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Palliative care during the pandemic: being human and facing finitude

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Abstract

People's routines, especially of individuals affected by chronic illnesses, underwent significant changes due to the emergence and widespread dissemination of the COVID-19 pandemic. Thus, this literature review analyzed the impact of palliative care in chronically ill patients during the pandemic. The fear and feeling of loneliness produced by social isolation enhanced their suffering, highlighting the importance of palliative care teams in aiding the sick and their core family face this reality, especially at end of life. In this regard, humanized care brings psychosocial benefits to patients, as well as economic advantages to the health system. Theoretical discussion highlight that implementing palliative care teams is fundamental to afford qualitive of life and dignity to these individuals.

Keywords: Bioethics. COVID-19. Chronic disease. Palliative care.

Resumo

Cuidados paliativos na pandemia: ser humano diante de sua finitude

A emergência e a ampla disseminação da pandemia de covid-19 acarretaram mudança significativa na rotina da população, em especial daqueles acometidos por doenças crônicas. Diante disso, esta revisão de literatura busca compreender o impacto de cuidados paliativos em pacientes crônicos na pandemia. Sabe-se que o medo e o sentimento de solidão decorrentes do isolamento social acentuaram o sofrimento desses pacientes, evidenciando a importância de equipes de cuidados paliativos para auxiliar doentes e seu núcleo familiar a lidar com essa realidade, em especial na fase terminal da vida. Nesse sentido, salientam-se os benefícios psicossociais relacionados à humanização do cuidado, bem como vantagens econômicas ao sistema de saúde. A reflexão teórica demonstra a necessidade de implementar equipes de cuidados paliativos, a fim de promover qualidade de vida e dignidade aos indivíduos.

Palavras-chave: Bioética. Covid-19. Doença crônica. Cuidados paliativos.

Resumen

Cuidados paliativos en la pandemia: el ser humano frente a su finitud

El surgimiento y la propagación generalizada de la pandemia de la covid-19 llevaron a un cambio significativo en la rutina de las personas, especialmente aquellas con enfermedades crónicas. Así esta revisión de la literatura pretende comprender el impacto de los cuidados paliativos en los pacientes crónicos en la pandemia. Se sabe que el miedo y el sentimiento de soledad resultantes del aislamiento social profundizaron el sufrimiento de estos pacientes, lo que muestra la importancia de los equipos de cuidados paliativos para ayudar a los pacientes y sus familias a lidiar con esta realidad, especialmente en la fase terminal de la vida. Se destacan los beneficios psicosociales relacionados con la humanización de la atención, así como las ventajas económicas para el sistema de salud. La reflexión teórica apunta a la necesidad de implementar equipos de cuidados paliativos para promover la calidad de vida y la dignidad a las personas.

Palabras clave: Bioética. Covid-19. Enfermedad crónica. Cuidados paliativos.

Research

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According to Van Rensselaer Potter[1], bioethics represents a bridge between biological sciences and ethics, being necessary for the survival of the human species by maintaining a harmonic system. Bioethics thus seek to preserve human existence and all life forms.

From this understanding, the following bioethics principles stand out: beneficence, the act of doing good, seeking to benefit others; non-maleficence, avoiding interventions that disrespect the patient's dignity as a person; and autonomy, providing patients the ability to understand the treatment process, communicate their needs, and participate in deciding the interventions that better fit their needs[2]. These concepts are essential since they raise awareness among healthcare providers about the growing need for palliative care[3].

The growing number of chronic patients in the current context make palliative care stand out since it not only enhances the quality of life of patients and their families but also relieves them from physical, psychosocial, and spiritual distress[4]. Palliative care is also recommended for individuals who require some kind of special attention due to the curative treatments [not being available]. One can thus understand that palliative care is allied to the bioethical understanding of protection of the right to life.

Beyond existing concerns toward the healthcare system, in December 2019, a new coronavirus variant was detected in Wuhan, China, known as SARS-CoV-2 and identified as the cause of COVID-19. In March 2020, in the face of the rapid spread of the virus, the World Health Organization (WHO) declared the COVID-19 pandemic[5]. Therefore, a context of humanitarian crisis was observed, in which emergency demands such as the treatment of COVID-19 patients were prioritized over palliative care, which could have relieved the suffering of individuals[6].

Method

This literature review is based on cultural, ethical, and bioethical aspects—an interdisciplinary perspective. Scientific information has demonstrated the impact of the COVID-19 pandemic on the entire population, particularly affecting individuals with comorbidities and their immediate families. This review was based on the following research question: "How does palliative care impact the quality of life of chronic patients in the pandemic context?". Once the research question was established, the keywords for literature search were defined as "bioethics," "COVID-19," "chronic diseases," and "palliative care" in both English and Brazilian Portuguese.

