

# Who Cares?

Palliative Care: A Special Report

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ing and awareness raising, the Fund works to secure sustainable improvements in the lives of the most disadvantaged people in the UK and around the world. The Palliative Care Initiative's aim is for palliative care in sub-Saharan Africa to be integrated into the care and treatment of people with HIV/AIDS, cancer and other life-limiting illnesses

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**The African Palliative Care Association**

Central to the work of the African Palliative Care Association (APCA) are patients, their families, and carers. They, and the millions of people who need palliative care but who are not fortunate enough to receive it, are behind everything APCA does. It is the regional voice for palliative care,

speaking for the whole of Africa and has a strategic vision is to ensure access to palliative care for all in Africa. In the past, less than effective health delivery systems have posed a substantial challenge to APCA's attempt to realise this vision. According to the World Health Organization there are six fundamental building blocks of a generic health system. A critical component of WHO's service delivery building block is a package of integrated services. However, despite being defined as an essential component of a comprehensive package of care for people living with life-limiting illnesses, palliative care is a variable component of service delivery models in Africa. A health system that excludes palliative care services is deficient and not working optimally. Strengthening health systems to ensure the public health delivery of palliative care therefore underpins APCA's strategic direction.

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**Palliative care in Africa: an overview**

For the majority of Africans with progressive and life-limiting illnesses, access to culturally appropriate, holistic palliative care is inadequate Faith Mwangi-Powell and Olivia Dix explore the issues

**HIV– the medical game changer**

Medicine used to be about curing people. But HIV has changed that as the focus has had to shift to also alleviating suffering. Emmanuel Luyirika discusses the essential change

**NCDs: the future burden looms large**

With non-communicable disease incidence predicted to grow by 27% in the next 10 years, the impact on health resources is going to be significant. Liz Gwyther assesses the required response

**Pain and symptom management, preserving quality of life**

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**Palliative care for children: pain is inevitable, suffering is optional**

Why do we allow children to suffer from pain if it is possible to control it in almost all cases? Hanneke Brits and Joan Marston explore why this is so

**Hospital-based palliative care**

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## Palliative care in Africa: an overview

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Faith Mwangi-Powell and Olivia Dix explore the issues

### Why palliative care?

Palliative care, has been defined by the World Health Organization (WHO) as 'an approach that improves the quality of life of patients and their families facing the problems associated with 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, psychosocial and spiritual.'<sup>1</sup> It is applicable from the point of diagnosis, through the course of the disease and into bereavement.

In sub-Saharan Africa, the need for palliative care is significant. In 2009, an estimated 22.5 million people were living with the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) – 67% of the global disease burden – with 1.8 million new infections reported in that year alone.<sup>2</sup> There were over 700 000 new cancer cases and nearly 600 000 cancer-related deaths in Africa in 2007,<sup>3</sup> and cancer rates on the continent are expected to grow by 400% over the next 50 years.<sup>4</sup> In addition, as people's lifestyles on the continent change, Africa may experience an increase in the incidence of chronic non-communicable diseases (NCDs).<sup>5</sup> Most Africans, however, have no access to effective screening, early diagnosis, treatment or palliative care; those with cancer and other life-threatening illnesses experience a painful and distressing death. For people with AIDS, antiretrovirals (ARVs), where available, have had a profound impact on patient morbidity and mortality, but they have not negated the need for palliative care. Palliative care has a crucial role in providing effective monitoring of ARV therapy, managing any associated toxicity and side-effects, as well as addressing the new co-morbidities resulting from the prolongation of life.<sup>6</sup>

### Barriers to palliative care development

Following WHO's estimation of the need for palliative care as being 1% of a country's total population,<sup>5</sup> approximately 9.67 million people are in need of palliative care across Africa. Despite this, for the overwhelming majority of Africans with progressive and life-limiting illnesses access to culturally appropriate, holistic palliative care is at best limited, and at worst non-existent.<sup>7</sup>

Several factors exert an adverse influence on the provision of palliative care services for the majority of

people in Africa. Firstly, palliative care is a relatively new discipline in the continent and its development is hampered by the fact that it is not integrated into health systems. Out of 53 African countries, only 4 have palliative care integrated into either their health or their cancer strategic plans (Kenya, South Africa, Tanzania, and Uganda), while two (Rwanda and Swaziland) have developed stand-alone national palliative care policies. Most palliative care is provided by non-governmental, faith, or community-based organisations with no in-built sustainability. Additionally, only five countries have palliative care integrated in the curriculum of health professionals, of which four (Kenya, Malawi, South Africa, and Uganda) have recognised palliative care as an examinable subject, so there is a significant skills training deficit.<sup>8</sup> These challenges are exacerbated by poor health and social care infrastructures in many African countries and the lack of available health financing. In addition there is a widespread lack of understanding of what palliative care is and its benefits. It is often seen as only valuable at the end of life and yet the benefits of palliative care are vital from the point of diagnosis.

Access to medication is crucial to high-quality and effective pain and symptom management. However, in many African countries, access to even the simplest pain-relieving medication is limited, while strong painkillers, e.g. opioids, are legally restricted.<sup>8,9</sup> Systemic challenges in the supply chain – from ordering to administering opioids – are compounded by the lack of pharmacists in public health services and the restriction of prescription authority. So, for example, in 2008 the vast majority of morphine was consumed in industrialised countries, while in Africa the regional mean was only 0.33 mg per capita compared with the global mean of 5.98 mg.<sup>10</sup>

There is also a lack of methodologically robust evidence-based information on the effectiveness of palliative care; given the wealth of clinical and academic

#### Patient's quote

*'With the medication to help my pain, I can cycle again. I used to cycle 25 km to work every day. I would be in real trouble if the hospice doctor didn't come.'* Albert Tembo, 58, HIV patient, Zimbabwe.

