



Models of hospice and palliative care in resource poor countries: issues and opportunities

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Preface

Hospice and palliative care is delivered in various shapes and forms. For example, it can be delivered at home, in hospital, in a hospice, and in a day-care facility or nursing home. The management committee of the *UK forum for hospice and palliative care worldwide* asked Help the Hospices to commission Michael Wright to review how this delivery is occurring in Africa and Eastern Europe.

Help the Hospices was fortunate to have someone of Michael's calibre and experience tackling this issue. We recognise that we have benefited from knowledge gained by the International Observatory on End of Life Care (now at the University of Lancaster). The Observatory has recently received grants from the Diana, Princess of Wales Memorial Fund and the US based Open Society Institute to review services in Africa and Eastern Europe respectively. Their website in particular makes fascinating reading - see <http://www.eolc-observatory.net/>.

Michael's reflections in this paper helps us to understand how hospice and palliative care is an approach "without walls", often structured in ways markedly different from services in the UK and the developed world. The ways in which hospice and palliative care has adapted to the developing and transitional world context is fascinating reading. This paper in particular demonstrates the importance of cultural, social and economic contexts.

Help the Hospices would like to take this opportunity to thank Michael for this paper, which offers unique insights into how hospice and palliative care has and is developing. The paper also identifies the challenges ahead, and I hope, provides some clarity to debates in this area.

David Prail
Chief Executive

October 2003

About Help the Hospices

Help the Hospices represents the views of independent, charitable hospices to key opinion formers and decision makers. It co-ordinates UK-wide fundraising initiatives; offers information and advice; gives grants to hospice staff and volunteers; and provides and subsidizes specialist training. Help the Hospices raises awareness and understanding of hospice care and supports hospice care internationally, through the sharing of ideas, knowledge and skills between hospices in the UK and overseas.

Help the Hospices assumes no responsibility for any errors or omissions. The views expressed may not be necessarily those of Help the Hospices.

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Introduction

The purpose of this paper is to contribute to the policy debate of the *UK forum for hospice and palliative care worldwide*. In this context, it reviews the models of hospice and palliative care found in resource poor settings with reference to the countries of Central and Eastern Europe and Central Asia (CEECAS) and the continent of Africa.

The paper is in four parts. Part one, *Background*, places care of the dying, population growth, and the development of palliative care within a global context. The next section, *Two regions*, focuses upon the demographic and epidemiological features of CEECAS and Africa. This is followed by an exploration of the 'resource poor' notion and its relationship to hospice development using five indices: gross domestic product; the human development index; health expenditure; overall health system achievement; and morphine consumption. Part three, *Models of care*, identifies the range of palliative care models developed within the countries of each region, followed by two country vignettes: Russia and Swaziland. In the last part, *The way ahead*, consideration is given to issues which surround these models; to ways in which the international community has given its support; and to the relevance of this support to the aims and policy development of the *Forum*.

Background

Care of the dying is a global issue. Worldwide, around 56 million people die each year; more than a million every week. Around 80 per cent of these deaths are in developing countries.

In the developed world, life expectancy continues to rise, a trend which has its roots in a 19th Century epidemiological transition which saw a shift in the dominant causes of death; from infectious diseases to diseases of longer duration. During the next 50 years, it is estimated that the world's population will increase by around one third - from six billion today to around nine billion in 2050. Significantly, this increase will occur in developing countries, while the populations of developed countries will remain the same.¹

It is estimated that 60 per cent of dying people could benefit from some form of palliative care. Yet only a small minority of dying people ever receive the support of hospice and palliative care services, and unrelieved suffering persists on a large scale. Developing countries of the world have two thirds of the global disease burden, but only five per cent of the world's resources (doctor, nurse, drugs, equipment, and funds). In many African countries, over half of the population will never encounter a doctor or nurse in their lifetime.²

Around 8,000 hospice or palliative care initiatives now exist, or are under development, on every continent of the world in around one hundred countries. Remarkably, services have become established in the poorest of countries and lessons learned from these initiatives offer insights into possibilities for future development.³

Two regions

Central/Eastern Europe and Central Asia (CEECAS)

The countries of Eastern Europe and Central Asia reach from the Adriatic Sea to the Pacific Ocean; a region of more than 400 million people. Known formerly as the communist bloc, the largest country is Russia with a population of 144.7 million; the smallest is Slovenia, population two million. The countries fall into two sub-regions: the area widely known as Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS), ie elements of the former Soviet Union.

A defining feature of this region has been the collapse of communism, removing old certainties and creating new risks. Most notable has been a process of transition - as governments explore the democratic process, health systems de-centralise, and insurance-based models of re-imburement gain ground. During the 1990s, widespread difficulties led to hyper-inflation which in Poland reached 585% at the beginning of the decade; in Russia wages fell by 40 per cent during 1998. Health care is chronically under-funded.

Life expectancy is lowest for men in Kazakhstan (58.8) and for women in Turkmenistan (66.5). The highest life expectancy for both men (71.9) and women (78.8) is found in Slovenia. Age standardised death rates per 1,000 population are highest for men in Russia (440) and for women in Kazakhstan (209). They are lowest for men in Slovenia (164), and for women in Slovenia and the Czech Republic (73). Concerning the disease group most identified with palliative care, age standardised death rates for cancer per 100,000 population also show a steep gradient. Led by Hungary (265.6), the Czech Republic (234.1) and Slovakia (222.3), they are lowest in Uzbekistan (80.5), Georgia (85.9) and Azerbaijan (110.5).⁴

Africa

The World Health Organization (WHO) recognises 47 countries in Africa, a continent with a total population of over 700 million. Nigeria (117 million) has the largest population, Equatorial Guinea (0.5 million) the smallest.

Life expectancy is greatest for men (67.7) and for women (71.1) in Algeria; it is lowest for both men

(32.7) and women in Sierra Leone (35.9), where healthy life expectancy is also lowest: 24.0 for men and 29.0 for women.⁴ In parts of Africa, life expectancy continues to fall; a notable contrast to the ageing populations of the developed world. While human conflicts have taken their toll, health issues figure prominently - compounded by the impact of poverty, population growth, the inaccessibility of safe water and poor sanitation.

It is estimated that in Africa, a woman's risk of dying from maternal causes is one in 15: around ten times higher than in Latin America and 2,000 times higher than in North America. Each year, around 90 per cent 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.⁵

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 worldwide, 29 million are in Sub-Saharan Africa - an area which also has the highest adult prevalence rate of 8.8 per cent.⁶ These rates vary both between countries and within countries. A recent study (2002) showed that 38 per cent of pregnant women in Swaziland were HIV positive.⁷ In high prevalence areas, life expectancy is expected to fall below 35 years over the next decade.

