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Finitude of life in a reference hospital for infectious diseases: a descriptive study

Abstract

Background: Patients living with serious infectious diseases, such as infection by human immunodeficiency virus (HIV) or tuberculosis (TB), are candidates for palliative care from diagnosis to the advanced stage of the disease. There is a scarcity of studies on palliative care for infectious diseases. The purpose of this study was to describe the clinical and care aspects related to palliative care in patients with severe serious illness that occurs in a referral hospital for infectious diseases.

Methods: We conducted a cross-sectional, retrospective study of patients who died of severe advanced disease during hospitalization in a Brazilian reference hospital for infectious diseases from January 2017 to March 2018. We defined serious illness as a health condition that presented a high risk of mortality, and negatively affected a person's daily function or quality of life, or overloaded their caregivers.

Results: There were 95 deaths during this period, of which 77 (81%) were included for analysis. Forty-nine (63.6%) were male. The mean age was 56.3 years (SD 17.34). The average time from hospitalization to death was 8.15 (SD 15.67) days. Of the 77 patients, 24 (31.1%) had active TB, 37 (48%) had HIV infection, and 21 (27.2%) had advanced neoplasia. At the time of death, 49 (62.8%) were admitted to the ward, 8 (10.2%) to the emergency unit, and 21 (26.9%) to the ICU. At the time of death, 51 (63.5%) used vasoactive drugs, 49 (62.8%) used mechanical ventilation, 17 (21.7%) underwent hemodialysis, 56 (71.7%) had a central venous catheter, 55 (70.5%) had an indwelling urinary catheter, 59 (75.6%) were on enteral diet by nasoenteral tube or gastrostomy, and 58 (75.3%) received antibiotic therapy. At the time of death, only 10 (12.9%) patients used opioids to control symptoms of late life, such as pain and dyspnea.

Conclusions: Assistance for suffering in patients with severe health conditions and finitude of life, even in a hospital unit specialized in infectious diseases, occurred to a limited extent. It is necessary to evaluate the benefits of a specialized service in palliative care in order to provide better assistance to patients with this profile.

Keywords: palliative care; infectious diseases; AIDS; tuberculosis

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Background

According to the World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients and family members who face problems associated with life-threatening diseases. Palliative care prevents and relieves suffering through early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual. It is a multiprofessional active care activity involving the control of physical, psychological, social, and spiritual symptoms.[1,2]

Palliative care is understood as a worldwide public health need, with a humanitarian character, which must be offered to all patients with serious and incurable diseases, and must be adapted in each country to its current health model.[3,4] Since its inception, practitioners of palliative care have understood that patients who live with serious infectious diseases, such as infection by the acquired immunodeficiency virus (HIV/AIDS) and tuberculosis (TB), are candidates to receive this specialized care.[2–4]

Serious infectious diseases, such as AIDS and TB, are still expanding in some regions of Brazil, and the number of serious cases and hospitalizations of patients for these diseases is significant. The approximate number of people living with HIV/AIDS (PLWHA) in Brazil is 1 million, with 16,700 new infections and 10,994 deaths related to HIV/AIDS recorded in 2022. A large proportion of these individuals are already with the disease at an advanced stage, and it presents with chronic non-communicable diseases at the end of life.[2,3] With the introduction of highly active antiretroviral therapy (ART), HIV infection has become a chronic disease, and PLWHA have come to live longer.[3–6] However, the increase in mortality rates in this population occurs as the time of infection increases. European cohort estimates suggest that, although HIV-related neoplasms have decreased by 28% since 2011, non-infection-related neoplasms have increased by 44%. Data from Australia, Europe, and the USA revealed that while AIDS-related deaths are declining, cancer is the leading cause of non-AIDS-related deaths in PLWHA. In individuals diagnosed with malignancy, survival is lower in PLWHA than in the general population. In addition, AIDS is still a disease on the rise in almost all countries and, even with the progress of ART, many patients do not have access to ART, do not adhere to treatment, or have an impact on viral resistance.[7–11]

Palliative care for TB patients is also a relatively new form of care. TB is a curable disease. However, AIDS-associated TB has a worse prognosis and, each year, an increasing number of patients acquire or develop drug-resistant TB. The five year survival rate for patients with TB resistant to multiple medications such as rifampicin, isoniazid, and fluoroquinolones is as low as 23%.[9,11–13] Aspects related to the finitude of life in patients with severe infectious diseases are not well

known; nor are palliative care strategies aimed at this population in the reference services. In Brazil, publications that measure palliative care indications in patients with severe infectious diseases are still scarce, even in units that work with patients in end-of-life care. To redress these concerns, the present study aimed to analyze patients with serious infectious diseases who experienced the end of life period in a referral hospital in Brazil.