#### Doctor's quote

*'As a doctor, sometimes you see a patient with severe pain and you don't know what to do. Palliative care has changed my life and my practice as a doctor. It has made me enjoy my profession once again.'* Medical Doctor, Mulago Hospital, Uganda.

Dr Faith Mwangi-Powell, Executive Director, African Palliative Care Association, Kampala, Uganda; and Olivia Dix, Head of the Palliative Care Initiative, The Diana, Princess of Wales Memorial Fund, England.



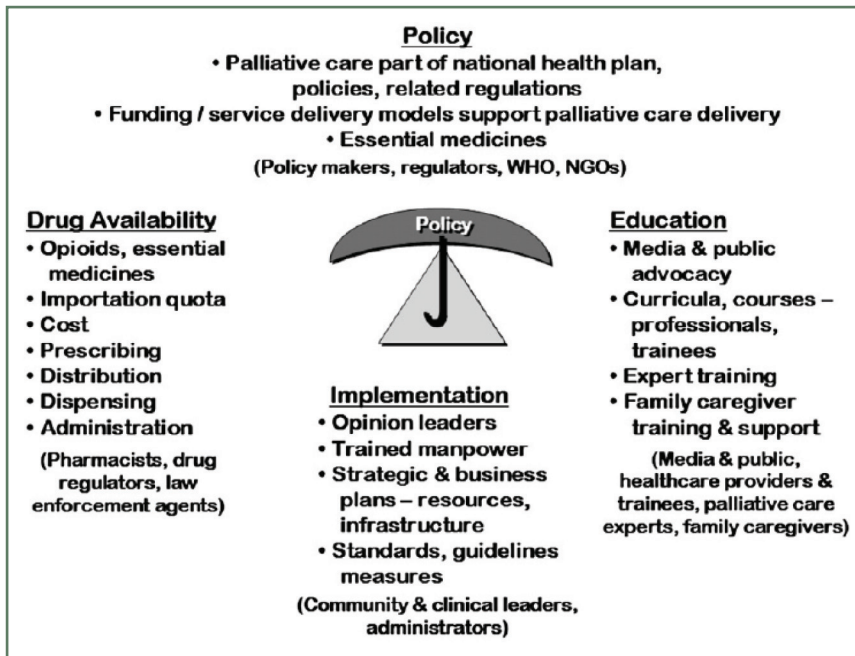


Figure 1 Enhanced WHO public health model.<sup>13</sup> Reprinted with permission from Elsevier

experience and yet the dearth of methodologically robust evidence,<sup>11</sup> research is required to inform the delivery of effective and appropriate care.<sup>12,13</sup>

Established in 2005, with a mission to ensure palliative care is widely understood, integrated into health systems at all levels, and underpinned by evidence in order to reduce pain and suffering across Africa, the African Palliative Care Association (APCA), encourages governments to use the four-pillar enhanced public health model of palliative care provision (see Figure 1)<sup>13</sup> to support a population-based approach to palliative care development that focuses on integration into national health systems to increase accessibility.

With regard to health systems strengthening, there is a global recognition that closing the inequitable gaps in global, regional, and national patient outcomes – such as those embodied in the health-related Millennium Development Goals (MDGs) – is dependent on the strategic strengthening of the delivery capacity of health systems. WHO has identified the goals for health systems as good health, responsiveness to the expectations of the population, and fair financial contribution.<sup>14</sup> The six fundamental building blocks of a generic health system include: service delivery; the health workforce; information; medical products, vaccines, and technologies; financing; and leadership and governance.

As well as responding to an urgent and unmet need, the holistic approach to the health needs of the patient, their family and community, and the structures created to deliver palliative care, mean that it has a significant contribution to make to health system strengthening.

For example, in terms of service delivery, palliative

Nobel Peace Prize winner Eli Wiesel noted, 'If I suffer and am silent, it can be a good silence. If I am silent when someone else is suffering, it is a destructive silence. We have had enough silence and destruction.'

care demonstrates important linkages between communities and health services and systems that can benefit health system resource allocation (e.g. care being provided at home rather than in expensive in-patient facilities). More importantly, these linkages ensure that patients receive care where they want it and provide effective referral systems in order that patients receive the right care and treatment from the right place. Palliative care provision also embodies the kind of trained multi-disciplinary team that will be crucial to strengthening the workforce in Africa. Indeed, palliative care in its insistence of an inter-disciplinary model of care provides an effective model for integrating the many aspects of care that are necessary to address HIV/AIDS: medicine, nursing, social care, family members,

religious and spiritual care, and more. Obviously, this model will be quite different from country to country but it is a concept where the focus of care is the patient within the context of their family and the wider community. This offers a point of departure from more traditional and linear means of organising healthcare.

In addition, palliative care is leading the task-shifting agenda on the continent. In Uganda, nurses and clinical officers have been trained through a 9-month specialist palliative care programme and legally allowed to prescribe opioids, thus ensuring that effective pain medication reaches patients wherever they are. This too requires an effective drug procurement, distribution, and quality assurance system that works in conjunction with other essential medicine systems. Palliative care services have demonstrated this is possible, providing valuable lessons for wider medicine distribution. Consequently, strengthening health systems by integrating palliative



Advocacy: the message needs to be broadcast as much in the community as in the hospital



care will have a dual effect; it will ensure that patients have a greater access to care and the systems will benefit from the multiple lessons that can be drawn from the palliative care approaches.

