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## Stage 3 HIV Patient with Severe Dysfunctional APGAR Score: A Palliative Approach

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### CASE REPORT

Mr. D, a 45 years old patient was visited at home for his HIV stage 3. The patient admitted that he had shortness of breath that was not affected by activity and there was no swelling in both legs. He also has a cough that produces sticky phlegm. He experiences diarrhea, even though it doesn't happen every day. He was diagnosed with HIV since 2012 and admitted that did not comply with taking ARTs. He underwent the test two years after his wife was diagnosed with HIV; during this time, he also had persistent shortness of breath and lost weight due to a co-infection with tuberculosis. He acknowledged not taking ARTs on a regular basis for about ten years after receiving his diagnosis because he believed he had accepted his predicament. Since four years ago, his wife has been gone, leaving him with their children.

He has two sons: the oldest, a 20-year-old who provides the family's foundation, and the younger, a 17-year-old who is still in school. The patient and their kids currently don't get along well because there isn't much communication between them and because the kids spend much of their time alone at home and don't say hello to each other. Because of the low economic status and the family's lack of concern for the patient's diet, the patient consumes the same foods every day, such as instant noodles or fried eggs.

The patient's shortness of breath prevents him from working and interferes with his daily routines. He stated that because he was alone at home and was experiencing discomfort with his shortness of breath, he could only rest and lie down there. The patient was urged to be referred to Sardjito Hospital by the doctor at the Community Health Center (Puskesmas), but he was rejected on the grounds that he could not have a companion with him.

his decision to work, the patient only completed grade 2 of vocational school. He moved to Yogyakarta in 1998 and began working as an inter-provincial driver.

During the first visit, a thorough physical examination was conducted. The results were: his body weight is 38 kg, height is 1.47 m, and the patient's body mass index (BMI) indicated he is underweight. The vitals such as temperature, pulse, and blood pressure were still within normal limits except for the respiratory rate of 28 breaths per minute which is considered to increase. The examination of his head, eyes, ears, and nose is normal. Nonetheless, oral hairy leukoplakia (OHL) was shown during the oral cavity examination. Examination of the lungs indicated suprasternal retraction and minimal wheezing sound on both sides. Regarding the cardiovascular system, the abdomen examination was within normal limits.

The patient lives in his own house in a fairly densely populated residential. The house is in 45 type with 2 bedrooms, a bathroom, living room, kitchen, a terrace and garage. The family kitchen is located next to the living room and in front of it, there is one bathroom between the bedrooms. The walls have been painted and the floor was tiled, the ceiling is fine, and the ventilation and lighting are both fairly nice. The source of clear water for the family members is from Municipal Waterworks or Perusahaan Daerah Air Minum (PDAM). The condition in the house seems not well organized and the members of his family give no attention to this situation because they are busy with their own business. Garbage disposals are well-organized, and drainage and water absorption are also excellent. Since the patient lives in a neighborhood, there is little direct interaction between neighbors, and they also do not know about his condition.

He was born and raised in Bandar Lampung. As a result of

When asked about the patient's ownership of social health

insurance, the patient said that he has Indonesia health insurance from the government, Badan Penyelenggara Jaminan Sosial Kartu Indonesia Sehat (BPJS KIS), which allows the patient to get some medicine drugs for free.

The patient is aware of his illness' state, how it may worsen, and the potential side effects of not taking his prescription as prescribed. He feels sad since he is unable to support his two children. The patient expects to stop experiencing breathlessness so that he can work as before.

## BIOLOGICAL DIAGNOSIS AND PSYCHOSOCIAL DIAGNOSIS

The biological diagnosis was HIV / B20 infection with observed shortness of breath. Dyspnea in PLWH (persons living with HIV) has a broad differential diagnosis. Infectious causes include pneumocystis pneumonia, bacterial pneumonia, tuberculosis, *Mycobacterium avium* complex, and viral etiologies like cytomegalovirus pneumonitis. Other causes of dyspnea in PLWH include malignancies like lung cancer and non-Hodgkin's lymphoma. In PLWH who present with dyspnea, pericardial effusion must be considered as an important differential diagnosis, especially when an infectious workup is negative. Pericardial effusion in an HIV patient warrants further workup for infective etiology and malignancies including lung cancer and lymphoma, often requiring further imaging studies and biopsy. A whole history taking needed to find out HIV infection in a patient with chronic infectious diseases, we need to explore the patient's complaints, the history of the patient's and his partner's illness, sexual behavior, and his job. In this patient, we found the existence of risk factors for HIV infection in his partner<sup>1</sup>.