National development and resource capacity indicators

When the 'resource poor' term is used in relation to countries, it is perhaps best regarded as a composite summary of national (human) development and resource capacity. Five indices are used here to give diverse perspectives on these factors and to provide a background against which hospice/palliative care initiatives may be viewed. These are: gross domestic product (GDP); the United Nations human development index (HDI); health expenditure; overall health system achievement; and morphine consumption.

Gross domestic product

Gross domestic product (GDP) is the market value of the total final output of goods and services produced in a country over a specific period, shown in this paper in international dollars (Intl \$).⁸

Among CEECAS countries: the highest per capita GDP is found in Slovenia (Intl \$16,927), the lowest in Tajikistan (Intl \$1,154); four countries have a GDP over 1,100 dollars (Appendix 1).

In Africa: the highest per capita GDP is found in Libya (Intl \$12,095), although this is almost 40 per cent higher than the second highest country - South Africa (Intl \$7,555); the lowest per capita GDP is found in Ethiopia (Intl \$360); 19 countries have a per capita GDP less than 1,000 dollars and three countries - Malawi, Tanzania and Ethiopia - have a per capita GDP of 500 dollars or less (Appendix 1).

Human development index

The human development index (HDI) gives an insight into a country's development in human rather than economic terms. Launched by the United Nations in 1990, HDI measures a country's achievements in three aspects of human development: longevity, knowledge, and a decent standard of living. It was created to re-emphasize that people - and their lives - should be the ultimate criteria for assessing the development of a country, not economic growth. Overall values range from 0.942 (Norway, 1/173 countries) to 0.275 (Sierra Leone, 173/173 countries).

Here, we see that in CEECAS: Slovenia is the

highest scoring country, rank 29/173; eight countries appear in the top 50; and four countries fall outside of the first 100 (Appendix 2).

In Africa: Libya is the highest scoring country, rank 64; just two countries fall within the first 100 and the 26 countries ranked lowest in the world are all African (Appendix 2).

Health Expenditure

Total health expenditure per capita for CEECAS countries are shown in Appendix 3. Slovenia (Intl \$1,462) is the highest spending country and Tajikistan (Intl \$29) the lowest. Two countries, Slovenia and the Czech Republic, spend over 1000 dollars per capita and four countries - Uzbekistan, Macedonia, Azerbaijan and Tajikistan - spend less than 100 dollars. When health expenditure is seen as a percentage of GDP, Croatia and Slovenia are ranked equal first at 8.6 per cent; Armenia (7.5 per cent) moves up from 19 to three and Georgia (7.1 per cent) from 17 to five. Azerbaijan (2.1 per cent) is ranked lowest.

Total per capita health expenditure for Africa is shown in Appendix 4. South Africa (Intl \$663) is the highest spending country, Liberia (Intl \$3) the lowest; 33 countries spend less than 100 dollars. When health expenditure is seen as a percentage of GDP: South Africa ranks highest at 8.8 per cent, Somalia lowest at 1.3 per cent. Malawi (7.6 per cent) moves up from 27 to three and Tanzania (5.9 per cent) from 37 to nine. Libya (3.3 per cent) falls from three to 36 and Algeria (3.6 per cent) from ten to 32.

Overall health system achievement

This composite measure of overall health system attainment⁹ is based on a country's goals relating to health, responsiveness, and fairness in financing. The measure varies widely across countries and is highly correlated with general levels of human development as captured in the human development index.

Among the countries of CEECAS: Slovenia is the highest scoring country, rank 29/191; seven countries appear in the top 50; just six countries fall outside of the first 100 (Appendix 5).

In Africa: Tunisia (77.5) is the highest scoring country, rank 77/191; only four countries fall within the first 100; and the 27 lowest ranked countries of the world are all African (Appendix 5).

Morphine consumption

Alongside education and governmental policy, drug availability is a foundation measure of cost effective palliative care. Among these drugs, opioids feature prominently, particularly morphine. There is some way to go, however, before morphine becomes generally available to resource poor countries.

In CEECAS, five countries (Armenia, Bosnia, Tajikistan, Turkmenistan and Uzbekistan) report no defined daily dose (DDD)¹⁰ consumption of morphine for the years 1994 to 1999.¹¹ Consumption amongst other countries was highest in Slovakia (583) and lowest in Georgia (19) (Appendix 6).

In Africa, just 11/47 countries report DDD consumption of morphine: South Africa ranks highest (265), Libya and Benin the lowest (one). Thirty six countries report no morphine consumption (Appendix 7).

Resource/ development indicators and hospice initiatives

In the regions of CEECAS and Africa, countries with hospice services attain higher average scores on every resource/ development measure outlined above than the average values for the region and for non-hospice countries within each region.

Within CEECAS, 22 countries have hospice/ palliative care services; five countries (Georgia, Kazakhstan, Tajikistan, Turkmenistan and Uzbekistan) have no reported service. A comparison of average values shows the per capita GDP for countries with hospices is almost double that of countries without. Average per capita health expenditure is about three times higher in the group of hospice countries - and consumption of the average defined daily dose of morphine is about five times higher amongst hospice countries than non-hospice countries (Table 1, page 6).

In Africa, hospice/palliative care services have been reported in 17/47 countries. A comparison of resource/development indicators (Table 2, page 6) reveals a similar pattern to that identified within CEECAS: GDP and HDI is higher among hospice countries; health expenditure is about double that of non-hospice countries; and DDD morphine consumption is about 16 times higher among hospice countries than non-hospice countries.

These indicators of development and resource capacity undoubtedly have a bearing on models of hospice/ palliative care found in resource poor settings. In areas of low (healthy) life expectancy, carers as well as patients may be chronically ill. Poverty inhibits early presentation, the use of expensive drugs, and payment for health professionals. Education and clinical expertise has to be sought outside of the country, and under-developed health systems struggle to integrate palliative care at the level of policy. These factors should be borne in mind as we turn next to consider the models of care currently found within CEECAS and Africa.

Table 1:Resource/ development indicators: average values - CEECAS

Index	CEECAS (region)	Countries without hospices	Countries with hospices
GDP per capita (Intl \$)	6, 245	3,440	6,884
Human Development Index	0.776	0.727	0.788
Health care pc expenditure (Intl \$)	380	162	429
Health care expenditure percentage GDP	5.3	4.5	5.5
Overall health achievement value	78.2	73.2	79.4
Morphine consumption DDD	135	31	159

Table 2:Resource/ development indicators: average values - Africa

Index	Africa (region)	Countries without hospices	Countries with hospices
GDP per capita (Intl \$)	2,102	1,956	2,364
Human Development Index	0.478	0.461	0.505
Health care pc expenditure (Intl \$)	100	77	141
Health care expenditure percentage GDP	4.4	2.5	5.3
Overall health achievement value	58.7	58.7	58.8
Morphine consumption DDD	0.77	1.67	27.0

Models of care

Questions arise regarding the essence of hospice/palliative care and how such provision may be identified among a groundswell of related initiatives. This is no mean task - made more complicated by a range of service types found within these regions which include: road-side consultations; open-air treatments; drop-in centres; AIDS clinics; lymphoedema clinics; free-standing hospices; day centres; home care teams; hospital inpatient units; hospital support teams; and nursing home teams.