### Conclusion

The agenda to address the issues raised here need not be developed by an isolated and limited number of specialists. It requires collaboration and strategic partnerships with the health professionals, especially the clinical experts leading the way in developing and embracing palliative care skills, so that the scale-up of the provision of palliative care in the resource-poor setting can happen. It is worth noting, however, that the provision of palliative care – be it by a hospital in sub-Saharan Africa or a clinic in a high-resource setting – can reflect to the patient, and eventually to the community, that they are worth caring for. It is this reflection of self-worth and dignity that is essential for improving health in low-resource settings. It is only when an individual or a community believes that their life is worth saving that behaviour and social norms can change, for example in the direction of reducing HIV-transmission risk. Palliative care offers this even when curative care remains elusive.

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## 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.<sup>1</sup> 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.<sup>2</sup>

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

Dr Emmanuel Luyirika, Country Director, Mildmay, Uganda and Chairperson APCA Board of Directors.

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.<sup>3</sup> These combined effects result in increased palliative care needs.<sup>3</sup>

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.<sup>4</sup>

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.<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup>

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.<sup>8</sup> 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.<sup>9</sup>

### 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',<sup>10</sup> 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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## NCDs: the future burden looms large

With non-communicable disease incidence predicted to grow by 27% in Africa over the next 10 years, the impact on health resources is going to be significant. Liz Gwyther assesses the required response

### The burden of NCDs for Africa

By 2020, the World Health Organization (2005) estimates that non-communicable diseases (NCDs) will be as prevalent as communicable diseases, which have been the main cause of high morbidity and mortality in sub-Saharan Africa. This emerging NCDs epidemic in the region is mostly associated with lifestyle, structural, and environmental changes and this requires comprehensive strategies that: develop effective primary intervention measures; tackle risk factors and the wider social, economic and environmental conditions; adopt evidence-based approaches for interventions for vulnerable groups and populations; and support governments in the implementation of effective, efficient, and sustainable NCD policies and programmes.<sup>1</sup> The NCD Alliance, comprising the International Diabetes Federation, the World Heart Federation, the International Union against Cancer, and the International Union against Tuberculosis and Lung Disease, make the statement on their website that 'For too long, non-communicable diseases – cancer, cardiovascular disease, chronic respiratory diseases, and diabetes – have been silent killers'.<sup>2</sup> It is estimated that globally NCDs will increase by 17% in the next 10 years, in Africa by 27%.<sup>3</sup> NCDs are the leading cause of death worldwide. In 2008, 63% of all deaths were due to NCDs and 80% of NCD deaths occur in low- to middle-income countries.

Chronic NCDs are mostly due to preventable or modifiable risk factors, such as high cholesterol, high blood pressure, obesity, physical inactivity, unhealthy diet, tobacco use, and inappropriate use of alcohol.<sup>4</sup> The World Economic Forum identifies NCDs as the second greatest threat to the global economy. Chronic illness has a major economic impact on individuals, health

### Cancer in Africa

- More than 70% of all cancer deaths occur in low- to middle-income countries.
- It is estimated that there will be 1 million cancer cases in Africa annually by 2020.
- The majority of patients with cancer present late in Africa. The 5-year survival rate in Africa is 10%, compared with 70% in developed countries.

### Cardiovascular diseases and hypertension in Africa

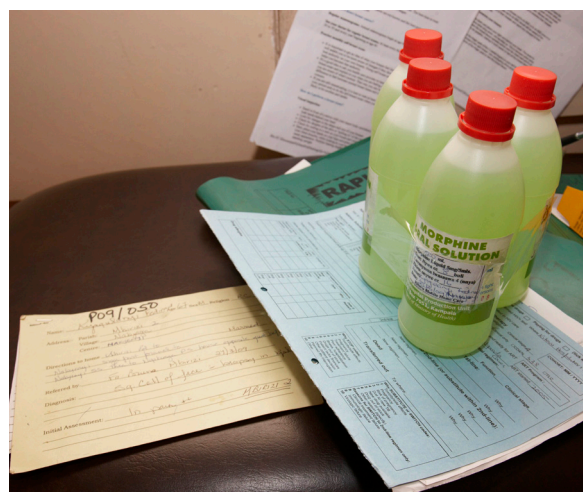
- WHO projects that the number of deaths from ischaemic heart disease in Africa will double by 2030.

systems, and communities. This is a threat to efforts to reduce poverty.

### Role of palliative care in NCDs

Although palliative care developed as a response to cancer patients suffering severe pain at the end of life, WHO defines palliative care as 'an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness.' The principles and skills of palliative care are applicable to any life-threatening or life-limiting illness and they include:

- *Communication skills* – it is important that all health-care workers are trained to discuss end-of-life issues in a sensitive way<sup>5</sup> and not to avoid these conversations because of uncertainty in prognosis.
- *Dealing with uncertainty* – the trajectory of illness in advanced cancer is usually that of a steadily progressive illness with a relatively short time to death. In cardiac and respiratory disease, there are intermittent episodes of serious illness from which the patient may recover to relatively good performance status. However, a patient may die during an episode of serious illness and patients, family members, and clinicians need to be prepared for this.
- *Management of distressing symptoms* – it is essential that all clinicians are trained in assessment and management of pain and that all governments ensure that opioid medication is available to manage severe pain. Clinicians also require training in the management of other symptoms experienced in advanced illness – shortness of breath, nausea and vomiting,



Over half of African countries (29) reported no use of morphine in 2003

Dr Elizabeth Gwyther, Chief Executive Officer, Hospice and Palliative Care Association of South Africa.



