

REFLECTION

Palliative Care in Colombia: home care services, access barriers, and progress in the implementation of these programs during the COVID-19 pandemic

Cuidados paliativos en Colombia: atención domiciliaria, barreras de acceso y avances en la implementación de estos programas durante la pandemia por COVID-19

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Abstract

Palliative care aims to comprehensively alleviate the suffering of patients with chronic, degenerative and terminal diseases, and thus improve their quality of life by including physical, psychosocial, and spiritual aspects in the care process.

In Colombia, the provision of palliative care services is regulated by Law 1733 of 2014, but access to them is limited since the health care centers where these services are provided are concentrated in the large capitals of the country. Furthermore, the general population is unaware of the existence of this type of care.

The fear of contagion during the COVID-19 pandemic created additional barriers, hindering even more the access to palliative care. For example, the access of health personnel in charge of these services to patients' homes was restricted and it was observed that people avoided attending their appointments at health centers.

Similarly, isolation and social distancing measures further worsened the psychosocial suffering of both inpatients and their families, as the support and presence of their loved ones was extremely limited during the end-of-life period, making, in turn, the grieving process more difficult when these patients passed away.

Bearing this in mind, the objectives of this reflection were to explore the current situation of palliative care services in Colombia and analyze the impact that the COVID-19 pandemic has had on their provision at home.

Resumen

Los cuidados paliativos buscan aliviar de manera integral el sufrimiento de los pacientes con enfermedades crónicas, degenerativas y terminales, y, de esta forma, mejorar su calidad de vida al incluir aspectos físicos, psicosociales y espirituales en la atención.

En Colombia, la prestación de los servicios de cuidados paliativos está regulada por la Ley 1733 de 2014; sin embargo, el acceso a los mismos es limitado, ya que los centros de atención donde se prestan estos servicios se concentran en las capitales departamentales; además, la población general desconoce la existencia de este tipo de atención.

El temor al contagio durante la pandemia por COVID-19 ha creado barreras adicionales que dificultan aún más el acceso a los cuidados paliativos; por ejemplo, se ha restringido el acceso del personal de salud encargado de estos servicios a los domicilios de los pacientes y se ha evidenciado que las personas evitan asistir a sus consultas a los centros de salud.

De igual forma, las medidas de aislamiento y distanciamiento social han empeorado aún más el sufrimiento psicosocial de los pacientes hospitalizados, así como el de sus familias, ya que el apoyo y la presencia de los seres queridos se han limitado seriamente durante el periodo de fin de la vida, lo que a su vez ha hecho más difícil el proceso de duelo cuando estos pacientes fallecen.

Con esto en mente, los objetivos de la presente reflexión fueron explorar la situación actual de los servicios de cuidados paliativos en Colombia y analizar el impacto que ha tenido la pandemia por COVID-19 en la prestación domiciliaria de este tipo de cuidados.

Introduction

According to the World Health Organization (WHO), the aim of palliative care is to improve the quality of life of patients and their families who are facing problems associated with life-threatening illness by preventing and relieving suffering through the identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual symptoms.¹

In Colombia, palliative care is regulated by Law 1733 of 2014,² which establishes that people with terminal, chronic and degenerative diseases have the right to receive information and palliative care, to get a second medical opinion, to sign a living will (*documento de voluntad anticipada* in Spanish), and to actively participate in their care and decision-making process regarding the treatments they will receive. Likewise, this law defines palliative care as that which takes into account psychopathological, physical, emotional, social, and spiritual aspects, and which attempts to improve the quality of life of terminally ill patients by means of comprehensive treatments that reduce pain and alleviate suffering. Moreover, it is worth mentioning that, according to this law, “palliative medicine affirms life and deems death as a normal process.”²

However, despite these regulations, there is significant imbalance in the country in terms of access to palliative care services due to various barriers that impact not only outpatient care, but also home care. At present, measures adopted to fight the COVID-19 pandemic have also had a major impact on patient care and have led to the appearance of new barriers to access to care services, including palliative care services.

In this context, the objectives of the present reflection were to explore the current situation of palliative care services in Colombia and to analyze the impact of the COVID-19 pandemic on the provision of palliative care at home.

