

HATiP

HIV & AIDS Treatment in Practice

Issue 89 | 15 August 2007



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Towards a comprehensive package of preventive and palliative care

A mission to care

It sometimes gets overlooked in the race to enrol as many people in immediate need of ART onto treatment as soon as possible, but since its inception, one of PEPFAR's primary goals has been to support the provision of care for 10 million people infected or affected by HIV/AIDS (including families, orphans and vulnerable children).

PEPFAR's treatment, prevention and care goals are complementary. Most people who come in for voluntary counselling and testing, and who test positive with HIV are not in immediate need of ART. But having an established care programme of preventive and palliative care services could improve retention in care for people with HIV who are not yet in need of ART or other immediate treatment (for TB or other infections), and lead to more timely referrals (and improved outcomes) for when those individuals do become ill or qualify for ART.

Programmatic experience has shown time and again that without such services, after HIV testing and counselling, people often just disappear with their positive test result, only to reappear when they are gravely ill or on their deathbeds.

During this time away from care, many opportunities may be missed to prevent or treat coinfections and opportunistic infections; to improve quality of life and to reduce pain, psychological trauma and other suffering; to improve nutrition, to avoid the loss of work and to support children and the preserve the family; to prevent onward transmission of HIV to the person with HIV's sexual partners, or diagnose and offer care and treatment to those family members who are already infected (and prevent the breakdown of the family structure).

In addition, palliative and preventive care are also important in people on ART, because they remain at greater risk for illnesses such as tuberculosis (TB), still suffer pain (which may even be aggravated on some antiretroviral regimens) and other complications, and they may benefit from more support to adhere to treatment.

Definitions of palliative care

Although this article refers to both preventive and palliative care, we should be clear that we do not mean to imply that they are the same thing — however both should be part of the basic care package (BCP).

There is more than one definition of palliative care in circulation; the meanings differ somewhat in tone. Palliative care is commonly thought to pertain to pain and symptom relief at the end of life; but even though it should include this, palliative care should be an approach to a person with a life-limiting illness, that takes into consideration their family and culture — with the ultimate aim of improving their quality of life.

The WHO definition of palliative care

Palliative care is an approach that:

- Improves the quality of life of patients and families facing the problem of life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual...
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy or antiretroviral/OI therapy and includes those investigations needed to better understand and manage distressing clinical complications

(Sepulveda et al, JPSM Nov 2002).

PEPFAR takes a somewhat broader view: "Palliative care... aims to achieve optimal quality of life for PLWHA and their families and minimize suffering through mobilizing clinical, psychological, spiritual, and social care throughout the entire course of HIV infection. It also provides the routine monitoring ... and it continues during and after the initiation of treatment. Palliative care includes and goes beyond the medical management of infectious, neurological or oncological complications of HIV/AIDS to comprehensively address symptoms and suffering throughout the continuum of HIV disease."

"PEPFAR's working definition of palliative care is 'Everything that isn't ART,'" said Dr Mermin at last year's Implementer's meeting, "including pain management, spiritual and psychosocial care, end-of-life care, TB, HIV counselling and testing, management of sexually transmitted diseases, opportunistic illnesses, nutrition and HIV prevention counselling."

Although such a comprehensive approach is laudable, with too broad a definition, there is a danger that key aspects of palliation could be lost — particularly in the many settings where access to analgesics (opioids and other agents) are limited by supply problems, regulatory issues, too few prescribers, inadequate training, habit or other constraints. Programmes that only provide *supportive care*, glossing over pain assessment and management, or fail to tackle dealing with the more difficult issues such as suffering and death are not really providing palliative care (more on this below).

Preventive care

Preventive care interventions are activities, tools or treatments that can prevent the onset of severe or life-threatening conditions such as bacterial pneumonia, TB, malaria, diarrhoea and malnutrition that can complicate or threaten the lives of people with HIV, even at early stages of HIV disease.

In the industrialised world, long before the advent of ART, some of the first victories in the fight against HIV and AIDS involved preventive therapies such as cotrimoxazole prophylaxis to prevent PCP (*pneumocystis jirovecii* pneumonia) and other antimicrobial preventive therapies. Although the illnesses that most impact upon people with HIV in sub-Saharan Africa can be somewhat different, the principal, that prevention is better than a cure, is the same.