The WHO defined palliative care in 1990, laying emphasis upon psychological, social and spiritual problems, in addition to symptom control.¹² This definition was revised and broadened in 2002¹³ to include: early intervention alongside life-prolonging therapies; quality of life enhancement; a team approach to care; and support for family members during the patient's illness and in their bereavement; (Appendix 8). It is unclear, however, how this expanded definition will impact upon developed countries, let alone those with limited resources.

In circumstances where the definition of palliative care has become contested, identifying such services in resource poor settings can be problematic. A review of hospice and related developments in Eastern Europe and Central Asia¹⁴ addressed this issue by drawing on a family-resemblance model found in the sociology of religion.¹⁵ Using this model, 'hospice/ palliative care' developments were investigated for evidence of multidimensional, overlapping characteristics, based on the constituent elements of the WHO definition. Where several (not necessarily all, nor even the same) characteristics were identified, the organisation was considered, on the balance of evidence, to provide a hospice/ palliative care service.

In CEECAS, the first hospice (the Society of Friends of the Sick) was established in Krakow (Poland) in 1981 and took the form of a home-care service. Nine years later, an inpatient hospice was opened in St Petersburg by the British-based journalist Victor Zorza. During the next few years, hospice developments throughout the region depended heavily on these two models. Home-care services were founded in Hungary (1991), Bulgaria (1992), Romania (1992), Slovenia (1992) and Albania (1993); and free-standing hospices were developed in Poland (from 1992), the Czech

Republic (1992), Bulgaria (from 1996) and Latvia (1997). The first hospital unit was established in Poznan (Poland) at the Karol Marcinkowski University of Medical Sciences, in 1987. Although slower to gain ground than the free-standing hospice, by 2002, the hospital unit was second only to home-care in its utilisation by countries throughout the region (Table 3, page 8).

In Africa, an in-depth review of hospice/palliative care provision has yet to be undertaken¹⁶ but current information suggests that a broad range of models are being developed. 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 countrywide by 1997. Hospice services developed in South Africa during the 1980s, with Greta Schoeman admitting the first inpatient to Highway Hospice, Durban, in 1982.¹⁷ After initially investing in early British-style free standing hospices, South Africa is now achieving wider coverage by the adoption of an Integrated Community Home-Care Model.¹⁸ Hospice Uganda began as a home care service in 1993. Founded by Anne Merriman, a fruitful collaboration has been developed at the level of government - resulting in the adoption of palliative care as an essential service in the government's five year plan, 2000-2005.¹⁹ An overview of palliative care models found in Africa is shown in Table 4. (page 8)

Table 3: Models of hospice care in the countries of CEECAS

Type of service	Country
Home-care	Albania, Armenia, Azerbaijan, Bosnia-Herzegovina, Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Lithuania, Moldova, Poland, Romania, Russia, Serbia-Montenegro, Slovakia, Slovenia, Ukraine (18)
Hospital unit	Hungary, Kyrgyzstan, Latvia, Macedonia, Poland, Romania, Russia, Slovakia, Ukraine (9)
Free standing inpatient hospice	Bulgaria, Czech Republic, Kyrgyzstan, Lithuania, Poland, Romania, Russia, Ukraine (8)
Day-care	Hungary, Latvia, Poland, Romania, Russia (5)
Hospital support team	Czech Republic, Hungary, Poland, Slovenia (4)
Nursing home	Hungary (1)

Table 4: Models of hospice care in the countries of Africa

Type of service	Country
Home-care	Botswana, Cameroon, Congo, Gambia, Ghana, Kenya, Namibia, Nigeria, Sierra Leone, Malawi, South Africa, Swaziland, Tanzania, Uganda, Zambia, Zimbabwe (16)
Hospital unit	Botswana, Nigeria (2)
Free standing inpatient hospice	Sierra Leone, South Africa, Zambia (3)
Day-care	Botswana, Gambia, Kenya, South Africa, Tanzania, Uganda (6)
Hospital support team	Egypt, Kenya, South Africa, Tanzania (4)

National vignettes

In this section, vignettes are used to locate these models within their national and cultural contexts, drawing upon public health and ethnographic data to illuminate the narrative of hospice development and the experiences of local palliateurs.

Russia

Geo-political context

A country covering 17million sq km; population 144.6 million. Since the break-up of the Soviet Union (1991) Russia has struggled to achieve economic growth and a strong market economy. GDP per capita is Intl \$7,621; total health expenditure per capita is \$405 (5.3 per cent of GDP); HDI is 0.781 (60/173 countries)⁴ and overall health system achievement is 74.3 (100/191 countries).

Demographics/Epidemiology

From the 1980s life expectancy has declined and mortality rates have increased. At present, around 60 per cent more are dying than are being born - a rise in mortality unprecedented in a 20th century industrialised nation. The standardised adult mortality rate (per 1,000) is 440 for males, 159 for females. Life expectancy is 58.9 for males, 72.3 for females. Healthy life expectancy is 51.5 for males, 61.9 for females.⁴

Hospice begins in Russia

Victor Zorza founded the first Russian hospice at Lakhta (St Petersburg) in 1990. A Polish Jew, he fled to Russia and then England after the Nazi invasion of Eastern Poland (1941). His motivation sprang from the death of his daughter, Jane, in an English hospice - a time when her pain was relieved and she found periods of happiness. Shortly before she died, he recalls: *I had put on a Mozart tape for her, just as she was waking up. She slowly opened her eyes, listened with obvious enjoyment for a few minutes and glanced at me. What can she be thinking of, I wondered, when she is listening to Mozart - that she will have to leave all this loveliness behind her, to go into nothingness? She was not thinking that at all. "How beautiful you are making it for me to die", she said slowly.*²⁰ Zorza then spent much of his life fulfilling Jane's request that he support and publicise hospice care. Visiting Russia during the decline of communism he saw the suffering of the people and was determined to help. Finding a kindred spirit in the psychiatrist Andrei Gnesdilov, he secured a 'social hospital' for conversion to a

British style hospice. Zorza remembers it as: *a broken-down, terribly neglected, long, wooden hut, which had been a dumping ground for those sick whom no other hospital in the city wanted. Some terminal cases - by no means all - just people that for various reasons the other hospitals didn't want. It was not just a shambles, it had been looking after these hopeless cases for years without adequate resources, without adequate staff: and one sort of example of what it meant in physical terms was that the patients who couldn't often be moved and taken to the toilet would pee in their beds, and this would just seep down on to the floor, and into the floor, and into the walls for years and years. When I first came to that place, the stench outside, before I even got within kicking distance of the door, was so overwhelming that I sort of had to take a terrific grip on myself to actually go into the hut.*²¹ Despite all the difficulties, the venture was a success. Mayor Sobchak gave his support, funds were allocated from the city budget, and hospice care became integrated into St Petersburg's cancer care programme. Today, the city has seven inpatient units and 17 home-care teams operating in 12/19 districts of St Petersburg.