Theoretically, there are four stages of HIV infection. In the first stage, it is Patients who are asymptomatic or have persistent generalized lymphadenopathy (lymphadenopathy of at least two sites [not including inguinal] for longer than 6 months) are categorized as being in stage 1, where they may remain for several years. In the second stage, patients may demonstrate several clinical manifestations. Clinical findings included in stage 2 (mildly symptomatic stage) are unexplained weight loss of less than 10 percent of total body weight and recurrent respiratory infections (such as sinusitis, bronchitis, otitis media, and pharyngitis), as well as a range of dermatological conditions including herpes zoster flares, angular cheilitis, recurrent oral ulcerations, papular pruritic eruptions, seborrheic dermatitis, and fungal nail infections<sup>2</sup>.

In the third stadium, additional clinical manifestations may appear. Those encompassed by the WHO clinical stage 3 (the moderately symptomatic stage) category are weight loss of greater than 10 percent of total body weight, prolonged (more than 1 month) unexplained diarrhea, pulmonary tuberculosis, and severe systemic bacterial infections including pneumonia, pyelonephritis, empyema, pyomyositis, meningitis, bone and joint infections, and bacteremia. Mucocutaneous conditions, including recurrent oral candidiasis, oral hairy leukoplakia, and acute necrotizing ulcerative stomatitis, gingivitis, or periodontitis, may also occur at this stage.<sup>2</sup> In the fourth stage (the

severely symptomatic stage) designation includes all of the AIDS-defining illnesses. Clinical manifestations for stage 4 disease that allow presumptive diagnosis of AIDS to be made based on clinical findings alone are HIV wasting syndrome, Pneumocystis pneumonia (PCP), recurrent severe or radiological bacterial pneumonia, extrapulmonary tuberculosis, HIV encephalopathy, CNS toxoplasmosis, chronic (more than 1 month) or orolabial herpes simplex infection, esophageal candidiasis, and Kaposi's sarcoma. Additional conditions that should raise concern that a patient is in the clinical stage include extrapulmonary cryptococcosis, disseminated endemic mycoses like coccidiomycosis, penicilliosis, or histoplasmosis, disseminated non-tuberculous mycobacteria infection, tracheal, bronchial, or pulmonary candida infection, or visceral herpes. However, if these conditions exist without the AIDS-defining illnesses, confirmatory testing should be requested<sup>2</sup>.

The psychosocial diagnoses were depressive episodes. The patient's shortness of breath makes it impossible for him to work and obstructs his everyday activities. He claimed he could only rest and lie down there because he was by himself at home and was uncomfortably short of breath. He was completely aware of his condition and the consequences he would face if he stopped using ARTs, but he nevertheless made the decision to stop taking them because he had lost hope and thought he had accepted his situation. The patient was urged to be referred to Sardjito Hospital by the doctor at the Community Health Center (Puskesmas), but he was rejected on the grounds that he could not have a companion with him. Being unable to provide for his two children makes him depressed. The patient wished for normal breathing so that he could get back to work.

## FORMULATION OF THE PROBLEM

Health problems in chronic patients currently require important care to prevent complications and greater treatment costs. Monitoring and evaluation are required in the aforementioned case scenario for HIV patients receiving lifetime ARV therapy, particularly with regards to the degree of adherence to the therapy, to ensure that there are no more significant changes in the stage of HIV. Eleven years ago, a 45-year-old male patient was diagnosed with HIV stage 3. Every month, his son would accompany the patient to the puskesmas for treatment, but the patient never actually attended. A brief history of the patient's illness course is given after defining the meaning and purpose of the visit, with the aim of the home visit being to conduct an introduction and approach concerning the role of the family doctor. During home visits, the patient's condition frequently exhibits a lack of interest and a reluctance to greet visitors. There are still few patient resources available to educate them about the illness, and there are no programs in place to avoid HIV-related consequences. The only thing the patient is aware of is that the disease is incurable and that he will need to take medication for the rest of his life. The patient still smokes and does not follow the guidelines for a balanced diet, and neither their lifestyle nor diet follows the doctor's recommendations.

