options with curative intention are limited and death is perceived as a negative event (4).

Unpreparedness for dealing with difficult conversations has been made evident in different studies conducted in this country (2,5) which suggest that problems of communication could be due to lack of training, education and experience when it comes to explaining management and the care required during this process (5,6).

Some of these skills cannot be developed, as is the case with the ability to dialogue, listen, reassure and provide support (2,7). However, tools to improve communication are available, such as identification of concerns and recognition of signals, asking open-ended questions in order to glean what patients know about their disease and what questions they have, listening actively and informing about the stage of cancer while assessing the level of understanding of the information provided, as well as being empathetic and respectful of emotions (8,9).

A study conducted in 2019-2020 examined perceptions and opinions about end-of-life decision-making in cancer patients in three hospitals in Colombia. This approach to learn about the opinion of the healthcare professionals found that, top among their concerns about the patient was suffering, in particular pain, as well as the recognition of empathy and trust as attributes of the doctor-patient relationship that are enhanced through communication (5). In other studies, situations that create concern among physicians and nurses had to do with the lack of privacy for patients and families at the time of death, and the lack of support for physicians from a board to help them with the management of difficult cases (6).

Some healthcare professionals are of the opinion that providing support during the final stage of life - even though it means a huge emotional burden - has purpose and meaning when it is underpinned by

the rapport established with the family and the patient, when the therapeutic management goal is focused on comfort (10), and when it is based on identified patient needs in terms of environment, culture and beliefs; and this is something that requires time and genuine interest (11).

## END-OF-LIFE OF THE CANCER PATIENT: PATIENT PERSPECTIVES

The approach to care at the end of life must be centered on the patient and the family. It is important to recognize that the diagnosis of advanced disease has a profound impact on patient and family life. Patients and families must prepare to face changes in family dynamics, daily routines and physical appearance, loss of independence, increased health expenditures (12), changes in their plans and dreams that will not materialize, feelings of grief and loss of faith (13), not to mention the need to deal with all the paperwork that characterizes a fragmented health system. All these are situations that call for patient support from a place of compassion.

A qualitative study carried out in 2019-2020 in Colombia, based on in-depth interviews of 12 patients with advanced cancer, highlighted the importance of adequate symptom control, the need for independence, concerns related to family and financial issues, and problems of communication with the healthcare staff which, being very blunt when it comes to discussing diagnosis and prognosis in some cases, creates a negative impact on patients and families. This is in contrast with the need of some patients and families to receive accurate information about the disease condition (13).

Communication ends up being a significant challenge for patients. It has been shown that quality of life and death of patients with advanced disease improves when they can communicate their preferences regarding their treatment and medical care, both to the medical

team as well as to their family members and caregivers (13,14). It is important for patients to be able to express their concerns and wishes regarding the end of their lives, to say goodbye to their loved ones, settle pending matters, or even ask for help to accelerate the end. Several patients also mentioned the importance of talking about death and end of life with the people around them (15). However, the patient's environment often denies the notion that death is near and, prompted by their best intentions, family members reject any reference to the end of life with the argument that they need to keep on fighting (16,17) —situation which is not limited to the Colombian context.

Another reason for not discussing disease and end of life is to avoid the pain and discomfort that these conversations can create. It is important for healthcare institutions to provide support to patients in their communication about their disease and the end of their life with the healthcare team and their family members.

A frequent concern among Colombian patients is the delay imposed on diagnosis, symptom management and treatment by administrative paperwork. This is very worrisome due to rapid disease progression and worsening of short-term prognosis in certain cases (13,18). Also of concern is the lack of sufficient units to provide outpatient or home care to cancer patients, thus limiting their visits to the emergency room for symptom control. Symptoms could be managed in palliative care units that offer greater comfort to patients and families (19) and promote privacy and dignity as fundamental principles for a good death (10,13).

One important end-of-life need is associated with spiritual care. Spirituality, either formal or informal, offers support to many patients as they come to the end of their lives, allowing them to find solace and peace (20); in some instances, though, waiting for a “miracle” can hinder important parting and closing processes with the family. Other patients see religion as something negative, in particular

if they perceive that they are being forced to participate in certain rituals or conversations (13).