"But despite ART expansion [in the developing world], the majority of HIV-infected people do not receive care. Comprehensive

HIV prevention is rarely included in clinical programmes, and prevention-focused programmes that provide care vary in quality,” said Dr Mermin at last year’s Implementers’ Meeting. So for almost a decade, Dr Mermin (now based with the CDC in Kenya) and other colleagues in Uganda have been at the forefront of establishing an evidence base on which preventive interventions are useful for people with HIV living in sub-Saharan Africa.

The work grew out of an understanding of the severe constraints on the healthcare system serving the remote rural parts of Uganda (as well as many other regions in Africa). In such an environment, it becomes all the more important to prevent illnesses because diagnosis may be beyond the local health clinic’s capacity, treatment may be expensive (and come too late), and there may be inadequate staffing to care for large numbers of ill people with HIV.

Furthermore, the HIV-infected population often live far from clinics and have only limited means of transportation. Most are also extremely poor, and live in homes without access to basic sanitation, clean water or electricity.

However, the clinical and operational research conducted by Dr Mermin with a cohort, along with experience from TASO and other care providers in Uganda, has shown that simple and inexpensive interventions can have a significant impact on quality of life and survival and should be part of the routine care for people with HIV.

Additionally, even though healthcare staff may be limited in a region, many of these interventions can be packaged in a kit, and effectively delivered within HIV support groups, by traditional healers or as a part of a home-based care programme (HBCP) by trained lay people from local faith-based or community based organisations. This has the added benefit of providing ongoing support to people with HIV and their families.

Furthermore, the establishment and successful delivery of a comprehensive BCP by a HBCP, primary health clinic or some other community-based care programme could provide the foundation for subsequent delivery of ART “both on an individual basis — since persons receiving care gain experience with HIV disclosure to family members, daily medication and prevention, and on a health system level since it requires a drug and commodity distribution system that can be expanded for ARVs,” said Dr Mermin.

Components of the basic care package (BCP)

Dr Mermin suggested the following checklist for evidence-based and, in most cases, highly cost-effective interventions that could be considered as part of the BCP at last year’s HIV Implementers’ Meeting. Since then, the evidence base has increased for several of the interventions.

- Family VCT
- Prevention with positives and condoms
- Cotrimoxazole prophylaxis
- Insecticide-treated bed nets
- Safe water intervention (safe vessel, chlorine tablets)
- Isoniazid TB prophylaxis
- Multivitamins
- Pain management

Of course, ART (where it is available) and TB treatment should be provided to anyone in immediate need of treatment.

Other potential options with less supportive evidence (at present)

- Food supplementation

- Aciclovir prophylaxis
- Azole prophylaxis against fungal infections
- Circumcision
- STD diagnosis and treatment
- Family planning

PEPFAR has also released guidance suggesting that focus-countries should consider implementation of a standard “preventive care package” as part of their palliative care programmes, noting that “components of a care package are likely to vary within regions, and even within countries, depending on the setting and the capacity of the partners who are implementing such programmes (see

<http://www.pepfar.gov/documents/organization/77004.pdf> for adults, and

<http://www.pepfar.gov/documents/organization/77005.pdf> for children aged 0-14 years.

In the HBAC study, ART and TB treatment were added to the BCP, which included cotrimoxazole, ITNs, safe water, family VCT and prevention counselling with condoms.

Family-based VCT/Prevention with positives

The partners and family of individuals with HIV are at much higher risk than the general population either of being HIV-infected or becoming HIV-infected — but many traditional VCT programmes or clinics offering HIV testing have found it difficult to reach other family members, especially male partners. As a result, a substantial proportion of family have undiagnosed HIV.

However, in earlier HBAC studies in Uganda, over 95% of 6,000 household members accepted VCT when it was offered to them during home visits from volunteers from The AIDS Support Organisation (TASO). One study found that the HIV prevalence among 15 to 44 year-olds who shared a house with someone already diagnosed was three times the estimated national average — so the approach could be highly cost-effective (Were)

(see

<http://www.aidsmap.com/en/news/1AD39BE5-74F6-4038-9668-4332C712DF1F.asp>).