The clinical status of the patient is the starting point for

the clinical diagnosis of HIV. Clinical stage 3 was assigned to this patient, which is indicated by chronic diarrhea of unknown origin lasting longer than one month and a substantial fall in body weight for no discernible reason ( $>10\%$  of estimated body weight or body weight). Patients with pulmonary TB, oral candidiasis, or intermittent or ongoing fever of uncertain etiology for more than a month<sup>2,3</sup>.

It's critical for family doctors to pinpoint the underlying causes of patients' problems so that a more targeted approach may be implemented. After the home visit evaluation, it became clear that the patient's primary issue—which deteriorated his physical state and the rehabilitation process—was a lack of psychosocial family support. For the successful treatment of HIV patients, careful and thorough assessment and evaluation are crucial. In-depth assessments must be performed in a number of key areas, including past substance use, past familial and social support, employment status, and current health. Don't forget about additional psychological issues related to having hiv, such as humiliation, sexual abuse, and guilt. The patient's present quality of life cannot be explicitly shown in the aforementioned information. A doctor can predict how a patient's state will evolve in the future, which requires him to plan out suitable therapies that might be administered as soon as possible to avoid more issues related to the patient's psychological condition<sup>4</sup>.

One week after the home visit, the patient's child brought him to the Community Health Center (*puskesmas*) for diagnostic testing, supportive psychotherapy sessions, and treatment plans that could be carried out at the primary care facility. Supportive psychotherapy has been shown to be beneficial for patients with psychological issues related to chronic illness. Despite the fact that mood disorders are common, there is some evidence to suggest that there is generally an increase in the prevalence of depression among hiv patients. Depression is treatable, and effective therapy increases the patient's quality of life and adherence to ARV therapy, perhaps increasing survival. The effectiveness of this depression treatment also lowers the prevalence of other ailments like hepatitis C, etc. Comprehensive HIV care must include the identification and treatment of depression, especially if it can be done in primary care. Sensitivity, attention, and targeted biopsychosocial management are essential to the efficacy of psychotherapy for HIV patients and can have a variety of effects on all facets of patient functioning<sup>5</sup>.

## DISCUSSION

Human immunodeficiency virus (HIV) is an infection that attacks the body's immune system. Acquired immunodeficiency syndrome (AIDS) is the most advanced stage of the disease. HIV targets the body's white blood cells, weakening the immune system. This makes it easier to get sick with diseases like tuberculosis, infections, and some cancers<sup>6</sup>.

HIV remains a major global public health issue, having claimed 40.4 million [32.9–51.3 million] lives so far with ongoing transmission in all countries globally. HIV is

spread from the body fluids of an infected person, including blood, breast milk, semen and vaginal fluids. It is not spread by kisses, hugs, or sharing food. It can also spread from a mother to her baby<sup>6</sup>.

Current antiretroviral therapy (ART) does not cure HIV infection but allows a person's immune system to get stronger. This helps them to fight other infections. ART must be taken every day for the rest of a person's life<sup>7</sup>.

Medication adherence can lead to fatigue, medication side effects, emotional stress, and social stigma, all of which impact quality of life. Over time, individuals may also experience complications associated with aging and chronic inflammation, even when viral suppression is achieved. In this context, a palliative care approach becomes increasingly essential. Palliative care in HIV is not limited to end-of-life situations but focuses on improving overall well-being throughout the course of the illness. It aims to relieve symptoms, support mental health, strengthen social relationships, and enhance treatment adherence through holistic and patient-centered care. Integrating palliative care alongside ART helps patients cope with the long-term demands of therapy, manage pain or opportunistic infections, and maintain dignity and comfort in daily life.

## Domain 1. Structure and Process of Care

Caring for patients with advanced HIV disease requires an integrated, continuous, and patient and family centered system. According to the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care (4th Edition), the structure of palliative care services should include a multidimensional assessment encompassing physical, psychological, social, spiritual, ethical, and legal aspects. The ideal service is delivered by an interdisciplinary team consisting of physicians, nurses, pharmacists, nutritionists, social workers, and spiritual counselors who work collaboratively to develop a patient goal-based care plan<sup>8</sup>.