Models of care

Zorza had a vision of four hospices piloting two models of care: the free-standing hospice and the hospital unit. Tula was established as a hospital unit in 1991, but Zorza died before he could make long-term comparisons. Since 1991, both models have developed side by side. In 2001, Georgi Novikov (MoH) claimed there were 45 free-standing hospices (19 planned) and 25 hospital units (ten planned) established throughout Russia.²² Most services also include a (sometimes minimal) home-care service.

Cultural issues

Wendy Jones, director of the British Russian Hospice Society describes the challenges facing palliative care: [Russia is] *a country where most cancer sufferers received no medical help once their disease passed beyond the point of cure. Pain was left largely untreated, or was inadequately treated, and other symptoms were generally neglected. Patients' sense of hopelessness, isolation, guilt, frustration, fear, depression, and a hundred other social, psychological and spiritual problems were also ignored, and their families left unsupported.*²³ These challenges were exacerbated by a culture of care which a) owed allegiance to the state rather than the patient b) retained strong death/dying and cancer taboos that inhibited truth-telling c) promoted inflexible hierarchies -

resulting in doctor-led care based on a rigid adherence to the medical model d) was reluctant to prescribe morphine - current DDD consumption of morphine is 160; in Slovakia, 583; in Poland, 486.

Education and training

Within Russia:

- unit-based courses and conferences
- regional courses and conferences
- extended placements by visiting clinicians

Outside Russia:

- international conferences (EAPC)
- clinical placements (Britain, Europe, South Africa)
- exchanges with 'twinned' hospices.

A Higher Education link has been established between Anglia Polytechnic University and St Petersburg State Medical Academy.

Issues to be addressed

One commentator from St Petersburg summarised the current palliative care problems in Russia as follows: no official recognition of palliative medicine; a shortage of funds needed to run the current services, a gap which has to be met by charitable subvention; the difficulties in obtaining certain drugs free of charge to patients (such as Fentanyl); difficulties prescribing opioids for home care; low salaries for hospice staff; high workloads leading to 'burn out'; a lack of volunteers.²⁴

Swaziland

Geo-political context

A small landlocked country in Southern Africa covering 17,364 sq km between South Africa and Mozambique; population 937,000. A former British protectorate, it has been independent since 1968 and is governed by King Mswati III, a hereditary monarch. GDP per capita is Intl \$5,029; total health expenditure per capita is \$210 (4.2 per cent of GDP);⁴ HDI is 0.577 (125/173 countries); overall health system achievement is 59 (164/191 countries).

Demographics/Epidemiology

Life expectancy is 40.2 for males, 40.1 for females; healthy life expectancy 33.8 for males, 34.1 for females. The standardised adult mortality rate (per 1,000) is 735 for males, 703 for females.⁴ It is estimated that 200,000 Swazis are HIV positive and 30,000 have developed AIDS. Regarding cancer: the lack of a screening programme means patients present late and have little chance of a cure.²⁵

Hospice begins in Swaziland

Stephanie Wyer - a former Macmillan nurse from Wales - established Swaziland Hospice at Home in 1990. When she accompanied her husband to Swaziland and her background became known, she was encouraged to found a hospice. She recalls: *we used the media; we'd been on television; we'd been on the radio, and we'd had an awful lot of help from the media all over Swaziland. And people were very, very interested. And I was invited to go out and give some talks about what I was doing and why, and it did seem to really grasp the imagination of these people and they really felt that it going to be a good service.*²⁶

Models of care

Swaziland has three home-care services and one inpatient service. Swaziland Hospice at Home (SHAH) provides national coverage with six nurses, one doctor and 150 volunteers. Each of Swaziland's four regions is served by a nurse. Patients are referred by hospitals, family or friends. In 2002, 638 patients were cared for. The Swaziland Community Care Programme was established in Mbabane by the Salvation Army in 1985. An increase in HIV/AIDS patients caused a palliative care programme to be initiated in 2000. Provision includes:

- home-care
- HIV clinic
- bereavement care
- orphan care - currently 300 children

At present 3/10 nurses provide palliative care alongside 50 (volunteer) community/ family carers. Around 180 clients are seen daily.²⁷ Parish Nursing began in 2000 supported by the Bristol Myers-Squibb Company²⁸ in partnership with the Catholic Diocese of Manzini and Maternal Life International.²⁹ Project leader Thandiwe Dlamini explains: *Parish Nursing aims to integrate the practice of faith with the science of nursing. It links nurses with churches to focus on health*

*related issues and provide a holistic approach in the healing and caring process of a patient.*³⁰ Currently 30 nurses see five to eight patients per day - within walking distance of their homes - throughout the four regions of Swaziland. Hope House was sponsored by World Vision International in partnership with the Catholic Church. The facility opened as an inpatient unit - modelled upon the Swazi homestead - which caters for the needs of AIDS patients at the end of life. Project leader Fr. Larry McDonnell states: *Swazi health facilities are unable to cope with the influx of AIDS patients, who are discharged when death is near. Swazis live in strong extended family units, but sometimes there is no one at a traditional homestead to tend to an AIDS sufferer. A father may be dead, a mother sick, and children incapable of the responsibility.*³¹

Cultural issues

Stephanie Wyer describes the (lack of) end-of-life care upon her arrival in Swaziland: *[patients] were being taken into the government hospitals, with whatever their symptoms were, they were told - it just wasn't told gently - they were told that they were going to die, they were taking up a bed and they would just have to go home and wait to die... There was just absolutely nothing available.*²⁶ Meeting this challenge in Swaziland is made more difficult by a) the volume of need b) a strong taboo associated with AIDS c) the operation of parallel health systems - 'western' and 'indigenous' - in which an estimated 70 per cent of patients visit traditional healers d) a widespread belief that illness is a consequence of being bewitched, or a punishment from ancestors e) an over-stretched health system where trained palliatours are deployed to other specialties or lost to other countries f) the inaccessibility of morphine - average DDD consumption in Swaziland is four, compared with South Africa 264; Namibia 97; Zimbabwe 36 and Benin one; 36/47 African countries have no recorded morphine consumption.