However, many couples are serodiscordant, and providing HIV prevention to both partners within their own homes could help protect those who remain HIV-negative. In another report from the HBAC programme, integrating prevention services into the BCP led to reductions in both sexual risk-taking behaviour and the estimated risk of HIV transmission among programme participants (see <http://www.aidsmap.com/en/news/6F55C5E7-4896-4C74-BBDC-DE412BE9064E.asp>) (Bunnell). *A future HATIP will discuss reports from the HIV Implementers’ meeting on integrating care and prevention.*

Cotrimoxazole prophylaxis

As already noted, cotrimoxazole prophylaxis was one of the first interventions found to reduce mortality in people with HIV in the U.S., Europe — primarily by preventing PCP and toxoplasmosis, infections which are not so commonly diagnosed in adults in sub-Saharan Africa. However, two studies from Cote d’Ivoire demonstrated that cotrimoxazole prophylaxis also decreased morbidity and mortality in HIV infected patients there too (Anglaret 1999; Wiktor 1999).

Some of cotrimoxazole’s benefit was attributed to the drug’s activity against community-acquired bacterial organisms that cause

diarrhoea, pneumonia and sinusitis and, possibly, malaria – however, there were concerns that cotrimoxazole might not be as effective in settings where these microorganisms have developed resistance to the drug.

These have largely been put to rest by a series of studies published over the last few years in adults, pregnant women and children in East and Southern African where there is a high rate of resistance to cotrimoxazole, with reductions in mortality ranging from 25-46%, and a 23-43% reduction in hospitalisation (Mermin 2004, Mermin 2005b, Mermin 2006, Nunn in press, Grimwade 2005, Walter 2006, Chintu).

One study reported slower annual rate of decline in CD4-cell counts and a slower annual rate of increase in viral load (Mermin 2004). Another noted that when family members with HIV took cotrimoxazole prophylaxis it was good for the whole family (it was associated with decreased morbidity and mortality among family members) (Mermin 2005b). Pregnant mothers with HIV have better birth outcomes. Others have clearly shown that it reduces the frequency of malaria in adults particularly when combined with insecticide-treated bed nets, despite high rates of resistance to Fansidar (the malaria medication to which it is most closely related (Mermin 2006).

Last year, WHO released guidelines recommending that cotrimoxazole prophylaxis should be widely used by people with progressing HIV disease and by all HIV-infected or exposed infants (until it is clear that they are uninfected). The reports offers clear technical guidance on the operational aspects of implementing cotrimoxazole prophylaxis especially in the context of scaling up HIV care in resource-limited settings (see

<http://www.aidsmap.com/en/news/F49B70EE-0089-4624-8C38-82AB06A800AF.asp>).

At the Implementer's meeting this year, even more supportive evidence was presented. Dr Adeodata Rukyalekere of Baylor College of Medicine Children's Foundation in Uganda presented data showing that the combined use of cotrimoxazole prophylaxis and ITNs was associated with a very low incidence and severity of malaria among HIV infected children (these data were previously reported at the Conference on Retroviruses and Opportunistic Infections (CROI), see

<http://www.aidsmap.com/en/news/512998AC-E72E-494D-B15D-97F84310494D.asp>).

Dr Eric Schouten presented a study from Malawi demonstrating that the coadministration of cotrimoxazole during the first six months on ART reduces mortality by 41% (these data were also presented at CROI, see

<http://www.aidsmap.com/en/news/1F9F2D35-099B-42A5-94EA-0FEC977756E6.asp>).

By this point, it would seem that there ought be universal consensus on cotrimoxazole prophylaxis.

However, some South African thought-leaders continue to express concerns that even though cotrimoxazole is part of the BCP there, the evidence-base is not as strong in South Africa where malaria does not occur, and where there is a high level of resistance among local pathogens. It is true that the two studies from South Africa are imperfect – one was an observational study (Badri) and the other was actually in people with TB (Grimwade).

Even so, the preponderance of evidence from, well, everywhere, consistently shows that cotrimoxazole prophylaxis reduces mortality and morbidity in adults, children and infants even in other settings where resistance is rife. One possible explanation is that the drug may still be able to prevent infections from becoming established,

even though it may not be an effective treatment. Regardless, at this point, the ethics of a randomised placebo-controlled study with cotrimoxazole in people with HIV would be highly questionable.

And it costs little. Using the data from Uganda, Pitter et al found that giving cotrimoxazole prophylaxis to all HIV-infected individuals produced 7.3 life-years and 7.55 disability adjusted life-years (DALYs) per 100 persons over 1 year compared with no prophylaxis. Using this algorithm, the intervention saved \$2.50 per person-year. Even if it only works against a smaller number of microbes in South Africa, it most likely still saves lives and the health service money.