This approach ensures continuity of care from diagnosis through end-of-life, focusing on quality of life, symptom control, and emotional support for both patients and their families. In the context of HIV, the WHO Consolidated Guidelines 2021 emphasize that integrating palliative components into HIV services is an essential part of a holistic approach. These components include screening for opportunistic infections (such as tuberculosis and cryptococcal meningitis), providing antimicrobial prophylaxis, initiating antiretroviral therapy (ART) as early as possible, and supporting long-term treatment adherence<sup>9</sup>.

Furthermore, the WHO Advanced HIV Disease (AHD) Package 2025 highlights the importance of cross sector coordination and strengthening referral systems between hospitals, primary health centers, and community based services to ensure that patients do not lose continuity of care. This model underscores that patients with advanced HIV disease require not only medical treatment but also continuous palliative support to address their complex symptom burden and psychosocial challenges<sup>10</sup>.



## Domain 2. Physical Aspects of Care

In advanced or end-stage HIV infection, the physical burden of disease is profound, encompassing multiple distressing symptoms such as chronic pain, dyspnea, nausea, diarrhea, profound fatigue, anorexia, and recurrent opportunistic infections (OI). These symptoms arise not only from the progression of immunodeficiency but also as adverse effects of long-term antiretroviral therapy (ART) and coinfections. The World Health Organization (WHO) emphasizes that routine symptom assessment and effective pain management are essential components of comprehensive HIV care and must be integrated into all levels of service delivery, including community and home-based care<sup>9,10</sup>.

A multidimensional approach to symptom control is required, combining pharmacologic and non-pharmacologic interventions tailored to the patient's clinical condition and preferences. Furthermore, patients with advanced HIV frequently experience cachexia and severe fatigue due to metabolic alterations and chronic inflammation. Nutritional support, hydration management, and physical therapy are therefore vital components of the care plan. Integrating palliative principles within HIV treatment supports a balance between symptom relief and disease management, ensuring that the patient's comfort, dignity, and functional capacity are prioritized. Evidence suggests that systematic symptom assessment improves both treatment adherence and quality of life in patients with advanced HIV<sup>11</sup>.

## Domain 3. Psychological and Psychiatric Aspects of Care

Psychological and psychiatric symptoms represent a significant and often under-recognized component of suffering among individuals with advanced or end-stage HIV disease. Depression, anxiety, delirium, and existential distress are highly prevalent and closely associated with poorer quality of life, diminished treatment adherence, and increased morbidity and mortality. Studies have shown that depressive disorders affect up to half of people living with HIV (PLHIV) in advanced stages, particularly those facing social isolation, stigma, or chronic pain. Integrating mental health support into the Advanced HIV Disease (AHD) package and within early palliative care is therefore essential to achieve optimal outcomes. This approach involves systematic screening for depression and anxiety, psychoeducation, counseling, and where necessary, pharmacological management with antidepressants or anxiolytics compatible with ART. In the palliative setting, non-pharmacologic interventions such as cognitive-behavioral therapy, mindfulness-based support, and relaxation techniques can also reduce anxiety and improve coping capacity. Importantly, early introduction of palliative principles creates opportunities for open communication, shared decision-making, and emotional preparation for end-of-life transitions<sup>12</sup>.

The World Health Organization (WHO) underscores the importance of a person-centred approach that recognizes the psychological and emotional dimensions of living with HIV, especially in those presenting late or experiencing

advanced disease. Such care requires collaboration between clinicians, mental health professionals, social workers, and community support networks to ensure continuous psychosocial support<sup>10</sup>.

Holistic management also involves addressing stigma, guilt, and existential suffering through empathetic dialogue and spiritual counseling when appropriate. Ultimately, addressing psychological and psychiatric needs is not peripheral but central to the palliative care model for advanced HIV. Effective mental health integration fosters better adherence to ART, reduces perceived isolation, and strengthens patient resilience. By recognizing mental well-being as a core component of comprehensive HIV care, healthcare systems can enhance both the quality and dignity of life for patients in the final stages of the disease.