### Success stories

The African Palliative Care Association<sup>6</sup> has been active in promoting the development of palliative care with a number of key advocacy initiatives such as those promoting access to opioids. Individual hospices in Africa, in particular, Island Hospice and Bereavement Service<sup>7</sup> and Hospice Africa Uganda<sup>8</sup> have been active in training and promoting palliative care development locally and internationally. The Hospice Association of South Africa<sup>9</sup> has a strong development focus and has assisted in the establishment of palliative care services throughout South Africa, as well as providing support and assistance to the African Palliative care Association in their development activities in other countries in Africa.

confusion, constipation to name a few. Many clinicians are not aware of the benefit that low-dose morphine brings to reduce the sensation of dyspnoea.

- *Psychosocial and spiritual support* – palliative care personnel will provide counselling to address anxieties associated with chronic illness, death, and dying. Financial concerns are often an issue for people suffering with chronic NCDs and palliative care personnel attempt to identify interventions that provide some financial relief, although few countries in Africa currently provide disability grants or other social relief. Planning future care for children who may become orphaned is also addressed. Bereavement care is an important support for families of people who die and can impact on future mental wellbeing.
- *Prevention messages* – while involved in the care of people with NCDs, palliative care personnel talk to the family and community members about healthy lifestyle, prevention of illness, and early detection of possible illness, encouraging people to seek medical care if symptoms of disease are present.

### Current responses and gaps

In their review of palliative care development in 47 countries in Africa, Clark and colleagues<sup>10</sup> found that these countries could be grouped into four categories:

- 21 countries with no identified hospice or palliative care activity.
- 11 countries where capacity building activity is underway to promote hospice and palliative care delivery.
- 11 countries where there is some localised provision of hospices and palliative care is in place.
- Only 4 countries where hospice and palliative care services are approaching some measure of integration.

Palliative care is provided mainly by the non-governmental sector although there are a few striking examples of hospital-based palliative care.

The authors also noted that among the countries that had no known palliative care development, 29 did not report any morphine consumption to the International Narcotics Control Board for 2003. More recent assessment of morphine consumption across the continent still shows low figures indicating that appropriate pain



*A caring hand (top) is key in caring for patients, most especially with young children (bottom)*

medication is still not adequate across the continent. This is a worrying trend given that pain is a key symptom for patients with NCDs. The review also noted that palliative care is provided mainly by the non-governmental sector although there are a few striking examples of hospital-based palliative care. This means that despite the importance of palliative care in managing NCDs, its limited development across Africa means that many patients with NCDs will not reap the benefits of such care.

### Recommendations

WHO recommends a public health strategy<sup>11</sup> to promote access to palliative care that comprises:

- appropriate palliative care policies;
- adequate drug availability;
- education of healthcare workers and the public in palliative care;
- implementation of palliative care services at all levels.

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# Pain and symptom management: preserving quality of life

Henry Ddungu explains the broad range of resources that need to be developed if real patient needs are to be met

## Symptom and pain burden

Life-threatening illnesses such as cancer and HIV infection, and neuromuscular disorders such as multiple sclerosis and end-stage heart disease, among others, are often associated with a multitude of symptoms that make a patient's quality of life unbearable.

Cancer patients might also suffer from a plethora of symptoms at all stages of their disease.<sup>1</sup> The prevalence of individual symptoms varies along the disease trajectory, but cancer is almost always associated with pain.<sup>2</sup> Distressing symptoms are a result of many factors, including the various treatment options: surgery, chemotherapy, and radiotherapy, among others. The symptoms caused by treatment may delay treatment or lead to premature treatment termination; when treatment is no longer possible symptom control becomes the focus of cancer care.

Pain may be the dominating symptom at the time of diagnosis of cancer, a sign of disease relapse, a symptom of late toxicity, and indeed, a key symptom in patients with advanced incurable disease. Cancer patients are often suffering from more than one symptom at a time, with fatigue, severe pain, lack of energy, weakness, and loss of appetite being the five most prevalent symptoms reported.<sup>3</sup> The prevalence of cancer pain ranges from 30–50% in patients under chronic treatment and it increases to more than 70% in patients with advanced cancer.<sup>4</sup> In a review of the existing epidemiological evidence on the occurrence and epidemiological characteristics of cancer-related pain, Goudas and colleagues concluded that cancer pain is a substantial burden for the cancer patient but it is frequently underestimated and under-treated.<sup>3</sup>

The HIV epidemic has affected sub-Saharan Africa more than the rest of the world, with over 67% of the global prevalence for HIV infection and 75% of AIDS global deaths.<sup>6</sup> There is a high prevalence of symptoms in HIV infection, irrespective of the disease stage.

HIV care, therefore, needs to go beyond an antiretroviral-focused approach to a focus on the heterogeneous and complex elements of long-term infection, chronic disease management that recognises primary care.<sup>7</sup> Primary care, defined as the provision of integrated, accessible health services by clinicians accountable for addressing a large majority of personal health needs, has been found to be associated with improved survival.<sup>8</sup>

Pain is also a common symptom in HIV infection

although it is usually under-rated and under-treated by clinicians. In a study in Nigeria to determine the frequency of pain and its various forms and correlates, in a cohort of HIV-positive patients attending an antiretroviral therapy clinic, pain was present in 27.8% of the respondents.<sup>9</sup>

In another study aimed at: i) measuring symptom burden prior to antiretroviral therapy initiation, in a population of adults with low CD4 counts presenting for HIV care and treatment in Uganda; and ii) exploring the relationship between World Health Organization (WHO) stage, CD4 count, and symptomatology, the study showed that the burden of HIV-related symptoms in such individuals is significant and debilitating.<sup>10</sup>

The burden of symptoms among HIV/AIDS patients, irrespective of CD4 counts, remains enormous even in high-income countries. In a report of an ongoing prospective longitudinal study describing symptoms experienced by 317 men and women living with HIV/AIDS in San Francisco, the median number of symptoms was 9 with symptoms experienced including lack of energy (65%), drowsiness (57%), difficulty sleeping (56%), and pain (55%). The report also noted that those with an AIDS diagnosis had significantly higher symptom burden scores, as did those currently receiving antiretroviral therapy.<sup>11</sup>

Depression is a common serious HIV co-morbidity in sub-Saharan Africa. A cross-sectional population-based study of adults in Botswana examined for depressive symptoms, found that 25.3% of women and 31.4% of men had depression.<sup>12</sup> Such findings highlight the need to integrate mental health counselling and treatment into primary healthcare to decrease morbidity and improve HIV management efforts.