Insecticide treated bednets (ITNs)

ITNs are an effective preventative measure against malaria that should be included in the BCP in endemic areas. In one study by Dr Mermin, the combination of cotrimoxazole, ART and ITNs reduced the incidence of malaria by 96%. Compared with a baseline malaria incidence of 50.8 episodes per 100 person-years, cotrimoxazole prophylaxis was associated with 9.0 episodes per 100 person-years (adjusted incidence rate ratio [IRR] 0.24, 95% CI 0.15–0.38); ART and cotrimoxazole with 3.5 episodes per 100 person-years (0.08, 0.04–0.17); and cotrimoxazole, ART, and bednets with 2.1 episodes per 100 person-years (0.05, 0.03–0.08) (Mermin 2006b).

While the magnitude of the effect is less in people taking cotrimoxazole and ART, ITNs are still highly cost effective, costing only \$13 per DALY saved.

Safe water systems (SWS)

Diarrhoea is one of the leading causes of death among people with HIV in Africa, particularly where access to clean drinking water is limited or where people store water in open buckets or containers that haven't been properly sterilised.

One of the first BCP studies in Uganda compared the effect of supplying HIV-infected persons (and their households) with a safe water system (SWS) comprised of hygiene education, a locally produced closed-mouth plastic vessel, a dilute chlorine solution, against hygiene education alone. Over the course of about two years follow-up, there were 25% fewer episodes of diarrhoea, 33% fewer days with diarrhoea, and less dysentery (less visible blood or mucus in stools) (Lule).

Another recent study from Kenya reported that supplying people of unknown HIV status with an SWS reduced mortality by 1.6 per 100 person-years (Crump). If the mortality benefit is the same in the HIV-infected population (without reliable access to clean drinking water), supplying people with a SWS would only cost about \$11 per DALY saved (Shrestha).

TB preventative therapy/isoniazid prophylaxis (IPT)

In sub-Saharan Africa, one-third to one-half of HIV-infected individuals are coinfecting with *M. tuberculosis* and people with HIV are at a much greater risk of developing active TB, even while they are on ART.

It is well established that isoniazid can prevent the development of active TB. Meta-analyses have shown that giving IPT to people with HIV and positive tuberculin skin test (TST) is associated with 60% decrease in TB and a 20% reduction in mortality in subjects with a positive (TST). From a public health perspective, for approximately every 30 HIV-infected individuals who are found to be positive for purified protein derivative and who are treated with INH, one death will be prevented (Churchyard). If the local prevalence of latent TB is high, IPT may even be warranted without performing TST

— and when incorporating the costs of TB treatment averted, IPT can be quite cost effective.

However, despite convincing data regarding the efficacy and cost-effectiveness of isoniazid (INH) to prevent TB (IPT), it has not been widely implemented.

One concern is adherence, which, was rather low at pilot sites of one initiative that linked an IPT containing package of care to HIV counselling and testing, ProTest, in South Africa, Zambia and Malawi — ranging from 24% to 59% (WHO 2004). Factors such as having little money for transportation or food, fear of or actual side effects of INH, nondisclosure of HIV infection status, and the perception that INH might not be effective were all associated with poor adherence.

Similar concerns, especially that people who do not feel ill will not adhere to prophylaxis, were once used to resist the roll-out of cotrimoxazole prophylaxis. Clearly the model of delivery and adherence support that accompanies IPT is important for operational effectiveness.

The other concern regards being certain that active disease has been excluded — so that people with TB are not being treated with sub-optimal TB therapy (and potentially developing TB that is resistant to INH). Although a simple questionnaire for the key symptoms can be used to screen for active pulmonary TB at any level of healthcare delivery, those who screen positive will need to enter into the diagnostic process at a health facility with the capacity to diagnose TB. Routine screening is important to do on a regular basis for both infection control and to identify those who may benefit from preventive therapy.

However, TB screening results from the large ongoing randomised study on IPT in Botswana presented at CROI by Dr Taraz Samandari, Associate Director of TB/HIV Research for the BOTUSA Project has increased concerns that it may be more difficult than previously thought to exclude active TB when people have asymptomatic (or atypical) TB.

Out of a total of 4328 adults screened, 2608 patients who were asymptomatic (and thus may have qualified for IPT) had a chest X-ray. 305 (12%) of these had an abnormal chest radiograph, and 31 (10%) of those were found to have active TB. That means that, overall, 1.2% of all the subjects who might screen as negative for TB could actually have active pulmonary disease.