## Domain 4. Social Aspects of Care

The social dimension of palliative care plays a pivotal role in addressing the complex needs of patients with advanced or end-stage HIV disease. Beyond the biomedical manifestations, HIV profoundly affects individuals' social identity, family relationships, and community participation. Patients frequently experience social isolation, unemployment, loss of social roles, financial insecurity, and stigma, all of which exacerbate psychological distress and reduce engagement with healthcare services<sup>12</sup>.

The social burden is further intensified in resource-limited settings, where discrimination and limited access to social protection mechanisms hinder continuity of care. The World Health Organization (WHO) and the Advanced HIV Disease (AHD) framework emphasize that comprehensive HIV management must extend beyond medical treatment to include social support systems that empower patients and caregivers<sup>9,10</sup>.

This aspect involves strengthening social networks, facilitating access to social welfare and community-based resources, and fostering non-discriminatory environments within healthcare institutions. Effective social care requires the active participation of multidisciplinary teams including social workers, community health volunteers, and peer supporters who can provide education, advocacy, and psychosocial accompaniment throughout the trajectory of illness.

Evidence suggests that integrating community and home-based palliative care improves symptom control, treatment adherence, and psychosocial outcomes among patients with advanced HIV. Community models not only ensure continuity of care after hospital discharge but also reinforce dignity and autonomy by allowing patients to remain in familiar environments surrounded by their support networks. In addition, family centered interventions and caregiver training reduce caregiver burnout and enhance coping skills during the terminal stages of illness. From a public health perspective, addressing the social determinants of health such as poverty, stigma, and gender inequality is essential for sustainable HIV care. Social empowerment initiatives that combine education, employment assistance, and anti-stigma campaigns can mitigate discrimination and promote

reintegration into society. Therefore, the social domain in palliative care for advanced HIV underscores the ethical imperative to view patients not merely as clinical cases but as individuals embedded within families and communities whose social well-being is integral to holistic care<sup>13</sup>.

#### **Domain 5. Spiritual, Religious, and Existential Aspects of Care**

The spiritual, religious, and existential dimensions of care represent a fundamental component of palliative practice for individuals living with advanced or end-stage HIV disease. Beyond the physical and psychological manifestations of illness, patients frequently face profound questions of meaning, purpose, guilt, and hope. The experience of HIV often intertwined with stigma, moral judgment, and social exclusion can precipitate existential suffering that undermines self-worth and spiritual well-being<sup>14</sup>.

Recognizing and addressing these spiritual concerns is therefore essential to providing holistic, person-centred care. There is empirical evidence highlights the association between spirituality and improved psychological and physical outcomes among people living with HIV. Studies have shown that spiritual well-being correlates with lower depressive symptoms, higher resilience, and better adherence to antiretroviral therapy. Moreover, religious coping mechanisms such as prayer, meditation, or participation in faith communities provide comfort and social support, particularly in settings where HIV stigma persists<sup>15</sup>.

In the palliative context, spiritual care interventions may include compassionate presence, active listening, meaning-centered counseling, or collaboration with religious leaders. These practices enhance emotional acceptance and facilitate forgiveness, reconciliation, and a sense of transcendence. Spirituality is a universal aspect of human experience that connects individuals to themselves, others, and a broader sense of meaning. Integrating this dimension within the care of patients with advanced HIV allows clinicians to uphold not only medical responsibility but also human dignity and compassionate accompaniment at the end of life<sup>14</sup>.

#### **Domain 6. Cultural Aspects of Care**

Culture profoundly shapes how individuals experience illness, suffering, and death, making the cultural domain an indispensable component of palliative care for patients with advanced or end stage HIV disease. Cultural beliefs influence perceptions of HIV causation, attitudes toward disclosure, help-seeking behaviors, and decision-making regarding treatment and end of life care. In many contexts, HIV remains a stigmatized condition associated with moral or social judgment, leading to shame, secrecy, and delayed engagement in care<sup>12</sup>.