The burden of symptoms is significant among paediatric patients with life-threatening illnesses – cancer, HIV infection, and sickle cell disease, among others. However, paediatric clinical trials have traditionally focused on survival and treatment toxicities with minimal interest in the measurement of outcomes that reflect the impact of treatment on patients and families. In a study to determine symptom prevalence, characteristics, and distress in children with cancer, using an adapted Memorial Symptom Assessment Scale (MSAS) that was administered to 160 children with cancer aged 10–18 years, researchers found a high prevalence of symptoms overall and the existence of subgroups with high distress associated with one or multiple symptoms.<sup>13</sup>

There is also limited knowledge about parents' perceptions about the symptom prevalence and symptom burden for their children. In a study to describe

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which symptoms that, according to parents, cause most problems for children receiving cancer treatment; and to explore whether there is a relationship between parents' ratings of their children's symptoms and their own post-traumatic stress at 1 week (T1), 2 months (T2), and 4 months (T3) after a child's cancer diagnosis, the following symptom areas were identified to cause the most problems for children undergoing cancer treatment: emotional distress, fatigue, nutrition, and pain (most problematic). The opinions of both the patient and the parent are important in paediatrics.<sup>14</sup>

Children with cancer experience repeated invasive and almost always painful medical procedures such as bone marrow biopsies, lumbar punctures, dressing of wounds, etc. The American Academy of Pediatrics recommendations on the management of pain and anxiety associated with procedures for children with cancer are as follows:

- maximise comfort and minimise pain using both non-pharmacologic and pharmacologic interventions;
- prepare the child and family, consider the developmental age of the child;
- support family and child involvement;
- assure provider competency in performing procedures and sedation;
- use appropriate monitoring to assure safety.<sup>15</sup>

However, management of painful procedures in children with cancer must be tailored to the individual patient by effective communication between the child, parents, and medical staff of successful multimodal interventions.<sup>16</sup>

### Conclusion

Relief from pain and troubling symptoms is vital for preserving the quality of life for patients with life-limiting illnesses across Africa. It is important, therefore, that clinicians and providers continue to advocate for effective strategies that address the multiple challenges to opioid availability in the continent. More specifically, strategies are needed to facilitate the introduction of supportive policy environments, e.g. a task-shifting policy to enable suitably trained nurses to prescribe stronger medicines (such as morphine), educational initiatives to address the misperceptions of the general public and healthcare workers regarding opioids, and measures to address supply-chain obstacles that impede drug availability.

### Case study

A 9-year-old HIV-negative girl was referred to the Cancer Institute with a histological diagnosis of Burkitt's lymphoma (BL). She presented with a 5-week history of a right mandibular swelling and associated B symptoms. Her parents are peasant farmers with a very limited income and they could not afford treatment. The swelling was painful and she described it as 'too much' so that she could not sleep. She was unable to eat because of loose teeth and the growing size of the tumour. The swelling produced an offensive odour that was distressing to the patient and family. She had nausea and vomiting, and was extremely worried.

Physical examination revealed a firm tender swelling involving the right mandible with a foul-smelling discharge. The patient had loose teeth with some missing. She also had a hepatosplenomegaly and two small pelvic masses. Investigations revealed hilar adenopathy, bilateral ovarian masses, lymphadenopathy, and moderate ascites.

She was started on first-line chemotherapy (cyclophosphamide 30 mg/kg; Vincristine 2 mg/m<sup>2</sup> and methotrexate 15 mg/m<sup>2</sup>) but received only four courses out of six because the parents lacked the funds to take her back for chemotherapy. This resulted in disease progression and a need for second-line therapy for which she received only two courses with no improvement. Her symptoms were getting worse even when she was started on third-line therapy, following support from a well-wisher.

Her pain was controlled using oral morphine and NSAIDs and distressing symptoms were controlled with support from the palliative care team. The disease progressed and eventually she passed on peacefully at home.

### A doctor's comment

Over 95% of the patients on my cancer ward experience pain. By the time they are admitted most of them have been on NSAIDs (non-steroidal anti-inflammatory drugs) but without optimal pain control, and in need of strong opioids such as morphine. The second most common symptom is nausea and vomiting usually as a complication of chemotherapy. Most patients have more than one symptom and this is made worse by the absolute lack of funds to help meet the costs for investigations and medicines that might not be in the hospital. Sometimes we get frustrated seeing a patient suffering because they have no means of either buying the missing medicines and/or investigations. Some also come back late with advanced disease because they did not have transport to come back to the hospital.

We are lucky that there is a hospital palliative care team that helps our patients get their pain and other distressing symptoms controlled. Oral morphine is now readily available on the ward for patients with moderate-to-severe pain. *S Kibudde MD*

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# Palliative care for children: pain is inevitable, suffering is optional

Why do we allow children to suffer from pain if it is possible to control it in almost all cases? Hanneke Brits and Joan Marston explore why this is so

## Status of children's palliative care

Palliative care for children has been slow to develop in Africa. Few countries have established programmes, and South Africa is presently the only country with a national network of services. A recent mapping of children's palliative care by the International Children's Palliative Care Network shows the present situation (see Figure 1 below).