The eligibility criteria for the researched information were having a maximum publication date of 10 years, not presenting conflicts of interest, and having a direct relevance to this study subject and research question. Then, comparative data collection and reading of the selected texts were conducted to analyze the findings, aiming to generate the results and discussion for this article.

Results and discussion

Palliative care for chronic patients

Human dignity, the right to life, and healthcare access are essential conditions for human beings. The Constitution of the Federative Republic of Brazil establishes these conditions as inviolable and guaranteed to all[7], which, paired with bioethics principles, reinforces the need to ensure that these rights are present at the beginning, during, and at the end of life, as recommended by palliative care.

The concept of palliative care is not limited to specific conditions such as age, type of disease, or affected organ. It is characterized by the respect for life and the recognition of the right to it, considering personal needs of patients and their immediate families. Therefore, the proposal is to manage and reduce all symptoms associated with the patient's condition, aiming for an integration of physical, psychological, social, and spiritual aspects. This approach results in a positive intervention in the individual's clinical condition[8].

In this sense, among the precepts of palliative care, life is encouraged, supporting possible procedures according to each patient's needs. Furthermore, by emphasizing the value of life, it is understood that death is a natural process, and interventions should not seek to hasten or delay it. Such concept, combined with advance care planning, provides support not only for the patient but also for the family during the illness and the grieving process[3].

In the palliative approach, the complexity of caring for terminally ill patients who failed traditional therapy is emphasized. Therefore, there is a need to allocate resources and plan for the training of healthcare providers with both technical and human knowledge, allowing careful and individualized management. Lastly, the importance of a specialized multidisciplinary team with humanitarian skill is emphasized to provide comfort and well-being to patients[3].

COVID-19 and the reality of chronic patients

At the beginning of the COVID-19 pandemic, there were many uncertainties regarding the disease, but later, studies showed that most cases presented a satisfactory response to contamination, with asymptomatic conditions or flu-like symptoms. However, amid the large number of cases, it was found that some groups were prone to manifest severe forms of the pathology, with pulmonary involvement and prolonged hospital stays. This population was classified into different risk groups: individuals older than 60 years of age and individuals with diabetes mellitus, hypertension, cardiovascular diseases, obesity, chronic lung or kidney disease, and cancer[9].

As confirmed cases of the disease increased, several restrictions were proposed aimed at social distancing and, especially, containing COVID-19. Lockdown measures restricted access to public places, impacting the daily living of the population and primarily affecting chronic patients and other high-risk groups. Moreover, an economic crisis demanded social adaptation, such as transitioning from in-person to remote work or job loss, in addition to limitations on social interactions and in leisure activities.

The impacts of COVID-19 on the population's health and well-being are thus evident. Furthermore, the increase in the incidence of mental disorders and the excessive use of toxic substances, as well as domestic and child abuse, are noteworthy[10].

Besides the direct consequences of the disease, the impacts of social isolation are also noteworthy, which was prolonged in several places and included economic and psychosocial implications, in addition to a possibly higher prevalence than the pandemic itself[11]. In this sense, the effects of COVID-19-related restrictions such as loneliness, increased vulnerability, and premature aging promoted harm to health and favored the development of cardiovascular diseases[12]. In other words, the morbidity and mortality associated with mental health impairment surpassed that of the virus itself[13].

Therefore, the short period of time between the identification of the virus and its mass spread led to many doubts regarding the treatment of the first cases. Furthermore, very high mortality rates were recorded due to respiratory syndromes, which could have been reduced with preparation and training of the medical team and early monitoring of the clinical picture. For months, the lack of training caused healthcare providers to face a reality marked by uncertainties about the management of cases and the choice of patients who should be priorities.

Difficulties of implementing palliative care during the pandemic

In the pandemic context, healthcare professionals prioritized urgent life-threatening issues, given the need for immediate action and the lack of resources, at the expense of the aforementioned precepts of palliative care. The combination of knowledge and palliative care make evident several benefits to a patient's and to an individuals' clinical picture. Consequently, this approach includes symptom management, psychological support to patients, caregivers, and healthcare professionals, as well as assistance in screening and complex decision-making[14].

In this perspective, considering the challenge of ensuring a prompt, flexible, and humane response, the role of triage is emphasized as a determinant for the management of available resources. These resources, which were very scarce in the context of the pandemic, could be optimally allocated with the intervention of palliative care in triage.

However, despite the importance and benefits of palliative care, some of the highlighted obstacles to its implementation are the lack of institutional protocols, professional training, and respect to patient autonomy in decision making regarding their own conditions, difficulty in discussing death, risk of contamination, family resistance, and divergence among professionals in proposing palliative and non-curative treatment[4].

