Setting priorities for palliative care: each country sets its own agenda

It is interesting to observe how policies and priorities vary between countries. The pressure is on to scale up palliative support

Palliative care has seen a great deal of growth in recent years, as healthcare systems increasingly take a more holistic approach to patient support. However, there is still clearly a need to educate decision-makers, healthcare professionals, patients, and their families about the crucial role that palliative care plays.

Many confuse the term 'palliative care' with 'hospice care' and assume that these services have to do with end-of-life treatment. While palliative care can and does assist patients and their families up to and including death, it is also a useful approach for assisting people dealing with chronic or long-term illnesses, which living with HIV is increasingly becoming.

The broadest approach to palliative care is to consider it as that which improves the life experience in all aspects for those living with incurable conditions. Palliative care is meant to address not only physical treatment issues such as pain management, but also the psychosocial needs of the patient living with long-term illness. In the context of HIV and AIDS in particular, this means addressing stigma and discrimination in addition to addressing the complex needs of a patient dealing with depression, adherence to treatment, and other associated issues.

In many countries, the fight against AIDS has been structured around individual interventions: counselling and testing, antiretrovirals, treatment for opportunistic infections, income-generating activities for those rendered destitute by illness, and peer support groups to provide information and help manage psychological stumbling blocks. Palliative care seeks to reunite these disparate interventions under one management structure.

There are a number of challenges inherent in instituting a palliative care approach. In addition to the need to educate and raise awareness, trying to reunite a panoply of various services under a lead healthcare professional or institution can be difficult, if not impossible, particularly in countries where the healthcare infrastructure is already weak. On the other hand, studies have consistently shown that the best health outcomes occur when people living with HIV are provided with a continuum of care from diagnosis, through the duration of their lifelong therapy, to the management of opportunistic infections and pain. Restrictions on the supply of opioid pain medications are also limiting their availability for people in need in many countries, and integrating this aspect into an overall care plan may contribute to improving policies in this regard.

There are a number of countries implementing palliative care services within programmes supported by the Global Fund, primarily with regards to HIV and AIDS. In Botswana, however, palliative care services centre mainly around providing home-based care for patients with tuberculosis. In South Africa, palliative care services were being provided from the inception of the HIV grant in 2004, primarily around the management of end-of-life issues. As treatment guidelines have evolved, and as medication has become more available and effective, the roll-out of the ARV treatment programme has led to a decrease in the number of terminally ill patients requiring this care. As a result,

Demakatso (left) witnessed a woman accusing her ex-boyfriend of giving her HIV, so she suspected she might be affected as well. Her status was confirmed after she went to a doctor with a terrible skin rash. She is now a peer counselor and loves her job. Nseki (right) found out she was HIV-positive when she was first diagnosed with TB in 1998. She lost two partners to AIDS and has three children who are healthy. The ARVs changed her life. She feels strong and can lead a normal life. She loves being a peer supporter and is thankful she can spread a message of hope and get people on ARVs.

This article has been written by the Communications Department at the Global Fund headquarters in Geneva, Switzerland

the palliative care services have started focusing more on ensuring support to patients who no longer require acute care but who cannot yet be supported through home-based care. These services includes a number of areas critical to ensuring treatment adherence, such as ensuring adequate food supply, safe water supplies, information, and community support.

On the other hand, some countries are seeing palliative care moving down in the priority list. Particularly in situations where financial resources are constrained, there is a lot of pressure (both within the country and from donors) to put funding to work on the 'highest impact' interventions. Palliative care, while a necessary component, is not as immediately or financially impactful, and has not been subjected to the same degree of cost-effectiveness research. Therefore many national programmes find themselves in a position where resources are being concentrated on individual interventions such prevention, diagnosis, and treatment initiation and adherence – rather than on developing one overall approach.

Zambia, for example, has recently reduced the proportion of its Global Fund grant financing allocated to palliative care because the country anticipates that by increasing funding for treatment and adherence support, the number of people who are chronically ill and who require home-based care will eventually decrease.

Nonetheless, the need for palliative care will continue to exist. Despite advances in education and treatment, there are still many people who seek out treatment too late in the progression of their disease, and who will need a coordinated system of care which includes not only medical interventions but also psychosocial support in dying.

While the Global Fund finances all programmes or interventions which can be proven to be scientifically sound and technically feasible, it does not prescribe which approach countries should take, relying instead on local expertise to design strategies and priorities appropriate to the local context, epidemic, and culture. This is the cornerstone of the Global Fund model, or what is known as country ownership.

As countries evolve from an emergency response to a more sustained and sustainable management of the fight against the three diseases, so too will their approach to providing health care to those affected by HIV, TB, and malaria.

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