Status of palliative care and home care services in Colombia

Despite existing regulations in the country,² palliative care services are at an advanced stage of integration into the health system only in Bogotá and Antioquia; in other words, these are the only places in which there is a variety of providers of such services and permanent availability of the drugs required for delivering them, such as morphine and potent opioids.³ Meanwhile, in Amazonas, Guainía, Vaupés and Vichada, there is no evidence of any palliative care program, and the other Colombian departments are in an intermediate stage of implementation of palliative care services in their health systems. Based on this distribution, it can be concluded that there is a significant geographical imbalance in Colombia in terms of access to palliative care services,^{3,4} which may be attributable to the fact that in most parts of the country there are multiple barriers to access to care, not only in the field of palliative care, but also to health in general.

Barriers to access to palliative care services include the general population’s lack of awareness of the existence of such services (perhaps due to lack of visibility), difficulties in accessing opioid drugs, deficiencies in the training given to caregivers and relatives, poor recognition of the work of caregivers of patients who require such services, lack of incentives to develop typical palliative care activities, and limited development of palliative care in the home setting.⁵ In addition, the shortage of human resources specialized in palliative care nationwide generates a problem that aggravates geographical imbalance in the provision of these services, since most professionals specialized in pain medicine and palliative care are located in Bogotá, Antioquia, and Santander. This lack of trained personnel is mainly explained by an insufficient academic offer in this area.^{3,5}

As mentioned above, lack of access to drugs is another barrier faced by patients requiring palliative care. This occurs mainly because of a lack of training of health professionals in the use of opioids, fear of drug dependence, cultural practices that make it difficult to identify and handle pain in a timely manner, and health professionals' fear of the misuse of essential palliative drugs in illicit settings.⁶

In light of such barriers, the Colombian Ministry of Health and Social Protection developed technical tools to implement palliative care services through the creation of guidelines for comprehensive care in this area, establishing the responsibilities of territorial entities, benefit plan administrators, and health care providers.⁵ These guidelines were prepared in accordance with the current regulatory framework and based on the analysis of the current situation of palliative care services in Colombia, the strategic lines established by WHO, and the country's Comprehensive Health Care Model.

It should be noted that WHO's strategic lines include the creation of policies that integrate palliative care services at all levels of care and in the structure and financing of health systems at the national level, the creation of policies to strengthen and increase the human resources in health with training in this area, and the development of policies that ensure the availability of essential drugs for the treatment of frequent symptoms in patients who require these services.

Similarly, for the preparation of the guidelines, the Ministry of Health and Social Protection took into consideration both the development of registration mechanisms to obtain more reliable information and data on palliative care services and the use of indicators to characterize the status of this type of services in the country in outpatient and home care settings. This was done taking into account that it is necessary to monitor and make a progressive assessment of such services in order to measure, compare, and improve palliative care across the country.⁵

Given the characteristics of patients requiring palliative care, it is presumed that most of them develop progressive functional dependence to perform basic activities of daily living and, therefore, many of them see their ability to move impaired, which in turn prevents them from being able to go to health centers by themselves; in this context, home care plays a fundamental role. Although their situation is clear, home care programs for these services are very limited in Colombia, but it should be noted that the situation is improving: while there were only programs of this type in 16 of the 32 departments in 2018 and they were concentrated in Bogotá, Armenia, Barranquilla and Cali, as of April 2021 such services had been strengthened in the places where they were already available and were also implemented in the departments of Boyacá, Cauca, Magdalena, Meta, Norte de Santander, and Yopal.^{4,7}

According to the Atlas of Palliative Care in Latin America 2020, there are 79 palliative care teams in Colombia, of which 40 are exclusively in-hospital, 20 are exclusively out-of-hospital (home-based, community consultation, and hospice), and 19 are mixed. Thus, the rate of palliative care teams per million inhabitants in Colombia is 0.40 for exclusively out-of-hospital teams, a relatively low figure compared to countries such as Costa Rica, Panama and Uruguay, which have rates of 10.50, 8.65 and 5.76, respectively.⁸

In Colombia, access to home-based palliative care services is limited by various types of barriers, including geographic barriers, which are defined as the difficulty of accessing certain areas that are beyond the area of coverage of health care institutions; this is highly relevant since a large part of the country's rural population is located in areas where there is no such coverage.^{3,4} The provision of palliative care services through home care is also driven by socioeconomic factors, since patients need to upgrade their homes and ensure access to public services to be able to receive these services.