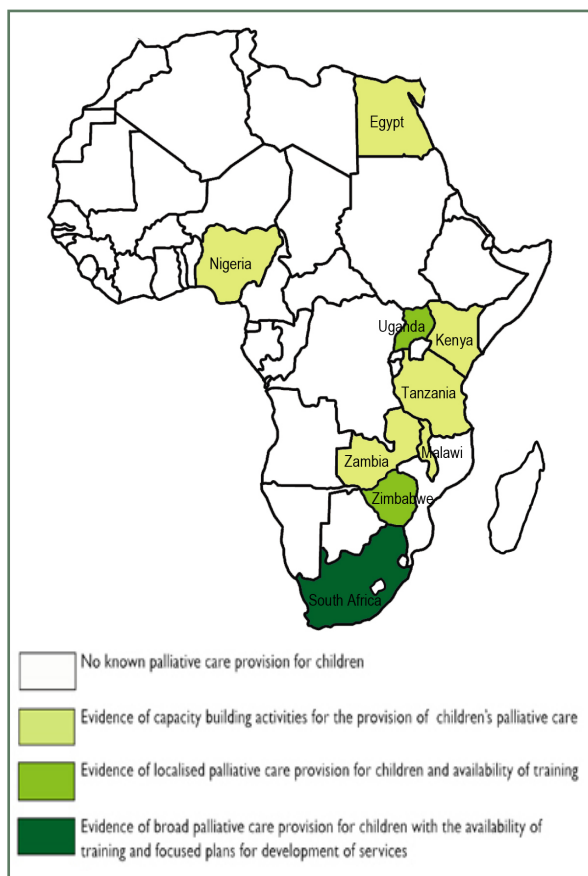


Figure 1 Status of children's palliative care in Africa

## Defining palliative care for children and young people

(see [www.who.int/cancer/palliative/definition/en](http://www.who.int/cancer/palliative/definition/en))

Palliative care for children is defined as:

- an active and total approach to care of the child's body, mind and spirit;
- beginning from the time of diagnosis of a life-threatening, life-limiting, or chronic condition;

Professor Hanneke Brits, Principal Specialist, University of the Free State; and Joan Marston, Chief Executive, International Children's Palliative Care Network.

- requiring a multi-disciplinary approach to meet the physical, emotional, social, spiritual, developmental, and cultural needs of the child and family;
- including the management of pain and distressing symptoms, and care through death and bereavement;
- focusing on the enhancement of quality of life and relief of suffering;
- including support for the family and continuing into the bereavement period;
- being provided in the child's home and in healthcare institutions.

## Children requiring palliative care

Children with life-limiting or life-threatening conditions including cancer, HIV, tuberculosis, severe malnutrition, malaria, severe disabilities, genetic and metabolic conditions, birth anoxia, organ failure, neuro-degenerative conditions, and many other conditions. The UK palliative care charity ACT (Association for Children's Palliative Care) has identified four categories of conditions in children requiring palliative care (see [www.act.org.uk](http://www.act.org.uk)).

In Africa we consider bereavement as a fifth category (see The Baobab Paediatric Palliative Care website [www.baobabppc.co.za](http://www.baobabppc.co.za)).

## Symptom burden of children

Children with HIV, cancer, severe malnutrition, and other conditions requiring palliative care very often experience mouth ulcers and fungal infections, which can be very painful and prevent them from eating properly. Poor feeding contributes to malnutrition and decreased immunity. Abdominal pain can be due to colitis, enlarged lymph nodes due to tuberculosis, or lymphoma, as well as diarrhoea as a side-effect of medication or from HIV disease. Procedural pain can be minimised with proper planning and timely topical or systemic analgesics. Peripheral neuropathy, as a side-effect of different drugs also contributes to the pain burden in children. Other distressing symptoms include shortness of breath, nausea and vomiting, and skin infections.

## Pain

Pain is inevitable, suffering is optional. Why do we allow children to suffer from pain if it is possible to control pain in almost all cases? Possible answers include:

- children are not assessed and diagnosed with pain as they seldom complain of pain;
- the correct pain medication and dosage is not prescribed;
- pain is not re-assessed and treatment adjusted as





Children should not suffer. Palliative care services can be integrated into existing services

- necessary;
- medications such as morphine may not be available;
- healthcare professionals do not have the knowledge and skills to treat paediatric pain.

### Pain assessment

Assessment should always include pain of the body, the mind, and the spirit. Pain can be considered as the fifth vital sign and should be assessed whenever vital

signs are taken. For children unable to communicate the FLACC pain assessment scale is most appropriate. The FLACC scale assesses: (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability. For more information visit <http://bcmartin.yolasite.com/resources/FLACCSCALE.pdf> (see Table 1). When assessing pain in verbal children older than 3 years, the Wong Baker FACES scale, which was validated in Africa, a simple numerical scale, or the Revised Faces Scale, may be used – see <http://www.geriu.org/uploads/painDVD/AdditionalMaterials/Wong-BakerPainScale.pdf>.

### Pain management

Before prescribing pain medication the following should be taken into consideration:

- What non-pharmacological treatment can be used?
- Does my medication match the type of pain?
- Is the dosage interval correct?
- What administration route is most appropriate?

The easiest and most effective non-pharmacological measure is distraction, where the attention of the child is guided away from the site of pain and focused on something that the child enjoys, e.g. looking at pictures in books, blowing bubbles, or singing.