Methods

This is a cross-sectional, retrospective, descriptive study performed at the São José Hospital for Infectious Diseases (HSJDI) in Fortaleza, Ceará, Brazil. All deaths of adult patients who died in the HSJDI from January 2017 to March 2018, and whose underlying cause of death was an advanced serious disease, were identified. Epidemiological and clinical data were extracted from the medical records. Severe advanced disease was defined as any health condition that presented a high risk of mortality, and negatively affected a person's daily function or quality of life, or overburdened their caregivers.[14,15] The following general variables were analyzed: age, sex, basic cause of death, length of stay, and the hospital unit where death occurred (ICU, emergency, ward). Among HIV/AIDS patients, it was identified how many used ART, and among those with active TB, how many received anti-TB drugs on the last day of life.

We identified patients who used invasive devices and advanced therapies at the time of death such as invasive mechanical ventilation, hemodialysis, central venous catheter, indwelling urinary catheter, vasoactive drugs, enteral diet by nasoenteral tube or gastrostomy, and antibiotic therapy. We also identified patients who in the active process of death received opioids to control end-of-life symptoms. To describe the characteristics of the patients, we calculated the absolute and relative frequencies of qualitative variables as well as the mean, standard deviation, minimum, and maximum of quantitative variables. The study was approved by the institutional Research Ethics Committee (Protocol CEP: 3.706.973).

Results

Table 1 reports the results of our study. There were 95 deaths in the study period. Of these, 77 (81%) were included in the study, of which 49 (63.6%) were male and 28 (36.3%) were female. The average age was 56.3 years. Among the 77 patients, 27 (35%) had HIV/AIDS, 21 (27.2%) advanced neoplastic diseases, 19 (24.6%) advanced TB, three (3.8%) had advanced chronic obstructive pulmonary disease, two (2.5%) had advanced dementia, two (2.5%) had severe heart failure, two (2.5%) underwent hemodialysis for chronic end-stage renal disease, and one (1.2%) had advanced chronic liver disease. The average time in days of hospitalization of patients until death was 8.15 days, ranging from 0 to 123 days. At the time of death, 49 (62.8%) patients were admitted to the clinical wards, eight (10.2%) to the emergency unit, and 21 (26.9%) to the ICU.

Table 1 Baseline terminal illness, mean age, and mean hospitalization days for hospitalized patients with severe illness

Severe advanced disease (underlying cause of death)	Total of patients	Average age	Average days of hospitalization
Dialysis chronic kidney disease	2	62	2.5
Cardiac insufficiency	2	66	4.5
Chronic obstructive pulmonary disease	3	67	8.6
Chronic liver disease	1	45	1
Dementia syndrome	2	63.5	16
Neoplastic diseases	21	54	6.8
Chronic tuberculosis	19	53	13
AIDS	27	40	12.8
Total	77	56.31 (17.34)	8.15 (15.67)

On the last day of life, 51 (63.5%) patients received vasoactive drugs, 49 (62.8%) were on mechanical ventilation, 17 (21.7%) underwent hemodialysis, 56 (71.7%) had a central venous catheter, 55 (70.5%) with indwelling bladder catheter, 59 (75.6%) received enteral diet by nasoenteral tube or gastrostomy, and 58 (75.3%) used antibiotic therapy.

Of the total number of patients, 24 (31.1%) had active TB, of which 22 (91.6%) received anti-TB treatment on the last day of life. Among the 37 patients (48%) with HIV/AIDS, 20 (54%) received ART. At the time of death, only 10 (12.9%) of the 77 patients with advanced severe diseases used opioids to control end-of-life symptoms such as pain and dyspnea.

Discussion

The global health community is responsible for bridging the gap in access to pain relief and other types of suffering caused by conditions of serious illness that threaten life span, both in finiteness and throughout life. However, unlike many other essential health interventions already identified as priorities, the need for palliative care has been largely ignored, even though it is understood as an essential element of universal health coverage by WHO.[15–18] In the report produced by the Lancet Commission on global access to palliative care and pain relief, evaluating the year 2015, it was identified that more than 25.5 million people who died that year experienced severe health-related suffering, which corresponds to 45% of the 56.2 million deaths registered worldwide in the same period.16 It is estimated that more than 61 million people are affected by severe health-related suffering and more than 80% of these patients live in developing countries, where palliative care and pain relief are scarce or non-existent.[16,19]

In our study, we identified that assistance to suffering for patients who experienced a condition of severe illness occurred to a limited extent, even in a hospital unit specialized in assisting infectious diseases. Corroborating with other authors, we understand that there are barriers that explain this neglect of health services. The main focus is the predominance of institutional policies, investments, and therapeutic strategies aimed exclusively at prolonging life. There is little direction for public policies aimed at health interventions that alleviate pain or increase dignity at the end of life.[16] Another barrier that is already well evidenced is "opiophobia", which refers to prejudice and misinformation about the appropriate medical use of opioids.[16,19] The present study identified that HIV/AIDS infection and cancer were the main conditions responsible for the largest number of people experiencing health-related suffering at a referral hospital

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for infectious diseases. Several other chronic and non-communicable diseases, including cerebrovascular disease, dementia syndromes, lung disease, liver disease, heart disease, and kidney disease have also been identified.