The latter aspect has been particularly relevant during the COVID-19 pandemic since access to water is a critical issue due to the need for hand washing;⁹ hence, providing palliative care services through home care in areas where hand washing conditions are not optimal has been more challenging because it increases the risk of infection for both the patient and the health care professionals. In addition, the provision of palliative care home services requires that the patient has a caregiver capable of performing basic care activities such as personal hygiene, feeding, medication administration, etc. Consequently, failure to have a suitable caregiver for patients with a poor social support network poses an additional obstacle to accessing this type of care.¹⁰

It is worth mentioning that barriers to access to palliative care services are also related to barriers to access to primary health care due to the limited resources available, since there are no paraclinical aids that would enable a timely diagnostic approach or medical equipment to perform certain procedures that require a higher level of clinical expertise.¹¹

It is also noteworthy that there are risks for health care professionals related to entering the patient's home to provide palliative care services; for example, if the patient becomes violent or disruptive, or if the families are in crisis, health care personnel are at risk of being assaulted.¹² In this sense, the family situation is especially pertinent in the context of palliative care, since patients' relatives must usually cope with a new scenario in which the death of their loved one is expected, and dealing with feelings of frustration or anger that may trigger aggressive behaviors towards health care personnel.¹³

Impact of the COVID-19 pandemic on palliative care services provision in Colombia

Even though the provision of palliative care services has increased, the current COVID-19 pandemic has created additional barriers to access. For instance, when the crisis first broke out, patients no longer attended their appointments and check-ups due to the fear of contagion resulting from feelings of anguish, anxiety and stress caused by repeated exposure to the media, which for several days, and even months, did not discuss any topic other than the new coronavirus and the havoc it was wreaking worldwide.¹⁴

On the other hand, the problem caused by the COVID-19 outbreaks in nursing homes demonstrated the importance of reducing the risk of infection and establishing infection prevention measures in vulnerable populations,¹⁵⁻¹⁷ which has a positive impact on public health. Nevertheless, some of these health protection measures implemented may be inadequate, as patient care has been limited because families have stopped using home care services to reduce the risk of contagion.¹⁸

In this sense, medical personnel working in palliative home care have experienced an overall rejection, mainly in geriatric homes, where not only visitors have been restricted, but also healthcare staff, in particular psychologists and social workers who do not deal with vital conditions from a biological point of view but are a fundamental part of palliative care. These restrictions negatively impact patients' quality of life and symptom control, and this in turn affects comprehensive palliative care, which not only addresses patients' physical conditions, but also involves psychological, social, and spiritual concerns. It is worth noting that in some of these homes, family members also refused care from therapists of different modalities (physical, respiratory, speech therapy and occupational) out of fear of being infected by COVID-19. Thus, refusal of medical care because of the fear of contracting COVID-19 correlates with a decrease in outpatient and emergency department visits and hospital admissions.¹⁹

At the same time, health care workers, faced with the fear of contagion, had to deal with the conflict of whether they should prioritize the performance of their jobs or the need to protect themselves and their families, which became a challenge for those who chose to leave their jobs, as it caused feelings of discomfort and guilt.²⁰ Another major challenge for health care workers when providing home-based palliative care services during the COVID-19 pandemic is that in some occasions they have to treat entire families infected and, given that compliance with protective measures such as the proper use of masks and physical distancing is subject to individual judgment due to the lack of control entities in the hospital setting, it is more difficult to fulfill their duties.²¹

Between the second and third quarter of 2021 (the most critical period of the pandemic in Colombia), the high occupancy of intensive care units, the collapse of the hospital network and the shortage of resources such as drugs, medical oxygen and medical staff caused difficulties for patient care in all areas of service delivery. For example, the shortage of medical oxygen affected the care of patients both in hospitals and at home, mainly those with respiratory diseases,^{22,23} and the recall of batches of hydromorphone contributed to the shortage of this opioid, which is one of the essential drugs for pain management.²⁴ Regarding the latter point, despite the existence of other opioids, hydromorphone, together with morphine, is essential for the treatment of pain and dyspnea in patients at the end of life, so its shortage led to complications in the adequate control of symptoms in patients undergoing palliative care.²⁵

