Eastern Africa covers 6.38 million km² (3.96 million sq mi). Its 342 million inhabitants constitute 32% of the continent’s total population and are distributed across 19 states: Burundi, Comoros, Djibouti, Eritrea, Ethiopia (which has the largest population in the region with 87 million inhabitants), Kenya, Madagascar, Malawi, Mauritius, Mayotte, Mozambique, Reunion, Rwanda, Seychelles, Somalia, Uganda, Tanzania, Zambia and Zimbabwe.

Disease burden

After southern Africa, the region is the second most affected by the HIV pandemic on the continent, with infection rates considered moderate-to-high. HIV prevalence in adults (age 15–49 years) ranges from <0.1% in Comoros to 14.9% in Zimbabwe (see Table 1).

While HIV prevalence among the wider heterosexual population has been reducing over the last two decades (in Kenya it has declined from 14% to 5%), there are growing concerns regarding emerging at-risk populations, including drug users, prisoners and soldiers.

Tuberculosis (TB) is also a problem. According to the WHO, there were, in 2011, an estimated 8.7 million new cases (13% combined with HIV) and 1.4 million people dying from TB (including approximately one million among HIV-negative and 430,000 among HIV-positive individuals). High TB incidences have been recorded in several eastern African countries (see Table 2), with rates of more than 440 per 100,000 people in Zambia, Zimbabwe and Djibouti.

TB is a potentially life-threatening condition from diagnosis, particularly in its severest forms, multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB. In 2010, the WHO estimated that there were 650,000 cases of MDR-TB in the region, with at least 150,000 resultant deaths occurring annually.

In Somalia, a 2011 survey reported MDR-TB among 5.2% and 40.8% of patients with new and previously treated TB, respectively – some of the highest figures in the region.

Global average cure rate for patients with drug-resistant TB being only 53%, there is an opportunity to address symptoms by systematically including effective palliative care.

Key points

- In eastern Africa, access to palliative care is problematic; however, Rwanda and Mozambique are developing national palliative care policies; Kenya and Uganda have achieved a degree of integration of palliative care into mainstream health services; and Tanzania is achieving a significant service scale-up.
- In recent years, the volume of research publications from eastern Africa has increased considerably. Most of that research is being undertaken in Kenya, Uganda, Tanzania and Zambia.
- Easing the clinical workload of professionals interested in research, increasing funding and providing mentorship and training on research methodology will go a long way towards making palliative care research a reality in eastern Africa.
care services in existing TB treatment programmes. A service model is emerging that suggests managing MDR-TB using a home-based care approach.8

Non-communicable diseases (NCDs), including cancer, diabetes, cardiovascular disease and chronic respiratory illness, are a growing challenge worldwide, accounting for 65% of all deaths.9 Eighty per cent of these deaths occur in developing countries.10 In Kenya, it has been estimated that there are 28,000 new cancer cases and 20,000 cancer deaths annually.11 In Zimbabwe, between 1990 and 1997, the prevalence rate of hypertension reportedly increased from 1,000 to 4,000 per 100,000 people, and that of diabetes from 150 to 550 per 100,000 people.12 In Malawi, NCD risk factors are a major public health problem, with at least one in four men smoking tobacco, one in five drinking alcohol excessively and at least one in four women being overweight.13 These morbidity and mortality rates are in part explained by health systems not delivering on disease prevention, screening, diagnosis and treatment.

**Healthcare systems**

People-centred and integrated health services are critical in reaching universal health coverage.14 Eastern African health systems, however, are generally weak, often dysfunctional, and poorly developed. Healthcare service provision is subsequently compromised due to insufficient access, acute shortage of health workers and other systemic weaknesses.15

Access to palliative care is problematic. This is in no small measure attributable to the fact that palliative care is not included in governmental policy and planning,16,17 and partly also to the lack of access to affordable essential pain medication18,19 despite the high need.20 Some countries are addressing the problem: Rwanda21 and Mozambique are
making exemplary progress by developing stand-alone national palliative care policies. Kenya has introduced a cancer control strategy – a potential entry point for palliative care into the mainstream healthcare system. Over the last decade, there has been progress regarding the integration of palliative care into mainstream healthcare services in Africa generally,22–24 but only a few countries have achieved a meaningful degree of integration; this is the case of Kenya and Uganda. Other countries have achieved a significant service scale-up; this is the case, for example, of Tanzania, which achieved this scale-up through a faith-based network.25,26

History and current status of palliative care

Palliative care started in Africa 35 years ago, when Island Hospice was founded in Harare, Zimbabwe, in May 1979.27 Today, although palliative care provision is inconsistent and often provided by isolated centres, positive developments exist.23,24

A survey of hospice and palliative care services in Africa in 2006 found that 21 out of 47 countries (44.7%) had no identified hospice or palliative care activity and that only four (8.5%) could be classified as having palliative care services that were somewhat integrated with mainstream services;25 figures were even poorer for children’s services, with 81% of countries having no identified paediatric palliative care activity.28 In contrast, a follow-up review undertaken by the World Palliative Care Alliance in 2011 showed that sub-Saharan Africa has seen notable developments, with nine countries moving from group 1/2 (no known activity/capacity building) to group 3a (isolated provision).22