We know that, as populations age and undergo an epidemiological transition, severe healthrelated suffering for these complex diseases becomes more common in relation to acute and preventable diseases. However, infection and health conditions associated with poverty continue to affect people in low-income and developing countries such as Brazil, where more than half of the burden of severe health-related suffering, in terms of the number of patients, is associated with premature and preventable deaths.[16,20–22] In our study, we identified that, even in a unit specialized in serious infectious diseases, there is also a large proportion of patients with advanced non-communicable chronic diseases, further increasing the need for palliative care to alleviate suffering associated with health conditions.

Understanding the high cost of public health with advanced life support measures, and the problem of availability of beds in intensive care for this purpose, it is of utmost importance that managers understand the equitable role of a palliative care policy that, in addition to promoting quality of care for serious health-related suffering, ensures the best distribution of scarce resources in developing countries. With regard to therapeutic strategies for relieving suffering, we found in the literature the use of opioids as an important isolated marker for measuring access to palliative care.[16,23] This is because the use of opioids to control symptoms such as pain and dyspnea is essential in approaching patients living with serious illnesses, throughout their lives, especially in the final phase of life and in the active process of death where these symptoms become very frequent. In our study, we identified that the use of opioids for this purpose was very low coverage.

When we analyze patients with serious infectious diseases, HIV infection is the condition with the highest incidence of serious health-related suffering. Early integration of palliative care can improve the clinical results of these patients and the health costs, in addition to being highly relevant to the wide range of progressive and incurable comorbidities observed among them, such as organ failure and malignant diseases. AIDS has an exception condition among advanced chronic diseases because, when in the terminal phase, in up to 6% of cases, it is associated with another severe advanced neoplastic disease.[22–24] It is therefore expected that, in a condition of more than a potentially fatal disease simultaneously, the patient presents a greater intensity and complexity of symptoms and, therefore, needs a different level of palliative care.[25]

Given that HIV infection alone already has a high prevalence of symptoms similar to other conditions of severe illness, such as neoplasms, there is clarity in the literature on the part of specialists that specialized services in palliative care are important in institutions aimed at meeting this need. population to manage common symptoms and concerns in the complex care plan for these patients.[24,25] When we expand attention to the totality of people living with HIV/AIDS, we know that most of these patients require a less complex palliative approach, with the possibility that the specialized service plays a fundamental role in the permanent education of health professionals, with training in basic palliative care approach on a continuous basis, enabling the relief of suffering to be accessible in a safe and effective way for all individuals at any level of assistance.[16]

The present study has clear limitations because it is a retrospective descriptive study, where the collected data was known to be selected from the death certificates issued at the referred institution and identified as a basic cause of death an advanced serious disease in the official document. Thus, we can infer that our analysis underestimates the real extension in the number of patients who, at the time of death, presented serious health-related suffering, which should correspond to an even greater number of cases. The implementation of person-centered care, through the early identification of patient preferences, with symptom management and advanced care plans, should allow professionals to support their patients in various moments of difficult decisions and throughout the care of those who live with serious infectious diseases.[23–25]

Conclusion

The present study described the clinical and care characteristics of patients with severe infectious diseases who were hospitalized and died in a reference institution in the State of Ceará, Brazil. The assistance to the suffering of patients who experience a serious health condition, even in a hospital unit specialized in the care of infectious diseases, occurred to a limited extent. Other works must be developed to better understand the humanitarian and emergency aspects of the integration of palliative care for this population, guaranteeing the relief of suffering in order to solve this serious and sanitary iniquity, promoting good public health management.

Ethics approval and consent to participate

Ethics approval for the study was obtained from the São José Hospital for Infectious Diseases (HSJDI) Research Ethics Committee (Protocol CEP: 3.706.973).

Authors contributions

JMF contributed to the conception and design of the work, acquisition, analysis, and interpretation of data, and have drafted the work; JMAS, LMP, LGRC and JGVC contributed to the conception and design of the work, and acquisition of data; EGMS contributed to the conception and design of the work, analysis, and interpretation of data; RJPN contributed to the conception and design of the work, analysis, and interpretation of data, and have revised the work. All authors read and approved the submitted version of the manuscript.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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