

HIV: the medical game changer

HIV/AIDS has taught doctors that medicine is not just about curing people; there has been a shift to also alleviating pain and suffering. Emmanuel Luyirika discusses the essential change

Introduction

HIV/AIDS has changed palliative care and it is necessary to understand how it has changed medicine. HIV/AIDS has made medicine understand that if it is only focused on cure and ignores suffering it is not doing its job. This has made the call to clarify what palliative care is all about imperative and the role of palliative care in fighting the global HIV/AIDS epidemic inevitable.¹ The amount of suffering is simply too great and the promise of cure too distant for too many to ignore. The clinical progression from first HIV infection to AIDS death in any one person is difficult to predict with certainty. What can be assured, however, is that suffering in material status, body, mind, and spirit will be inevitable. Multiply the suffering of one person dying from AIDS by 2.4 million people dying from the disease across Africa and you can calculate an enormous burden of suffering on the continent. Understand that suffering is the companion of not just the 2.4 million dying but of all those 22.5 million in Africa living with HIV/AIDS and their families and loved ones. Understand as well that there are another 15 million living with HIV/AIDS in other parts of the world and that global HIV incidence is increasing, and the burden of global suffering becomes intolerable.²

In addition to the most obvious need – for the relief of suffering – palliative care offers other essential capabilities in the fight against global HIV/AIDS. However, in Africa, many HIV-infected patients are diagnosed late, after the symptoms of the disease have already developed, and often these indicate that infection is present. In addition to the management of the HIV infection clinicians have to manage the presenting advanced opportunistic infections that may be viral, fungal, bacterial, and protozoal, as well as cancers and associated pain and other symptoms. Secondly, with advances in HIV-specific therapy and care, HIV infection is no longer a rapidly fatal illness. Instead, those patients who are able to tolerate antiretroviral therapy (ART) often experience a manageable, chronic illness. It is, however, important to note that even HIV patients who start on antiretrovirals (ARVs) but fail on available regimens, or who cannot access required second- or third-line medications, present an added burden for palliative care. Some of the patients who respond well to the ARV drugs may also have palliative care needs associated with lingering pre-treatment symptoms or those arising from the toxic effects of the drugs. An example of when this could occur

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is where programmes still use the drug stavudine, which can potentially lead to severe peripheral neuropathy or other mitochondrial toxicities, resulting in conditions such as pancreatitis.³ These combined effects result in increased palliative care needs.³

The burden of palliative care is normally a consequence of several symptoms, such as pain, vomiting, or diarrhoea. Some painful situations are easily managed by treating the underlying cause, but others, such as neuropathy, may linger and even require strong analgesics such as morphine. Some of the infections such as cryptococcal meningitis, TB meningitis, severe genital herpes, and others, which arise as a result of the compromised immunity, result in severe pain requiring well-planned palliative care and access to morphine. Essential medications for pain and other symptoms such as oral morphine, anticonvulsants, and antidepressants and other adjuvants, should be included in HIV programmes to adequately control the multiple symptoms.⁴

HIV patients may also experience the organic mental and neurological symptoms for which chronic care is



Immunocompromised people need a variety of medicaments

The patient with advanced HIV disease complains of one or more of the following: agitation, anorexia, chronic pain, constipation, cough, decubitus ulcers or pressure sores, delirium, dementia, depression, diarrhoea, dry skin, dyspnoea, fatigue, fever, increased secretions ('death rattle'), nausea, pruritus, sweats, vomiting, weakness, weight loss.

required.⁵ HIV programmes ought to anticipate, plan for, and meet these palliative care needs for all HIV-infected patients. For many of these patients provision of ARV drugs is not enough and their management will not be successful unless the lingering pain and symptoms are addressed. Failure to provide palliative care to such patients can also result in non-adherence to ARV drugs.⁶ The plan, therefore, should be to ensure that all programmes that provide HIV services provide palliative care services as well. The same system used to ensure a secure supply chain for ARVs should be used to deliver the palliative care and symptom-control drugs. As more patients survive as a result of improved access to ARV drugs and more HIV-positive individuals are recruited on to ARV programmes, the potential need for palliative care is increased and postponed and should therefore be managed.⁷

In addition to opportunistic infections, cancers – such as Kaposi's sarcoma, cervical cancer, and lymphomas – are well documented among HIV patients. Such cancers increase the burden of palliative care, both as a result of the complications caused by these cancers in various organs and the interaction of the anticancer drugs or any other medications the patient may be taking. Some of the toxicities of the ARV and anticancer drugs, such as neuropathies, pancreatitis and haematological drugs, are made worse, therefore increasing the need for palliative care.⁸ HIV therefore increases the need for palliative care services and the same system used for HIV services should be used to plan for, identify, and deliver palliative care. The shortage of human resources for health generally, and for HIV and palliative care in particular, is a serious threat to provision of services to HIV-infected individuals. An effort should, therefore, be made to train all health workers to identify and provide palliative care to patients that need it. In addition, allocation of resources for human resource recruitment, development, and retention should also include palliative care human resources in order to ensure sufficient manpower to support its provision.

How to provide palliative care for HIV-infected patients

WHO recommends that in countries with low HIV seroprevalence, palliative care may be a routine part of hospital and clinic care; while in countries with a high burden of HIV infection, palliative care should be part of a comprehensive care and support package, which can be provided in hospitals and clinics or at home by carers and relatives. In many settings, HIV-infected people prefer to receive care at home. The provision of palliative care can be augmented significantly by the involvement of family and community carers. A combination of psychosocial support, traditional or local remedies, and medicines can be recruited to provide palliative care that surpasses that found in many overcrowded or poorly staffed hospitals.⁹

Conclusion

Despite the increased attention being given to developing palliative care within HIV, it is also important to note that there are other diseases where palliative care

is necessary. In the recent past HIV/AIDS has attracted a substantial amount of donor funding, especially from the President's Emergency Plan for AIDS Relief (PEPFAR) and The Global Fund to Fight AIDS, Tuberculosis and Malaria. One of the critical consequences of this current funding prioritisation in Africa is the neglect of palliative care for cancer on the continent, which remains in the 'shadow of HIV/AIDS',¹⁰ despite the burgeoning nature of the epidemic. It is, therefore, important that palliative care programmes similar to those advocated for HIV are developed to support palliative care provision for cancer and other non-communicable diseases.

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