Education and training

Stephanie Wyer received nurse tutor status from St David's Foundation and began courses in palliative care sponsored by the local sugar company. From this time, SHAH became Swaziland's main education and training resource - originally running programmes from the hospice caravan but more recently from a two-storey administration and conference centre donated by the American Embassy. In 2000, a national home based care strategy was implemented which included differentiated palliative care education for health professionals and civic groups. SHAH played a key

role. Thulie Msane (director, SHAH) writes: *As government initiated the strategy, there was a need for hospice to train care givers (Rural Health Motivators), civic society, churches and schools in raising awareness of the home based concept and palliative care concept.*³²

Modules include:

- the palliative care concept
- symptom management
- death, grief and bereavement
- pain management
- home based care g) spiritual care
- HIV/AIDS symptom management

As of June 2003, a total of 4316 people have been trained across a broad range of groups and services (Tables 5 and 6, page 12)

SHAH also sponsored a hospice nurse, Sibusiso Dlamini to undertake a BSc in palliative nursing in England. He now works within the Prime Minister's office as National Co-ordinator: Care and Support.

Issues to be addressed

The following have been identified as key issues for palliative care development in Swaziland:

- funding - for training, medications, staffing and administrative costs
- increased drug availability
- post-basic education and training
- capacity building - the palliative care workforce
- support for palliative caregivers
- establishment of a national palliative care association
- development of palliative care standards

In the next section, consideration is given to the issues raised by hospice/palliative care in resource poor settings and their implications for the *UK Forum*.

Table 5: Personnel trained under the national home based care strategy, Swaziland, 2000-02

Year	Doctors	Nurses	Student nurses	Civic group	Community carers	Total
2000-01	31	63	35	1,217		1,346
2001-02	25	466	70	993	807	2,361

Table 6: Personnel trained under the national home based care strategy, Swaziland, 2002-03

Year	Health professionals	Defence force	Civic group	Correctional services	Total
2002-June 03	500	40	474	150	1,164

Source: Thulie Msane, personal communication - 18 June 2003

The way ahead

Issues

Despite their regional location, these developing services reveal generic issues which include:

The context of care

In resource poor settings, palliative care is integrally linked to socio-economic factors in ways which bear little resemblance to its counterpart in developed countries. In the following extract, Sibusiso Dlamini comments on the effects of malnutrition upon palliative caregiving:

*While we would like to ensure control of our clients' physical symptoms, starvation is the first symptom we face in Swaziland, and it is practically and professionally not possible to push a client to take a tablet or medication on an empty stomach. As a result, palliative caregivers are forced to scout for food to give to their clients as a first line of intervention.*²⁵

The culture of care

Palliative care cannot flourish in isolation from other health systems. Yet its people-centred focus and openness to disclosure may be considered to be problematic, particularly where a disease has become stigmatised or when openness challenges ingrained medical practices. Barrie Cassileth explains how the Soviet adherence to deontological, duty focused ethics has left a detrimental legacy to palliative care development:

Most of Russia's bioethical standards and behaviour stem from two important features of deontology. One is the physician's oath. In the former Soviet Union, that oath required physicians to protect first the interests of the State, not the interests of the patient. This conflict between responsibility to State and patient often worked to the patient's detriment, and it is diametrically opposed to principals of physician responsibility in other countries.

The second influential feature is the fundamental deontologic principle that obliged Russian doctors to protect patients from knowledge of potentially fatal diagnoses. This rule required that physicians not reveal diagnoses such as cancer, and it had

*the further effect of quelling communication with patients generally.*³³

Attitude change

Notions of 'communication', 'holistic care' and 'accompaniment' form part of the essence of palliative care, yet in many instances these ideas cannot be embraced without a change of attitudes on the part of the caregiver. Nurse Gabriela Baila recalls some of the changes associated with the new hospice service at Casa Sperantei (Romania):

*We learned in [nursing] school that you are not allowed to sit on the bed with the patient, and you are not allowed to touch if the patient has a wound or a fever. You have to try to keep yourself safe. So patients were really surprised when somebody comes and takes their hands, shares their grief. It was something new.*³⁴

Community empowerment

Despite the lack of resources, there is evidence of endemic systems and rituals, honed over many generations, which give a structured, communal perspective to suffering and dying, particularly in Africa. Such a perspective acknowledges the impact a death can make upon the family, the community, and even an entire society, and contrasts sharply with the individualism prevalent in some western societies.³⁵

In her survey of 173 terminally ill patients in Kampala (Uganda),³⁶ Ekiria Kikule found the home to be the preferred site of care, despite all respondents having access to healthcare services within five kilometres of their homes. Jan Stjernwård and David Clark suggest these strong communal structures could be utilised to attain a wider palliative care coverage:

Old cultural traditions for curbing pain, which is spiritual, existential, and physical, could be harnessed to simple modern techniques for the relief of suffering. Symptom care, bedsore prophylaxis, appropriate food and hygiene could be enhanced through the empowerment of family members. Finding ways to empower families and communities in such ways is an urgent priority and in this socio-economic and cultural solutions will be as

*important as medical ones if meaningful palliative care coverage is to be achieved.*²

Cost and availability of medicines

With about half of the world's population (2.8 billion) living on less than two US dollars per day, and 1.2 billion people living on less than one US dollar a day,³⁷ the cost of medicines is critical. Yet so often the pricing structure renders them unavailable to those who need them most. The problem is exemplified by the following cameo from Russia.

In 2001, Natalya Michnovskaya³⁸ of the St Petersburg Health Committee stated that new regulations had been introduced to allow increased dosages of morphine. She applauded the availability of slow release morphine - but considered the tablets too expensive for general use. At that time, ten 60mgm MST tablets cost 30 US dollars in Russia; in the UK they cost the equivalent of 8.60 US dollars.

It is hardly co-incidental that 36/47 African countries - the poorest in the world amongst them - have no recorded morphine consumption. Yet unrelieved pain is unacceptable, since it is generally avoidable. According to the WHO:

*National policies and strategies...should be established to ensure the availability of analgesics, particularly low cost oral morphine, and other essential drugs. Current restrictive regulations should be revised....Nurses need to be equipped with the skills to provide palliative care when needed, and nurses with specialised training should be given authority for prescribing and dispensing analgesics. However, professional nurses are also scarce and often are not available at the level of community clinics. Training of primary caregivers in prescribing morphine, with adequate supervision by specialised district nurses, may prove to be a valid solution for improving patients' access to morphine.*³⁹

An inclusive approach

In developed countries, palliative care has become strongly associated with cancer, exclusively so in some cases. Such an approach is inappropriate in Africa, however, where the HIV/AIDS pandemic is stripping families of their parents and communities of their workforce. Calls abound for a more inclusive approach to disease

categories despite the perceived difficulties. These include reluctance on the part of cancer patients to be associated with an HIV/AIDS unit and reticence among HIV/AIDS activists to divert their attention to other disease categories.⁴⁰ In her analysis of the relationship between palliative care and HIV/AIDS, Sue Lucas makes a telling point:

*In resource poor settings, diagnostic facilities are lacking for both conditions. People with cancer don't seek help until they have pain or other symptoms of advanced disease, and HIV is often not diagnosed until the end-stage disease is reached. Family implications are therefore not addressed until the end of life, making the process of dying more difficult to come to terms with for both the patient and the family.*⁴¹