The analysis also found that, even before the pandemic, the structure was already precarious, especially in the healthcare sector. A study estimated the death of 153,000 people per year due to poor-quality healthcare and 51,000 due to lack of access to healthcare services[15]. The spread of COVID-19 thus worsened the situation, with confirmed cases and social isolation evidencing the frailty of the healthcare system and the challenges to implement public policies, which, in turn, hindered access to humanized care.

Difficulty faced by professionals

From a medico-legal perspective, the preservation of health must be prioritized to ensure the lives of the population. Thus, the regulatory standard of medicine in Brazil values the principles of non-maleficence, beneficence, and justice by stipulating health as the object of medicine and imposing on physicians the obligation to pursue it without discrimination[16].

Considering the importance of humanization in patient care, several moral and ethical conflicts of physicians in the pandemic grew more apparent. In the face of the urgency and emergency of cases, high technologies and technical knowledge were surpassed by a need for basic health care. Thus, amid the experienced humanitarian crisis, the scarcity of resources and professional fatigue characterize the collapse of the healthcare system.

Such a scenario led to conflicts such as having to choose which patients would receive the resources at hand, a decision that should not be the sole responsibility of one person[17]. As a result, the pandemic increased the decision-making responsibility of physicians, in addition to fostering a work environment marked by stressful situations that significantly changed the routine of multidisciplinary teams.

These difficulties demonstrate a lack of preparation by the multidisciplinary health team to provide palliative care, as qualified professionals are needed to ensure the care of terminally ill patients[18]. Furthermore, the trust between the healthcare provider and the patient creates bonds of support and prepares them to deal with such conditions, contributing to alignment within the team.

Healthcare providers are also exposed to highly stressful situations, such as the risk of contamination with diseases and the subsequent transmission to people in their social circle; a sense of helplessness combined with the limitation of State action and resource scarcity; and post-traumatic stress disorder resulting from fatigue and impending loneliness[19].

Therefore, to promote comprehensive and humanized care, a good physician-patient relationship is essential. This involves prioritizing the patient's quality of life and dignity, in addition to making joint decisions. In this way, actions determined within the scope of health and medicine are based on the bioethical principle of autonomy, which recognizes the patient's control over their own life[2].

Benefits to patients with comorbidities

Patients with chronic diseases and their close ones experience significant impacts on their daily routines, often requiring frequent visits to healthcare services, adopting new dietary habits, and adhering to physical activity practices. Considering these impairments, it is currently recommended to implement palliative care in the early stages of a progressive, advanced, and incurable disease. The objective is to provide relief to the patient and enhance their understanding of the condition, as well as that of their family[3].

Regarding this matter, it is known that hospitalizations of chronic patients typically involve prolonged periods of hospital stay, which can lead to suffering for the affected individuals and significant consumption of healthcare resources. In this sense, the proposal to reduce costs and improve the quality of care by implementing palliative care teams is noteworthy[20].

These teams are crucial when considering the aging process of the population, which is associated with diseases that present high morbidity and mortality rates. A similar situation occurs with individuals infected by COVID-19 and its sequelae, which can significantly impair their daily activities and autonomy[3].

Other benefits of implementing palliative care are noteworthy, such as reducing healthcare system expenses via lower hospital readmission rates, shorter average length of stay, fewer diagnostic and therapeutic procedures, and fewer admissions to intensive care units[21]. Thus, the economic and social benefits for both patients and the healthcare system resulting from the implementation of palliative care teams become evident since investments in the organization and implementation of such services would aid public administrators in decision making.

Final considerations

Terminally ill patients faced intense suffering during the COVID-19 pandemic, and the consequences of the massive spread of the virus are psychological, stemming from social isolation and the fear of contracting the disease, and physical. As a result, the advantages of implementing palliative care teams that provide humanized care from the early stages of chronic illness to death and grieving become indisputable. Thus, the suffering of patients and their families are alleviated, especially in a context of humanitarian crisis.

In this sense, the proposal of palliative care is emphasized as fundamentally ethical, seeking interdisciplinary understanding between bioethics and medical science, guided by the protection of the right to a dignified life. Finally, it is worth highlighting that the effort to humanize care has been an indispensable public health issue for those affected by terminal conditions. It represents dignity and the pursuit of individual well-being.

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Participation of the authors

Rafaela Rossi participated in the conception of the article, research in databases, selection, and analysis of articles. Manoela Duarte Selbach contributed to the development of the discussion and conducted content revision. Euler Renato Westphal guided the project, assisted in content review, and made content adjustments. All authors approved this final manuscript for publication.

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