Although the percentage seems small, the consequences of under-treating this small but possibly significant proportion of active TB cases are unclear at present. Another study has suggested that patients with subclinical TB who do have breakthrough TB on IPT do respond well to subsequent TB treatment (see

<http://www.aidsmap.com/en/news/05FBEC7A-F4C9-47FD-913F-1DDD0C87C7E0.asp>) (Mtei).

Requiring chest x-rays for each patient would obviously complicate the logistics and change the cost-benefit analyses of adding IPT into the package of care. As a result, many programmes are stalling on implementing IPT, waiting to observe results from pilot projects and a number of larger ongoing clinical trials.

Micronutrient supplementation

Several studies suggest that inexpensive micronutrient supplementation could slow the progress of disease or improve the quality of life. For instance, in one trial of HIV-infected men and women in Thailand supplementation with a tablet containing 21 micronutrients was associated with a 63% reduction in mortality in people with advanced HIV disease (Jiamton 2003) (see

<http://www.aidsmap.com/en/news/F432BEF8-92E9-4786-B212-35486CC7E8B5.asp>).

Meanwhile studies in Tanzania have shown that micronutrient supplementation reduces the risk of HIV disease progression and death in HIV-positive pregnant women, lowers the risk of MTCT, improves the birth weight among their infants and benefits CD4 cell counts and viral load — although vitamin A may reduce the benefit and increase the risk of MTCT (<http://www.aidsmap.com/en/news/75C280E7-7B23-4C4E-9602-25639B0BC066.asp> and <http://www.aidsmap.com/en/news/A2FEC5A3-06C7-4B50-A51D-51075AEE849E.asp>) (Fawzi 2004, Fawzi 2003, Villamor 2005). Meanwhile, it is well established that children benefit from vitamin A supplementation.

HIV care programmes should emphasise that people with HIV have an adequate intake of essential vitamins and minerals — especially in areas of the world where diets are often micronutrient deficient. A number of funding partners, such as PEPFAR, support multivitamins for adults and children who have inadequate dietary intake.

But there is some controversy about whether the BCP should include other forms of dietary support, such as food supplementation. Some funding partners feel that the delivery of food to every person with HIV is not sustainable, and that funds should instead go to shoring up the local capacity to produce food or the local economy so that people have options to buy locally produced food.

However, having a person with HIV in the family sometimes leads to severe food insecurity — especially if that person is a breadwinner. It is hard to imagine “palliative care” that would not at least perform nutritional assessments and, on a case by case basis, try to find ways to help those most in need at least until their recovery on ART is underway

“I think nutrition is a vital component of any palliative care package and should be written into policy as such,” said Sister Cunningham. “We have been running a ‘ready to use’ and therapeutic food programme for people on ARVs and are currently in the process of doing evaluation on that. Just to give you an example, a man called desperately from Lusaka and asked to commence on ready to use food last December. He weighed 37 kilograms and he took that for three months. After three months his weight increased to 57 kilos. He was not able to walk, he was not able to do anything when he went onto the nutrition, and now he has left the hospital after one year. He is up and walking, and has shown very dramatic progress.”

Pain management

Pain is common in people with HIV, particularly in sub-Saharan Africa. 80% of people with advanced HIV/AIDS experience severe pain; the likelihood of severe pain increases in advanced disease; and although other indicators of quality of life generally improve on ART, pain often doesn't — suggesting that pain management will continue to be important in Africa even when antiretrovirals become available (Harding).

According to the WHO about 80% of physical pain in HIV can be managed — with access to appropriate analgesia, as described in the WHO pain ladder

<http://www.who.int/cancer/palliative/painladder/en/>

The ladder is based on 3 steps:

1. A patient with mild pain should be started on a non-opioid such as aspirin or paracetamol.
2. Opioid for mild to moderate pain, something like codeine.

3. Opioid for moderate to severe pain, and the recommended opioid is oral morphine.

"In many places across the region you can only get step one or maybe step two analgesics. But if the client is in moderate or severe pain, you cannot access stronger analgesics." said Dr. Downing.

One poster presentation at the Implementer's Meeting, and a recent report stressed that much more advocacy and education around palliative care is still desperately needed in most countries (Powell). In many African countries, opioids are tightly regulated, and in most, only doctors can prescribe them.

For its part, PEPFAR has urged focus-countries "to develop appropriate policies related to... pain control." In countries where national legislation or government regulation or policy prohibits or severely restricts the use of opioids for palliative care, including end-of-life care, USG teams should advocate for changes in statute, regulations or policy to broaden access to pain medication in ways that will increase the ability of providers to alleviate suffering while continuing to maintain appropriate safeguards against abuse of medications."