Accessible technologies

Amongst laudable attempts to relieve human suffering there is sometimes a desire to support the patient by utilising the most up-to date technologies. Stephanie Wyer,²⁶ founder of Swaziland Hospice at Home, recalls how two recently-acquired syringe drivers were rendered ineffective in rural areas due to the absence of batteries to power the devices. A wind-up, clockwork version eventually solved the problem and the battery powered syringe drivers were subsequently restricted to urban areas. Despite the parochial nature of this example, the principles of availability and accessibility are important ingredients of egalitarian palliative care provision, as Callahan observes:

*It is better to have poorer and older technologies that are available to all, than more recent technologies that must be rationed. A fair and general allocation of health resources, even with less than up-to-date technologies, is better than a system creating a massive technological gap between rich and poor.*⁴²

Opportunities for support

Notwithstanding these challenges, in conditions which could only be described as sub-optimal, the impetus towards palliative care became irresistible as activists confronted institutions and hardened attitudes with resolve. Recognising a variety of opportunities to support these embryonic services, the international community rallied to give assistance. Education and training featured prominently, as multidisciplinary teams were dispatched to

train local palliateurs in situ, and in-house placements were offered by palliative care organisations worldwide. Volunteers raised funds. Equipment and supplies were donated. Supportive relationships developed between like-minded institutions and, in some cases, whole services were established and maintained (Table 7).

Table 7 Types of support given by the international community to developing hospice/palliative care services

Type of support
Advocacy <ul style="list-style-type: none"> ■ government level ■ community level ■ donors and partners
Assessment of need <ul style="list-style-type: none"> ■ incidence/ prevalence of diseases ■ cost effectiveness of care ■ services available
Dissemination <ul style="list-style-type: none"> ■ translation of texts ■ professional publications (eg journals) ■ service publications (eg newsletters)
Education and training <ul style="list-style-type: none"> ■ unit level ■ international conferences/ seminars ■ academies and universities
Equipment and supplies <ul style="list-style-type: none"> ■ beds, syringe drivers ■ medicines ■ dressings
Funding <ul style="list-style-type: none"> ■ generic ■ earmarked
Information service <ul style="list-style-type: none"> ■ hospice/palliative care database ■ factsheets/ reports ■ courses
International Observatory <ul style="list-style-type: none"> ■ global analysis ■ country reports ■ translation of information into intelligence
Personnel <ul style="list-style-type: none"> ■ clinical placements ■ administrative support
Physical resources <ul style="list-style-type: none"> ■ premises ■ building extensions ■ transport
Service provision <ul style="list-style-type: none"> ■ establishment of new initiative ■ funding/ maintenance ■ staffing/ staff training
Standards development <ul style="list-style-type: none"> ■ multidisciplinary/ multi-agency collaboration ■ organisational/ clinical/ educational dimensions ■ audit tools

Towards a Forum policy

Against this background, the *UK forum for hospice and palliative care worldwide* was established with the following stated objectives, to:

- develop a UK network and share experiences and information
- support hospices and palliative care worldwide
- facilitate twinning and information exchange between hospices in the UK and worldwide
- establish a training and education programme

Since inception in 2001, the *Forum* has initiated a range of innovations, which include:

- network building (for members; with organisations - BOND, WHO, EAPC, IAHP, SPCSG)
- liaison with government and donors (DIFID, UK Treasury, OSI, Diana Princess of Wales Memorial Fund, European Union, VSO, Skillshare, BESO)
- identification of funding streams
- skills database
- policy papers (Advocacy, Palliative Care and HIV/AIDS)
- email newsletter
- seminars (National Associations Seminar, The Hague)
- workshops (Advocacy, Volunteering)
- awards/ grants (conference delegates, IOELC)

Building on these successes, the *Forum* is developing an increased capacity for palliative care support. Amongst the palliative care community, awareness has been raised of a new player on the international stage. Ambitious initiatives have impacted at the level of clinician and national organisations. New funding has generated new opportunities.

Members may now wish to consider the benefits of a policy against which the *Forum's* objectives and strategies may be viewed. In essence, this policy may be shaped by the adoption of a series of principles, some of which are listed below:

- to develop a special focus upon hospice/ palliative care in resource poor settings
- to create opportunities for both proactive and reactive activities

- to generate a portfolio of support drawn from the types outlined in Table 7
- to review contextual, cultural and ethical considerations underpinning proposed initiatives
- to extend the *Forum's* enabling/ facilitating role (eg to include needs assessment or standards construction)
- to adopt a tiered approach to need (where projects allow) which encompasses
 - the service
 - the community
 - the government
- to maintain a continuing commitment to education and training
- to develop a heightened awareness of the opportunities for advocacy

Conclusion

As the patchwork of hospice and palliative care services continues to grow, imaginative models have been developed to meet the needs of local people worldwide. In many instances, these services have been established by the prompting of visionary individuals and like-minded pioneers, sometimes with meagre resources, yet united by the common aim of providing better care for dying people. Significantly, many of these services have developed during the last decade - and there are impressive examples of continuing support from the international community. However, much more work needs to be done to ensure that the number of people who have access to palliative care increases.

Within this scenario, the *UK Forum* has come to support hospice developments on a variety of fronts. Though a young organisation, it has established a distinctive role and identity, becoming known within the field at the level of government and donors, national organisations, services and palliateurs. During the past two years, notable gains have been made as the *Forum* strengthened its base and pursued its objectives with vitality. The adoption of a policy to articulate the *Forum's* relationship with palliative care services and inform future action - particularly in resource poor settings - is timely; and the process of review, debate and policy-creation may well become the catalyst for a wider and more focused range of support.

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Appendix 1: GDP per capita (Intl \$): CEECAS and Africa, 2000

GDP per capita (Intl \$): CEECAS, 2000		GDP per capita (Intl \$): Africa, 2000	
Country	GDP per capita	Country	GDP per capita
Slovenia	16927	Libya	12095
Czech Republic	14236	South Africa	7555
Hungary	12439	Tunisia	6717
Slovakia	11654	Botswana	6014
Poland	9590	Gabon	5771
Estonia	9123	Namibia	5152
Russia	7621	Swaziland	5029
Belarus	7598	Algeria	3960
Croatia	7390	Morocco	3706
Lithuania	6941	Egypt	3604
Latvia	6888	Equatorial Guinea	3013
Romania	6475	Zimbabwe	2331
Kazakhstan	5677	Guinea	1675
Turkmenistan	5269	Côte d'Ivoire	1637
Bulgaria	5021	Lesotho	1580
Macedonia	5001	Angola	1457
Serbia-Montenegro	4242	Dem Rep of the Congo	1410
Albania	3727	Kenya	1396
Ukraine	3689	Togo	1283
Bosnia-Herzegovina	3404	Djibouti	1257
Georgia	2768	Cameroon	1256
Azerbaijan	2676	Central African Republic	1252
Armenia	2546	Ghana	1223
Kyrgyzstan	2426	Mauritania	1211
Uzbekistan	2333	Senegal	1207
Moldova	1802	Congo	1135
Tajikistan	1154	Gambia	1115
		Sudan	1072
		Uganda	932
		Nigeria	884
		Zambia	866
		Burkina Faso	864
		Benin	842
		Rwanda	774
		Guinea-Bissau	700
		Mozambique	697
		Liberia	668
		Sierra Leone	659
		Mali	640
		Chad	623
		Eritrea	578
		Niger	568
		Somalia	555
		Burundi	501
		Malawi	500
		Utd Rep of Tanzania	457
		Ethiopia	360