On the other hand, during the peaks of the pandemic, some limitations have arisen regarding compliance with living wills because high hospital occupancy restricts access of terminally ill patients to hospital beds or palliative care units to provide them with end-of-life care, and, in many cases, they must die at home, a situation that some patients and/or families oppose for various psychosocial or spiritual reasons that also have a negative impact on the grieving process. However, there are patients who wish to die at home or continue to receive care there but suffer from respiratory diseases that require the use of oxygen and cannot be discharged due to the lack of oxygen supply and the absence of high-flow equipment for home care.²⁶

At this point, it is important to emphasize that the living will is a document in which people state their decisions in case they are unable to make them in the future, since they freely, consciously and informedly indicate their preferences in case they are facing a terminal, chronic and/or degenerative disease that impacts their quality of life, specifying whether or not they wish to undergo certain medical treatments. In summary, the living will allows establishing patients' preferences regarding health care or attention in the event that they are unable to express their will due to various circumstances at any given time.^{2,27}

Patient's preferences regarding health care are a central part of palliative care and their importance lies in the principle of respect for patient autonomy, which implies that each individual has the right to act voluntarily and freely, and that, therefore, the treating physician should actively support their decisions, even if they are contrary to the recommendations or wishes of the medical team and the family.²⁸ For this reason, it can be concluded that the aforementioned limitations affect the main objective of palliative care, which is to ensure quality of life. Since there have been stressful reactions and fears during the COVID-19 pandemic, it is important to recognize that the information provided to patients and families must be comprehensive and understandable, in order to facilitate informed decision making based on the patient's and family's personal values and beliefs.²⁹

During the pandemic, patients have also been frequently avoiding their referral to emergency departments and hospitalization services due to fear of COVID-19 infection,

even in cases of life-threatening emergencies requiring immediate medical care, or when there is inadequate symptom control, thus leading to persistent suffering. Due to this situation, doubts have arisen about the meaning and scope of palliative care in a new scenario resulting from the ravages of a pandemic, which is influenced by what health care personnel and the patient believe is best, always considering that the family is at the center, but sometimes on the side of their loved one and other times on the side of the health care personnel. Such dilemmas lead to the understanding that there is no absolute truth or a single correct behavior, as every way of acting depends on the specificities of each patient and their psychosocial context.

Faced with these conflictive situations, palliative care professionals play a fundamental role in supporting decision making, so that aspects such as the relevance of diagnostic or therapeutic staging, the readjustment of the therapeutic effort, and the establishment of the therapeutic ceiling have gradually taken on greater importance compared to the scenario prior to the pandemic.^{28,29}

On the other hand, the provisions and recommendations introduced by the different governmental bodies and resulting from the pandemic have entailed socio-cultural changes with respect to social interaction in medical care. Biosecurity measures such as physical distancing and the use of personal protective equipment have imposed barriers in the care of patients, and this has had a particular impact on those who are in the most advanced stages of a disease and whose emotional needs are a fundamental part of care, since empathic and affective communication plays a key role in emotional containment for the patient and in satisfying their needs.^{30,31}

Besides physical barriers, stress in health care professionals as a consequence of the pandemic may have a negative impact on their ability to communicate with the patient. Accordingly, communication has also been affected as physicians must rely on technology and other remote means to provide information to family members, and in the cases where face-to-face interaction is possible, they must wear personal protective equipment that imposes an additional physical barrier to communication.^{32,33} All these obstacles have led health professionals to face new challenges when caring for their patients in the midst of the pandemic, making it necessary to strengthen the doctor-patient relationship.

The COVID-19 emergency has also brought positive developments. For example, Resolution 521 of 2020 of the Ministry of Health and Social Protection³⁴ established a home care procedure for patients over 70 years of age or with chronic underlying conditions during the pandemic in order to reduce their risk of infection. Likewise, the same institution implemented a home care procedure whereby a self-monitoring kit and oxygen treatment, when appropriate, are provided to patients infected with coronavirus in order to reduce the number of visits to medical services and preserve the epidemiological barrier.^{35,36} However, it should also be noted that some home health care institutions have collapsed during the pandemic because they were not only required to care for palliative care patients, but also for patients with chronic diseases and with COVID-19; in other words, they had to expand their functional capacity, sometimes even extending their working hours to full availability (including night hours and holidays).

