

VIEW FROM THE OBSERVATORY

A New Research Initiative in Africa

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Introduction

In the last issue (1) we introduced the work of the International Observatory on End of life Care (www.eolc-observatory.net) – a new research and development initiative which focuses on hospice and palliative care world-wide – and made a commitment to provide ongoing commentary about the Observatory's work through a regular update in this column. We continue here with information about a new research project in Africa, together with an article by Sibusiso Dlamini which traces the development of palliative care in Swaziland.

Background

In parts of Africa, life expectancy is falling; a notable contrast to the ageing populations of the industrialised world. While human conflicts have taken their toll, non-communicable and infectious diseases figure prominently – compounded by the impact of poverty, population growth, the inaccessibility of safe water and poor sanitation.

In Africa, it is estimated that a woman's risk of dying from maternal causes is 1 in 15: around 10 times higher than in Latin America and 2000 times higher than in North America. Each year, around 90% of the 600 million cases of malaria occur in Africa. Malnutrition continues to rise and the incidence of tuberculosis is the highest in the world (2). A rank order of countries using the UN's Human Development Index (3) reveals that the 25 'least liveable' countries in the world are all found in Africa.

The HIV/AIDS pandemic has become a huge burden for Africa, the world's most affected region, and more than 20 million African deaths have so far been linked to the disease. Among 42 million people living with infection

world-wide, 29 million are in Sub-Saharan Africa – an area which also has the highest adult prevalence rate of 8.8% (4). These rates vary both between countries and within countries. A recent study showed that 38% of pregnant women in Swaziland were HIV positive (5) and life expectancy in high prevalence areas is expected to fall below 35 years over the next decade.

Palliative care initiatives

Although the AIDS pandemic has caused the international community to pay increased attention to the dying in Africa, interest in hospice care began during the 1970s. In Zimbabwe, Island Hospice was founded by the parents of Frances Butterfield in 1979; a home care service with 17 branches country-wide by 1997. Hospice services developed in South Africa during the 1980s, with Greta Schoeman admitting the first patient to Highway Hospice, Durban, in 1982. Nairobi Hospice (Kenya) and Swaziland Hospice at Home were both founded in 1990; Hospice Uganda opened in 1993 and The Good Shepherd Hospice, Sierra Leone, began in 1994. Nascent services are now emerging in Congo, Gambia, Ghana, Namibia and Nigeria and interest is growing in Egypt and Morocco.

Support for hospice/palliative care in Africa has been forthcoming locally and internationally: at the level of government and policy-making; from community and faith groups; and from institutions offering education, exchanges and partnership arrangements. At present, The World Health Organization (WHO) is involved in a joint palliative care project for cancer and HIV/AIDS patients in Botswana, Ethiopia, Tanzania, Uganda and Zimbabwe. The Diana, Princess of Wales Memorial Fund has begun palliative care initiatives in the nine countries of Ethiopia, Kenya, Malawi, Rwanda, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe. Also active in the area is the Foundation for Hospices in Sub-Saharan Africa.

Notwithstanding the enormity of the task, there are clear indications of progress. The very existence of a hospice in Sierra Leone – ranked as the world's poorest country in terms of human development and overall health system achievement (6) – is in itself a symbol of hope, both to the people of Sierra Leone and to other resource-poor countries of the world. At the level of policy, palliative care for people with cancer and AIDS has been identified as a priority in Uganda's Health Sector Strategic Plan 2000–2005. In Swaziland, over 4300 health professionals, community carers and members of civic groups have received palliative

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care training under the national home-based care strategy (7). In South Africa, after an investment in early British-style free-standing hospices, wider hospice/palliative care coverage is being achieved by the adoption of an Integrated Community Home Care Model (8).

The project

Despite these service developments, we lack an informed overview of the factors which promote or inhibit change; of the opportunities which might be exploited, and the examples of good practice which might be shared and applied more generally. Nor is there comprehensive information on needs analysis, programme implementation, audit and evaluation of services.

From 1 September 2003, the Diana, Princess of Wales Memorial Fund has commissioned an 18-month project – conducted under the auspices of the International Observatory on End of Life Care – to review hospice and related developments in the 47 countries recognised by the WHO in Africa.

Building on our work in Eastern Europe and Central Asia (9), a review methodology has been developed to facilitate the collection of quantitative and qualitative data in this type of context. These methods include:

- 1) Collating and comparing relevant quantitative data (epidemiological, demographic, health system) gathered from governmental, public health and non-governmental sources,
- 2) Analysis of published hospice, palliative care and related sources, including the 'grey' literature, as well as information from web-based sources.
- 3) Production, country by country, of reports (against an agreed template) from personnel undertaking work in the countries of Africa.
- 4) Construction of a database of palliative care services and educational programmes in each country, across the continent.
- 5) Case-study analysis highlighting palliative care 'success stories' using site visits, interviews with key stakeholders and documentary analysis.

- 6) Development of a network of collaborating colleagues within each country to facilitate data collection and assist with the translation of information into intelligence.

Outcomes and value

Our recent experience in Eastern Europe and Central Asia indicates that research activities of this kind would be of value in drawing wider attention to hospice/palliative care needs across the continent of Africa, as well as sub-regions within it. We anticipate that this review would do a great deal to stimulate more informed debate and improved policy making among intergovernmental and governmental organisations surrounding the problems facing end of life care. Importantly, it would increase the evidence base concerning the palliative care provision which currently exists, highlighting the barriers to palliative care development and how they may be overcome. It would also provide opportunities to heighten awareness among international donors and create the potential for additional resources for new and existing programmes.

References

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