Understanding these cultural dynamics is therefore crucial for healthcare professionals to provide care that is both clinically effective and culturally sensitive. The European Association for Palliative Care (EAPC) further underscores the necessity of cultural competence as a professional standard, advocating for the adaptation of palliative care

models to local social structures and belief systems. For people living with HIV, especially in resource-limited or multicultural settings, culturally congruent care ensures that discussions about prognosis, antiretroviral continuation, or Advance Care Planning (ACP) are aligned with the patient's worldview and values. Moreover, culturally sensitive communication mitigates stigma and enhances the therapeutic alliance between patients and clinicians. Training healthcare workers in cultural humility and cross-cultural communication helps them navigate sensitive topics such as sexuality, religion, and death without reinforcing discrimination. Ultimately, the cultural domain in HIV palliative care calls for respect, inclusivity, and contextual awareness ensuring that every patient receives compassionate care that honors their identity, community, and dignity until the end of life<sup>16</sup>.

#### **Domain 7. End of Life (Hospice) Care**

The end of life phase in patients with advanced or end stage HIV disease is characterized by complex medical, emotional, and ethical challenges that demand a comprehensive and compassionate approach to care. As the disease progresses and opportunistic infections or malignancies become refractory to treatment, the goals of care shift from life prolongation to comfort, dignity, and quality of life. Effective hospice care in this context focuses on meticulous symptom control, open communication, and psychosocial support for both patients and families<sup>17</sup>.

Pain, dyspnea, cachexia, and cognitive decline are frequent in terminal HIV, necessitating individualized pharmacologic regimens and attentive nursing care. Equally important is the management of psychological distress, fear of death, and anticipatory grief. Patients benefit from honest yet empathetic discussions about prognosis, preferences for the place of death, and withdrawal of non beneficial interventions, enabling a more peaceful transition. Culturally sensitive communication and spiritual support also remain essential during this phase, allowing patients to reconcile personal beliefs and relationships before death. End of life care thus extends beyond clinical symptom management; it encompasses emotional closure, family reconciliation, and the preservation of dignity. For people living with HIV, hospice care affirms that even as life nears its end, compassionate care can transform suffering into peace and meaning. The World Health Organization (WHO) and the National Consensus Project (NCP) highlight that the final months or weeks of life require intensive coordination between healthcare providers to ensure continuity of care across settings<sup>8,10</sup>.

#### **Domain 8. Ethical and Legal Aspects of Care (Advance Care Planning)**

The ethical and legal aspects of palliative care in patients with advanced or end stage HIV disease center on preserving patient autonomy, promoting informed decision-making, and ensuring that medical interventions align with individual values and goals. As HIV progresses to its terminal stages, patients often face complex choices regarding continuation of antiretroviral therapy (ART), hospitalization, life-sustaining measures, and symptom management. These decisions require transparent

communication between patients, families, and healthcare providers, guided by ethical principles of respect for autonomy, beneficence, non-maleficence, and justice<sup>8,18</sup>.

Advance Care Planning (ACP) serves as a cornerstone of ethical practice in end of life HIV care. It involves a structured process of discussing and documenting patient's preferences for future treatment, preferred place of care, and designation of surrogate decision-makers should the patient lose decision-making capacity. Evidence from systematic reviews demonstrates that ACP not only improves patient satisfaction and quality of communication but also reduces the use of unwanted invasive treatments and hospitalizations near the end of life. Importantly, ACP promotes dignity and psychological comfort, allowing individuals to retain control over their care trajectory<sup>18</sup>.

However, research indicates that ACP remains underutilized among people living with HIV, often due to stigma, denial of prognosis, or inadequate clinician training in end of life communication. In resource-limited settings, legal and institutional barriers may further complicate documentation of patients' wishes. To address these gaps, healthcare institutions are encouraged to integrate ACP discussions early in the disease course ideally alongside ART initiation or during hospital admissions for opportunistic infections when patients are cognitively capable of participating<sup>19</sup>.

The World Health Organization and the National Consensus Project advocate for policies that institutionalize ethical decision-making frameworks and promote multidisciplinary collaboration in ACP implementation. Legal clarity regarding informed consent, confidentiality, and surrogate decision-making is also vital to safeguard patient rights. Ultimately, ethical and legal domains in HIV palliative care affirm that respect for human dignity extends beyond medical interventions, it encompasses empowering patients to shape their final journey according to their values, beliefs, and sense of self<sup>10</sup>.

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