Dosage interval should correspond with the half-life of the drug in order to keep the patient pain free, e.g. morphine solution should be prescribed every 4 hours.

Although most medication can be prescribed using different routes the oral route works rapidly and causes less discomfort for children and should be used whenever possible. Neonates may require reduced dosages.

### Re-assessment

Pain should be re-assessed and treatment adjusted if the child is still in pain before the next dosage of medication is given. Combine different drugs if necessary, e.g. paracetamol and ibuprofen; and use adjuvant drugs as required, e.g. morphine plus amitriptyline.

### Respiratory symptoms and shortness of breath

The worst death must be the inability to breathe freely.

Type of pain	Drug	Dosage
Mild pain	Paracetamol	10–15 mg/kg q4–6h po
Severe pain	Morphine	0.2 mg/kg q4h po
Muscle or inflammatory pain	Ibuprofen	10 mg/kg q8h po
Abdominal colic	Hyoscine bromide	5–10 mg q8h po
Raised intracranial pressure and swelling	Dexamethasone or prednisone	4 mg once daily po 1–2 mg/kg daily po
Peripheral neuropathy	Amitriptyline	0.2 mg/kg/day and titrate to 2 mg/kg if needed
Spasticity	Baclofen Diazepam	5 mg q8h po (max 20mg q8h for children) 1–2.5 mg q8h po
Procedural pain (local)	EMLA	1g/10 cm <sup>2</sup> – 1 hour before procedure
Procedural pain (sedation)	Diazepam	1–2 mg – ½ to 1 hour before procedure
Procedural pain (babies)	Sucrose 20%	Put on pacifier or give 1 ml po
Oral <i>Candida</i> infections	Nystatin	0.5–1 ml q6h po. Wipe away plaques with NaHCO <sub>3</sub> solution before application

Table 1 Pain medication for different types of pain (EMLA, entecic mixture of local anaesthetics; po, per os)



What works? Keeping a history of treatment can help when symptoms recur

Unfortunately many of the terminal conditions in children cause difficulty in breathing. It is, therefore, important to use all means available to address dyspnoea. Most important is to put the patient in a comfortable position, usually sitting up, and never leave the child alone. Ensure adequate ventilation in the room by opening windows or using fans. Speak to the patient and address all fears. Treat the cause of distress with appropriate drugs, e.g. co-trimoxazole for *Pneumocystis pneumonia* (PCP), furosemide for heart failure. Morphine is excellent to calm the patient, open the airways and decrease awareness of breathlessness. Start with 0.2 mg/kg q4h orally and increase if necessary. Do what you can with what is available, stay calm and be present.

### Providing palliative care for Africa's children

In a continent where access to healthcare is often limited, and palliative care services for children are few, the most effective way to reach children is to integrate children's palliative care into existing services for children – hospitals, clinics, and community organisations such as hospice programmes – and to build



Apparently happy. But are all needs addressed?

competence through integrating children's palliative care training into the undergraduate and post-graduate courses of all healthcare professionals. A project to develop Beacon Centres for Children's Palliative Care, in Uganda, Tanzania, and South Africa is increasing the number of skilled practitioners through education and clinical experience.

The few specialised children's palliative care programmes have led the way in highlighting that life-limited children are not little adults, but have specific developmental, psychological, spiritual, and clinical needs that must be addressed.

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- World Health Organisation. [www.who.int/cancer/palliative/definition/en](http://www.who.int/cancer/palliative/definition/en). St Nicholas Children's Hospice for Godfrey's story.

### Godfrey's story

Godfrey was 11 years old, HIV positive, and orphaned by AIDS, when he was admitted into a palliative care partnership between a hospital department of family medicine and a children's hospice. When admitted to hospital, he was diagnosed with pulmonary TB and right-heart failure. Transferred to a children's palliative care unit, he completed TB treatment and started on ARVs (3TC, d4T and EFV). He had a CD4 count of 78, viral load of 170000 copies/ml. An intelligent child, he expressed his emotions through art. He enjoyed a close relationship with the doctor and the chaplain, who visited him daily. He was encouraged to attend school each day for short periods of time. He did well on treatment and went to his family for the holidays. His family stopped his ART, and he was re-diagnosed with TB. Godfrey requested to go to the hospital, demanded to see 'his' doctor and to be admitted to the palliative care unit. He was also diagnosed with PCP (*Pneumocystis carinii pneumonia*) and became oxygen dependent. The multi-disciplinary team ensured that his physical, spiritual, and emotional needs were met and limited schooling and art helped meet his developmental needs. Godfrey developed arthritis and received effective pain management. He contracted chicken pox which led to his death, a death he predicted through a drawing. He was able to discuss his fears with the chaplain and died peacefully in the palliative care unit. Bereavement support was provided to his family, the staff, other children, and his school.



# Hospital-based palliative care

Care in the hospital setting is usually nurse-led and often has to bridge the specialities. Elizabeth Namukwaya advises on how this can be achieved



## Introduction

Hospital palliative care in Africa is a relatively new and developing area of palliative care that addresses the needs of hospital-based patients and bridges the gap in service provision for patients who get palliative care in the community but are unable to access it when in hospital. Many patients with life-limiting illnesses are seen in hospital for

significant periods of time before they are referred on to community-based services. Therefore hospitals provide a unique opportunity for the introduction of palliative care early in the disease trajectory. Hospital palliative care services also ensure continuity of care by referring patients to palliative care services in the community upon discharge.