Another important development during the COVID-19 pandemic has been the promotion of telemedicine, a modality of care that was already available in the country, but which has been significantly promoted during the pandemic. The most widespread use of telemedicine during this period is in outpatient care, followed by inpatient care in emergency, and inpatient settings.^{37,38} Some of the benefits of telemedicine include the reduction of expenses for patients as they do not have to go in person to health care institutions and the reduction of the risk of contagion of various microorganisms present in these places.³⁹

In the context of palliative home care, given the rapid growth of palliative care programs due to the spread of the pandemic and the collapse of some health care providers, telemedicine has been playing a fundamental role. For example, the use of telephone and video calls allows for an assessment of the clinical condition of patients in order to prioritize in-person care at home, which is similar to how triage is performed in emergency departments to determine the appropriate prioritization of in-person care by medical, nursing, psychology, social work or spiritual counseling professionals, depending on the needs of each patient. The importance of this aspect lies in the fact that, to avoid contagion, priority has been given to on-site care in cases that require immediate assessment and physical examination due to the urgency of the situation.^{33,40} It is also worth noting that the use of telemedicine in palliative home care has improved patients' access to the services of health professionals at home, giving them a sense of security and safety.⁴¹ Likewise, in some home-based palliative care programs in Bogotá, support from specialists over the phone has been very useful in guiding the management of patients at home, which also favors timely communication and facilitates important decisions.

Finally, it is worth mentioning that telemedicine has also favored the creation of virtual spaces for meetings between families and the palliative care team in which it is possible to answer questions and guide the therapeutic plan.^{42,43}

End of life and grief during the pandemic

As previously noted, the principle of respect for patient autonomy is fundamental in the framework of palliative care, so the living will is very useful in guiding the treatment plan in the event of clinical deterioration, since the patient has previously specified the therapeutic interventions they would be willing to undergo, the preferred setting for receiving medical care (hospital or home), and where they would like their life to end.³² Thus, patients who choose to receive home care only receive the necessary medical assistance and die at home in the company of their loved ones, in their own environment and with previously defined treatment goals, even in a pandemic scenario as experienced in recent months, when the common denominator was that people died alone and isolated in hospitals.^{44,45}

The fact that most people were separated from their loved ones in the end-of-life phase during the pandemic has had a significant impact on the grieving process because, when a patient enters the agonal phase while in nursing homes or hospice care units, these institutions implement restrictions on who can accompany the patient, as there are strict regulations to be followed in this regard.³²

Relatives often experience greater emotional pain if they feel that the process of death was traumatic or unexpected, and suffering increases if they were unable to say goodbye. Similarly, the traditional social support network generated after the loss of a loved one has been affected due to the isolation measures imposed by the authorities; at this point it should be borne in mind that, although electronic forms of communication are a useful means of support, they are not always accessible to all.⁴⁶

However, home-based palliative care services have allowed many patients to die at home accompanied by their nuclear family and under the care of personnel trained to provide them with the necessary care, which contributes to the relief of physical, psychosocial and spiritual suffering, both for the patient and their family, which may favor the grieving process. This scenario clearly differs from death in an in-hospital setting, in which isolation can generate additional suffering for the patient in the end-of-life process and hinder the grieving process of the relatives.

In this regard, further research is needed in the field of palliative care to assess the actual impact of home care compared to in-hospital care in the context of end-of-life during the pandemic and to analyze the frequency of signing living wills in view of their usefulness in palliative care.

Conclusions

Palliative care is a developing interdisciplinary area of health sciences that focuses on improving the quality of life of patients with chronic, degenerative, and terminal illnesses. Although these services have been regulated in Colombia since 2014, access to them is limited because most care centers and specialists are concentrated in the principal departmental capitals.

The COVID-19 pandemic has created problems in palliative care for patients because some virus containment measures, such as mandatory isolation of the majority of the population, have impacted end-of-life care processes. This has affected how the patient's physical, psychosocial, and spiritual suffering is managed, as well as the family's grieving process, so comparative research is needed on the impact of the pandemic on end-of-life care in patients treated at home or in health care institutions. There is also a need for further research into the signing of the living will given the importance of this instrument in the care of patients requiring palliative care.

Conflicts of interest

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