Source: World Health Organization (WHO) statistics

Appendix 2: Human development index values and rank order of countries: CEECAS and Africa, 2002

Human Development Index (HDI) values and rank order of countries: CEECAS, 2002			Human Development Index (HDI) values and rank order of countries: Africa, 2002		
Country	HDI value	Rank/ 173 countries	Country	HDI value	Rank/ 173 countries
Slovenia	0.879	29	Libya	0.773	64
Czech Republic	0.849	33	Tunisia	0.722	97
Hungary	0.835	35	Algeria	0.697	106
Slovakia	0.835	36	South Africa	0.695	107
Poland	0.833	37	Equatorial Guinea	0.679	111
Estonia	0.826	42	Egypt	0.642	115
Croatia	0.809	48	Gabon	0.637	117
Lithuania	0.808	49	Namibia	0.610	122
Latvia	0.800	53	Morocco	0.602	123
Belarus	0.788	56	Swaziland	0.577	125
Russia	0.781	60	Botswana	0.572	126
Bulgaria	0.779	62	Zimbabwe	0.551	128
Romania	0.775	63	Ghana	0.548	129
Macedonia	0.772	65	Lesotho	0.535	132
Armenia	0.754	76	Kenya	0.513	134
Kazakhstan	0.750	79	Cameroon	0.512	135
Ukraine	0.748	80	Congo	0.512	136
Georgia	0.748	81	Sudan	0.499	139
Turkmenistan	0.741	87	Togo	0.493	141
Azerbaijan	0.741	88	Nigeria	0.462	148
Albania	0.733	92	Djibouti	0.445	149
Uzbekistan	0.727	95	Uganda	0.444	150
Kyrgyzstan	0.712	102	Utd Rep of Tanzania	0.444	151
Moldova	0.701	105	Mauritania	0.438	152
Tajikistan	0.667	112	Zambia	0.433	153
Mongolia	0.655	113	Senegal	0.431	154
Bosnia- Herzegovina			Dem Rep of the Congo	0.431	155
Serbia- Montenegro			Côte d'Ivoire	0.428	156
			Eritrea	0.421	157
			Benin	0.420	158
			Guinea	0.414	159
			Gambia	0.405	160
			Angola	0.403	161
			Rwanda	0.403	162
			Malawi	0.400	163
			Mali	0.386	164
			Central African Rep	0.375	165
			Chad	0.365	166
			Guinea-Bissau	0.349	167
			Ethiopia	0.327	168
			Burkina	0.325	169
			Mozambique	0.322	170
			Burundi	0.313	171
			Niger	0.277	172
			Sierra Leone	0.275	173
			Liberia		
			Somalia		

Source: UNDP Report, 2002

Appendix 3: Total health expenditure (Intl \$) per capita and as a percentage of GDP: CEECAS, 2000

Health expenditure (Intl \$) per capita: CEECAS		Health expenditure (Intl \$) as a percentage of GDP: CEECAS	
Country	Per capita	Country	Percentage of GDP
Slovenia	1462	Slovenia	8.6
Czech Republic	1031	Croatia	8.6
Hungary	846	Armenia	7.5
Slovakia	690	Czech Republic	7.2
Croatia	638	Georgia	7.1
Poland	578	Hungary	6.8
Estonia	556	Estonia	6.1
Belarus	430	Poland	6.0
Lithuania	420	Lithuania	6.0
Russia	405	Moldova	6.0
Latvia	398	Kyrgyzstan	6.0
Bosnia-Herzegovina	319	Slovakia	5.9
Moldova	300	Latvia	5.9
Turkmenistan	286	Belarus	5.7
Serbia	237	Serbia-Montenegro	5.6
Kazakhstan	211	Turkmenistan	5.4
Georgia	199	Russia	5.3
Bulgaria	198	Bosnia-Herzegovina	4.5
Armenia	192	Ukraine	4.1
Romania	190	Bulgaria	3.9
Ukraine	152	Kazakhstan	3.7
Kyrgyzstan	145	Uzbekistan	3.7
Albania	129	Macedonia	3.5
Uzbekistan	86	Albania	3.4
Macedonia	64	Romania	2.9
Azerbaijan	57	Tajikistan	2.5
Tajikistan	29	Azerbaijan	2.1

Source: World Health Organization (WHO) statistics

Appendix 4: Total health expenditure (Intl \$) per capita and as a percentage of GDP: Africa, 2000

Health expenditure (Intl \$) per capita: Africa		Health expenditure (Intl \$) as a percentage of GDP: Africa	
Country	Per capita	Country	Percentage of GDP
South Africa	663	South Africa	8.8
Tunisia	472	Kenya	8.3
Libya	392	Malawi	7.6
Namibia	366	Zimbabwe	7.3
Botswana	358	Namibia	7.1
Swaziland	210	Tunisia	7.0
Gabon	171	Lesotho	6.3
Zimbabwe	171	Botswana	6.0
Morocco	166	Utd Rep of Tanzania	5.9
Algeria	142	Zambia	5.6
Egypt	138	Rwanda	5.2
Kenya	115	Djibouti	5.0
Equatorial Guinea	103	Mali	4.9
Lesotho	100	Sudan	4.7
Djibouti	63	Senegal	4.6
Guinea	56	Ethiopia	4.6
Senegal	56	Morocco	4.5
Cameroon	55	Cameroon	4.3
Angola	52	Mauritania	4.3
Mauritania	52	Mozambique	4.3
Ghana	51	Sierra Leone	4.3
Sudan	51	Eritrea	4.3
Zambia	49	Swaziland	4.2
Gambia	46	Ghana	4.2
Côte d'Ivoire	45	Burkina Faso	4.2
Rwanda	40	Gambia	4.1
Malawi	38	Liberia	4.0
Burkina Faso	37	Uganda	3.9
Central African Republic	37	Guinea-Bissau	3.9
Togo	36	Niger	3.9
Uganda	36	Egypt	3.8
Mali	32	Algeria	3.6
Mozambique	30	Angola	3.6
Guinea-Bissau	28	Equatorial Guinea	3.4
Sierra Leone	28	Guinea	3.4
Benin	27	Libya	3.3
Utd Rep of Tanzania	27	Benin	3.2
Congo	25	Chad	3.1
Eritrea	25	Burundi	3.1
Niger	22	Gabon	3.0
Dem Rep of the Congo	21	Central African Republic	2.9
Nigeria	20	Togo	2.8
Chad	19	Côte d'Ivoire	2.7
Ethiopia	17	Congo	2.2
Burundi	16	Nigeria	2.2
Somalia	7	Dem Rep of the Congo	1.5
Liberia	3	Somalia	1.3