Even where there is greater access to the medications, there is inadequate training about how to assess pain, or what to do about it if the patient is suffering (including where to obtain analgesics or refer the patient). Procurement and logistics challenges mean that analgesic drug supplies are generally limited – even for the non-opioid drugs. These issues are also tackled by a recent report: *Pain Relieving Drugs in 12 African PEPFAR Countries* (see <http://www.apca.co.ug/publications/painrelief.htm>).

In another poster by Kaur et al presented at the Implementer's Meeting, 41 of 45 patients referred to Hospice Africa, in Kampala, Uganda, during a three month period in 2006 reported pain, and in 31 it was of moderate-severe intensity. However, prior to referral, 49 were receiving no analgesia at all, including 11 out of 26 reporting severe pain. Two-thirds of these patients ended up on oral morphine. They were lucky to have received the referral – most patients don't, even in Uganda, where nurses can now prescribe opioids because, while organisations focusing upon palliation have been around for years, developing functional referral linkages with HIV programmes, appropriate training for each level of healthcare delivery and other aspects of integrating palliative care are only starting to be implemented.

"We did not have a specific intervention [in the HBAC study] focused on pain management," said Dr Mermin. "I wish we had, but we felt we didn't have the capacity to set that up at the time."

But this is changing through the efforts of such groups as the African Palliative Care Association, the Mpanshya Model described by Sister Cunningham, and the Integrated Community Palliative Care (ICPC) model, a collaboration between South Africa's Department of Health with Family Health International (FHI), which are working to enhance the capacity of other services to deliver more meaningful pain management and other aspects of palliative care. Service providers looking to incorporate better pain management and other support into their BCP would do well to seek the nearest palliative care organisations (some resources are listed below).

"We need to integrate palliative care into the existing health structures," said Dr Downing, noted an example of a programme she had spent time with in rural Namibia "They provided very good supportive care, they were very good at being there (and 'holding hands'), they were very good at providing psychosocial and spiritual care. They could provide basic hygiene (within the home), they could provide practical help (within the home), they could do some patient care such as bathing. But when it came down to pain management

and symptom management they felt helpless because they didn't know what to do. So it was easy not to ask."

So they were trained "to perform pain assessment and management, symptom assessment and management; and to provide: more meaningful emotional support," she said "Including some of the broader aspects of spiritual care; asking some difficult questions: 'how do you feel about the fact that you're dying, have you made preparations for your children, do you talk to your children about the future?' - some of the difficult questions that are hard to ask; providing bereavement care and support, but also providing good supervision of the care providers."

At the same time, Dr Downing also noted that another challenge is that there can be a number of ups and downs in people with HIV. "This disease has a complex disease process and there are complex treatments. One day someone can be feeling quite well, and then they can have opportunistic infections and then they can be very sick. And then again, hopefully they can have the fortune to become quite well again but it has a complex disease process, which offers challenges for us."

Ironically, some groups that have traditionally focused on pain management and bereavement are now adjusting to HIV sometimes being a chronic and manageable disease. In other words, palliative care is having to expand its repertoire by integrating other components, such as cotrimoxazole and ART, into its BCP, which can lead to profound improvements in quality of life. Sometimes, as demonstrated by the project in Zambia, Lazarus picks up his bed and walks.

Putting together the right BCP for patients

To implement a BCP, Dr Mermin recommended working with the Ministry of Health to develop policy around the various elements in the BCP and develop cooperative agreements with the partners who will be performing the implementation, to launch a national education campaign – so that people with HIV know that there are care interventions that they should be accessing and to develop a quality assessment and improvement system (or include elements of care into existing monitoring and evaluation).

Again, the specific components of the BCP will vary from country to country, and will be influenced by the available resources, the partners involved (and within which levels of the health system it is being implemented), and local policy.

How the package is being delivered is clearly important to its success, and an upcoming issue of HATIP will focus on models for improving delivery of family-based care and providing better active follow-up for patients through task shifting.

To provide truly holistic palliative care could require a team approach – but sometimes you have to work with what you have.

"I think one of the important lessons to be learned is that there is more than one approach," said Dr Malik Jaffer of USAID South Africa. "It should be holistic but ultimately you want to get improved quality of life: my recommendation being – even if it's not perfect, don't wait. Start with something and just get on with it and try to improve on it as you go along."

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