The process of integrating palliative care in hospitals requires involvement of several key stakeholders and use of several strategies. In Uganda, educating medical and nursing students who on qualification be working on the wards, as well as educating qualified health professionals, was one of the strategies used to support integration of palliative care into the main teaching hospital in Mulago. This strategy on its own, however, was not very successful, probably because the young healthcare professionals were not confident enough to influence senior colleagues who had never had palliative care training and who may have had underlying preconceptions about palliative care and drugs such as morphine. It was, therefore, important to train palliative care personnel in the hospital to support the young clinicians as well as to act as clinical models to demonstrate practical palliative care skills. Hospice Africa Uganda started providing hospital palliative care services for patients under their care who had been admitted to the hospital and also gave support to the health workers through Continuous Medical Education. While this was a welcome support for the health providers, there were some challenges with this system due to the difference in organisational cultures. Hospital systems are geared towards providing acute episodic care while the hospices focus on palliative care for patients with life-limiting illnesses, including end of life care. From

Dr Elizabeth Namukwaya, Palliative Care Doctor, Mulago Referral Hospital Palliative Care Unit, Kampala, Uganda.

these differences, it was clear that there was a need for systemic adjustment within the hospital to provide palliative and chronic care support. External consulting advice also raised concerns about accountability from senior hospital colleagues and administrators. Key to the approach of systemic integration and adjustment is ownership and credibility. This can be achieved by establishing hospital palliative care using staff of that hospital and support for the team by the hospital administration. Administration and government support is also important for sustainability. More importantly, it is important that key palliative care posts are identified and integrated into planning processes. In Mulago Hospital in Uganda, the hospital administration in collaboration with the Ministry of Health and the Palliative Care Association of Uganda identified and trained interested nurses in palliative care. After wide consultation with different stakeholders, and listening to the views of colleagues, a palliative care unit was established within the department of medicine, supported by a medical director, medical and nursing representation, and all doing palliative care full time. This has allowed good clinical practice to be demonstrated and also shown clear accountability. Integration within departmental activities as well strong academic links with Makerere University, participation in training, and the development of an evidence base for palliative care through research has further helped to establish palliative care in Mulago Hospital and given it credibility.

## Hospital team and patient care

Hospital palliative care teams in Africa are mainly nurse-led with a few teams having both nurses and doctors. They operate as consultancy services and patients are jointly managed with the referring teams on the wards. Most teams have no hospital in-patient beds of their own. The advantage of this kind of model is that it provides an opportunity to demonstrate credibility for palliative care to other colleagues and also enhances colleagues' palliative care skills. Because of the high need for palliative care in hospitals, (37% of all patients in a hospital census in Mulago Hospital), the skills should be part of every health professional's daily practice. A consultancy service is also easier to set up; there is no need to look for space for a new ward especially if space is limited. Some hospital palliative care teams in Africa follow up their patients through home visits, especially those which do not have established community services and district hospital services, and whose patients come from a limited geographical area. The advantage of this model is that it ensures continuity of care with already trusted health professionals and minimises loss to follow-up. Some services have outpatient clinics

## How to start a hospital unit

- Wide consultation with stakeholders.
- Know the culture of the organisation.
- Interest and involve administration of the hospital.
- Aim at ownership from the hospital.
- Build strong relationships with colleagues.
- Use champions and allies: influence those in authority.
- Identify interested staff with administration and train them.
- Educate health professionals about palliative care CME for increased referrals.
- Demonstrate the practical value of palliative care to colleagues.
- Respond quickly to referrals.
- Start small.

and patients who have come for review by another specialist use the same opportunity to be reviewed by palliative care teams, thus maximising use of resources on a single visit. A few in-patient hospital beds may be necessary for those on total palliative care and those who need intense palliative care and this may need to be considered by hospital teams. Some teams hold multi-disciplinary meetings with other medical specialties where patients are discussed and a joint treatment plan is made.

## Typical disease distribution case loads

Hospital teams tend to see a broader spectrum of diseases than community-based services, which are usually more focused on cancer, HIV, or both. This is a challenge for the hospital teams if patients without these conditions are discharged and need home-based palliative care services. In Mulago Hospital in Uganda, almost 90% of patients referred for palliative care have cancer. HIV patients are the second commonly referred group and they are referred if they have malignancy or difficult pain; This is probably because generalist palliative care is given by their primary physicians. Non-malignant terminal illnesses such as stroke, end-stage renal, cardiac, respiratory, and liver disease are increasingly being seen by hospital teams as more health professionals become aware of the need of palliative care for these groups. Tuberculosis, which is usually a curable infection is also increasingly being seen by hospital teams, especially with the increasing numbers of patients with multi-drug-resistant TB (MDR-TB). Most patients with MDR-TB have no access to second-line anti-TB drugs and therefore palliative care is vital. Patients on anti-TB treatments have many physical

symptoms due to the TB treatment, HIV co-infection, or treatment for HIV. Palliative care is important to enhance their adherence to their drugs through symptom control and psychosocial support, and hence limit further drug resistance.

## Referrals

Referrals come from both medical and nursing staff on the wards, collaborating organisations in Uganda, e.g. Hospital Africa Uganda, and through multi-disciplinary team meetings from colleagues. These referrals may be either written or verbal. Ward rounds are done daily with some days concentrating on ward areas where there are patients with unmet physical, psychological, social, or spiritual needs. A few major rounds are done as a team in the week to review all patients.

## Follow-up and linkages

On discharge, patients are linked to palliative care services in the community or their nearest district hospital palliative care service. Patients are followed up by phone to ensure they have been referred correctly. Some services follow up patients with home visits, sometimes using community volunteers. It is very important to have contacts of link services and regular meetings with them to chart out referral pathways. In Uganda, this is made possible by the Palliative Care Association of Uganda.

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