## END-OF-LIFE IN CANCER PATIENTS: FAMILY PERSPECTIVES

Feelings of powerlessness and anxiety emerge in the caregivers from the very moment they are told that their family member has cancer, because of the link between that disease and death. These emotions tend to be suppressed out of fear of discouraging the patient and other family members, imposing a significant emotional burden (21).

The lives of patients and family members change completely when a diagnosis of cancer is received. Caregivers must make adjustments and arrangements to care for the patient, making a considerable time investment in therapies aimed at controlling and treating the disease, situation that can impact the wellbeing of both the patient as well as the caregiver (22). Another consideration is the time required for paperwork, which may result in losses, even including the loss of a partner or a job (12). Patients find it difficult to accept their loss of independence in activities of daily living and having to depend on the help of their caregivers, because they do not want to be a “burden” (13).

A local study measured the financial impact that cancer can have on caregivers and showed that a significant percentage of them have to move, put their study or travel plans on hold, and even postpone treatments for their own health or that of another family member in order to be able to cover the expenses associated with the care of the cancer patient (12). Caregivers often lack psychological guidance, a situation that ends up disrupting their ability to carry out some activities of daily living and look after their own physical health. Long hours devoted to the care of their family member gradually take a toll on the health of the caregiver.

It has been shown that a high burden of depressive symptoms affecting the caregiver has repercussions on patient-reported quality of care. Hence the importance of including the caregiver in interventions designed to detect if they are overburdened and provide them with timely support (23).

These interventions must also cover the bereavement period because, when the cancer patient dies, the caregiver has to deal with his or her own grief apart from having to adapt to a world where the family member is no longer present (24).

## CONCLUSIONS

The growing number of diseases like cancer and, consequently, of patients facing the end of their lives, has rekindled during the past two decades in different countries the debate about the care provided to these patients. Differences are found between the wishes of the patients and the opportunities to discuss those wishes, legal matters (for example, advance directives), as well as ethical and health considerations (3,25).

It is important to train healthcare workers at all levels so that they can provide the right support and environment to the patient during the end-of-life phase. The lack of effective and compassionate communication is considered one of the most relevant care barriers (14). There are tools that can be used to discuss the disease, prognosis and decision-making about future medical care (advance directives) (14,26). It would be important to assess their use in the Colombian context, in order to make this process easier.

As a society, we must work on accepting death as a natural part of life, as this could limit the use of curative treatments at the end of life (27–29).

As healthcare professionals, it behoves us to reflect about our own passing (2) so that we can awaken the empathy we need in order to approach each individual case from a place of caring, identifying the right moment and the correct approach to

convey the information to the patient and the family, as needed. Patients should be given the opportunity to ask the questions they want answered at a given point in time and be reassured that they will have the support they need in terms of guidance and information about their disease, medications and prognosis (30) whenever they are ready to receive it.

Priority must also be given to the care that needs to be provided to caregivers, who need to be made part of the oncology support given to the patient, and also receive well deserved recognition for their labor of love and for their need to join with other family members to share the burden of care.

Cancer is a group of diseases which, apart from having a profound impact on patient physical condition and quality of life, also has huge effects on the social and economic environment. People suffering from cancer have to live in constant uncertainty associated with both diagnosis as well as prognosis, financial costs, and the time horizon. However, it is worth stressing that, in Colombia, healthcare professionals exhibit more interest, concern and empathy towards the suffering and pain of the patients facing the end of their lives, during which efficient and clear communication skills are increasingly necessary (5).

Barrier elimination in care processes, an increase in the number of palliative care units working round the clock, the inclusion of subsidies to help with out-of-pocket spending, the creation of institutions focused on providing end-of-life care with the level of comfort found in a non-hospital home environment, and home care units affordable to patients and families, are urgent matters for a public policy agenda designed to improve the end-of-life stage of cancer patients.

In many cases, patients, families and some physicians perceive death as a negative event. Feeling that death - which is in principle a natural phenomenon - is near, creates a huge emotional burden; therefore, good communication and accessible and timely care play a key role in improving

the quality of death for the patient and of bereavement for the family members. In this reflection we have presented some of the concerns pertaining to end-of-life in patients with cancer. We hope they will help treating teams and decision-makers develop tools to ensure a comprehensive approach and enhanced support.

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**AA and EDV:** Conception, writing, review and final approval of the paper.

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