After Zimbabwe, palliative care was next initiated in Kenya, where Nairobi Hospice, the first hospice in the country, was established in 1990. It started as a service addressing the needs of cancer patients; over time, it expanded its support to HIV-affected patients in the city and surrounding areas. In 1993, the first Ugandan hospice opened in Kampala, eventually providing 30 mg per day of reconstituted morphine for ten days at the cost of a loaf of bread.29

Since 1990, national palliative care associations have been set up in Kenya, Mozambique, Rwanda, Tanzania and Uganda, and service provision has increased considerably. Today, there are 40 hospices and palliative care units in public or private hospitals in Kenya, up from 14 in 2007 when the Kenya Hospices and Palliative Care Association (KEPHCA) was founded.

Status of palliative care research

In recent years, the volume of peer-reviewed, data-based research publications from eastern Africa has increased considerably. In line with the recent mapping of palliative care integration,22 the greatest output comes from those countries with the highest level of service integration, namely Kenya and Uganda. Tanzania and Zambia have also contributed to the palliative care literature.25,30 The areas covered are wide-ranging, from patient care31–33 and end-of-life care34 to palliative care guidelines and symptom management,35,36 pain and pain management31 and education.37

In those four countries, palliative care education is being delivered at certificate or diploma level. However, except Uganda, no eastern African country is offering palliative care education at university level. Most of the training provided focuses primarily on patient care and there are few career pathways open in palliative care research, which means that there are no permanent, experienced and funded national research groups that can advance national research agendas.

In Uganda, palliative care research has been conducted at Makerere University, with the African Palliative Care Association (APCA) closely involved. In Kenya, enthusiasm for
Palliative care research has recently been stimulated by collaborations between experienced researchers from abroad and local researchers at the University of Nairobi, with support from the APCA and KEHPCA.

Eastern African governments are increasingly recognising palliative care as a core component of healthcare provision, with many care units opening under the umbrella of the ministries of health. This potentially creates government-supported research opportunities, with outcomes directed specifically at improving patient care. However, major challenges remain. A major one is that many palliative care practitioners are too busy with daily clinical care provision to patients and with running their units to make research a priority.

Paediatric palliative care research is minimal, reflecting the fact that this discipline is relatively new in Africa, despite the huge need. A recent review found little evidence of paediatric palliative care research in Africa, although some studies were identified in Uganda. The review identified the lack of paediatric palliative care data as a significant weakness; however, a palliative care outcome scale for children in sub-Saharan Africa, which is currently being validated, will enable outcome studies to be conducted.

To reflect the diverse, holistic needs of patients with advanced disease in eastern Africa, multiprofessional research needs to be conducted by appropriate staff. While a lot of attention has been paid to pain relief, which has been a particular success in Uganda, research needs to be multidimensional. Evidence to underpin this comes from Uganda, where a study demonstrated that patients with advanced disease identify their spiritual needs as paramount. Research also needs to cover issues of policy and clinical practice, communication and information, and embrace a range of methods, such as the recently completed randomised controlled trial for intervention studies. Eastern Africa also needs more evidence to support home care and hospital-based palliative care.

Data are emerging from eastern Africa regarding the palliative care needs of people with an HIV diagnosis, and how to integrate care for those living with HIV. However, despite an aging African population, other NCDs are poorly investigated and research is yet to identify, for example, the palliative care needs of people with MDR-TB. There is more evidence regarding the needs and outcomes of HIV patients and HIV care provision than there is for other diseases such as cancer. More work is also needed on the cost-effectiveness of interventions.

International collaborations within Africa (for example, via the African Palliative Care Research Network), with low- and middle-income countries in other parts of the world (such as the workshop on outcome measurement between India and Africa) and between African and high-income countries (such as the Europe–Africa co-ordinating action on end-of-life care measurement) are excellent opportunities to share experiences.

There are also ongoing efforts to enhance research capacity by integrating research into palliative care education. Research methods are taught in the palliative care curriculum at Hospice Africa Uganda, one of the leading training institutions of the continent. In 2012, the Makerere University Palliative Care Unit offered an advanced research school that attracted participants from across Africa.

**Conclusion**

In many eastern African countries, palliative care as a clinical and academic discipline is just being recognised, but in a few of them, services are increasingly integrated within mainstream facilities and new palliative care units are being established. Easing the clinical workload of palliative care professionals interested in conducting research, increasing funding and providing mentorship and training on research methodology will go a long way towards making palliative care research a reality in eastern Africa.
This article is part of a series on palliative care research in Africa. An overview was published in the European Journal of Palliative Care Vol 20 No 4. Southern and central Africa have been covered in Vol 20 No 5. Next we will cover western and northern Africa.

Declaration of interest
The authors declare that there is no conflict of interest.

References

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