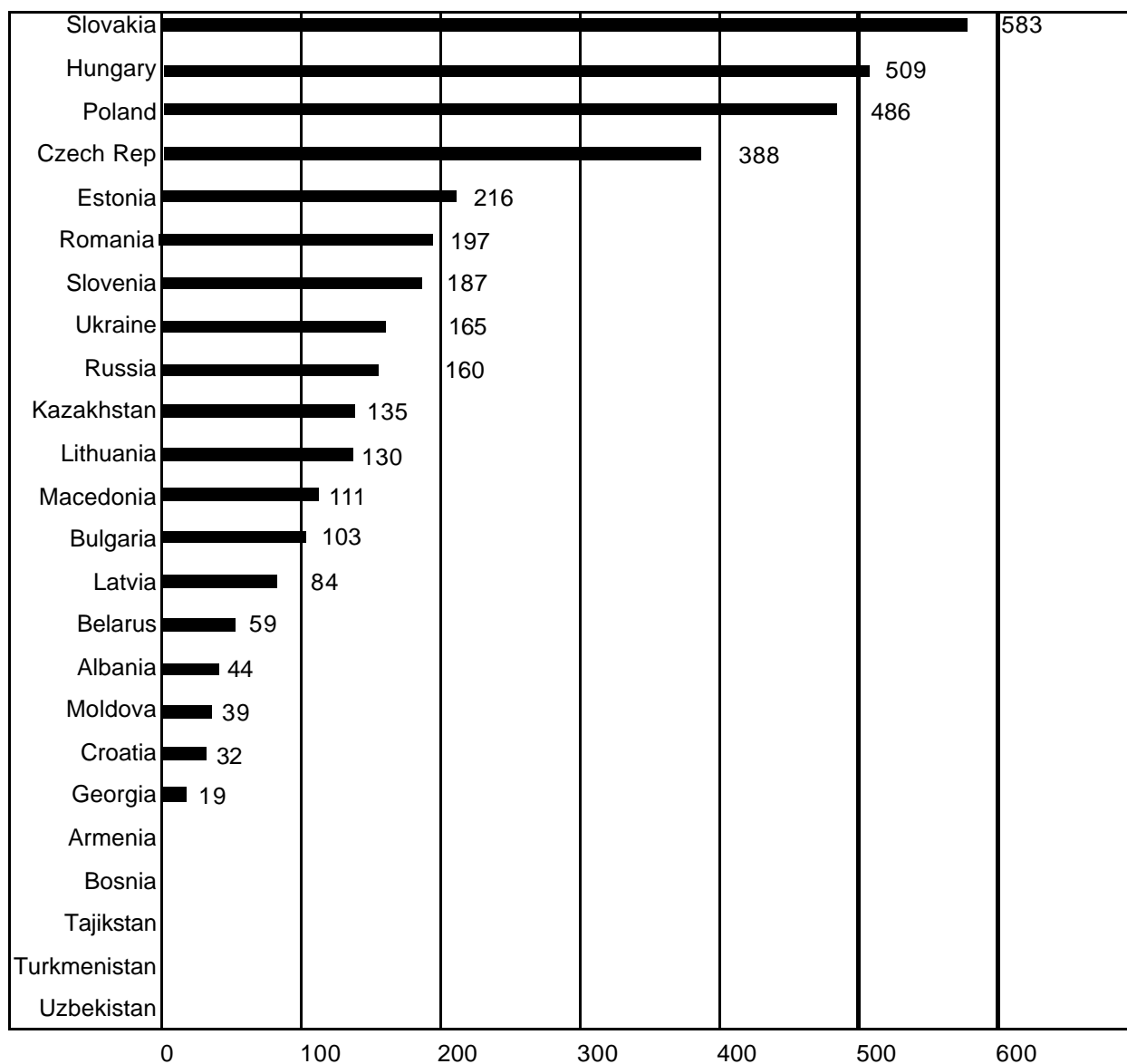
Source: World Health Organization (WHO) Statistics

Appendix 5: Overall health system achievement: CEECAS and Africa

Overall health system achievement: CEECAS			Overall health system achievement: Africa		
Country	Achievement index	Rank/191 countries	Country	Achievement index	Rank/191 countries
Slovenia	87.9	29	Tunisia	77.5	77
Czech Republic	87.8	30	Morocco	75.7	94
Poland	85.8	34	Libya	75.3	97
Croatia	85.1	36	Algeria	74.4	99
Slovakia	84.7	39	Egypt	73.5	110
Hungary	83.4	43	Senegal	70.5	118
Estonia	81.7	48	Ghana	68.5	139
Lithuania	81.0	52	Gabon	64.5	141
Belarus	81.0	53	Kenya	64.3	142
Ukraine	80.1	60	Benin	64.2	143
Kazakhstan	79.0	62	Zimbabwe	62.3	147
Latvia	78.0	67	Sudan	62.3	148
Romania	77.8	72	South Africa	61.0	151
Bulgaria	77.6	74	Equatorial Guinea	60.2	152
Georgia	77.5	76	Gambia	60.2	153
Bosnia-Herzegovina	77.3	79	Congo	60.1	155
Armenia	77.0	81	Togo	60.0	156
Albania	76.7	86	Côte d'Ivoire	60.0	157
Macedonia	76.4	89	Utd Rep of Tanzania	60.0	158
Moldova	76.1	91	Burkina Faso	59.4	159
Serbia-Montenegro	75.5	95	Burundi	59.3	161
Russia	74.3	100	Uganda	59.3	162
Azerbaijan	74.0	103	Cameroon	59.1	163
Uzbekistan	73.5	109	Swaziland	59.0	164
Tajikistan	68.3	127	Namibia	58.8	165
Turkmenistan	67.7	130	Botswana	57.4	168
Kyrgyzstan	67.0	135	Mauritania	57.2	169
			Djibouti	56.8	170
			Rwanda	56.5	171
			Guinea	56.3	172
			Lesotho	56.0	173
			Zambia	55.6	174
			Eritrea	53.7	176
			Chad	53.6	177
			Mali	53.3	178
			Dem Rep of the Congo	52.6	179
			Angola	52.4	181
			Guinea-Bissau	52.4	180
			Malawi	52.3	182
			Nigeria	51.7	184
			Mozambique	50.6	185
			Ethiopia	50.5	186
			Liberia	50.4	187
			Niger	50.1	188
			Somalia	49.4	189
			Central African Rep	45.9	190
			Sierra Leone	35.7	191

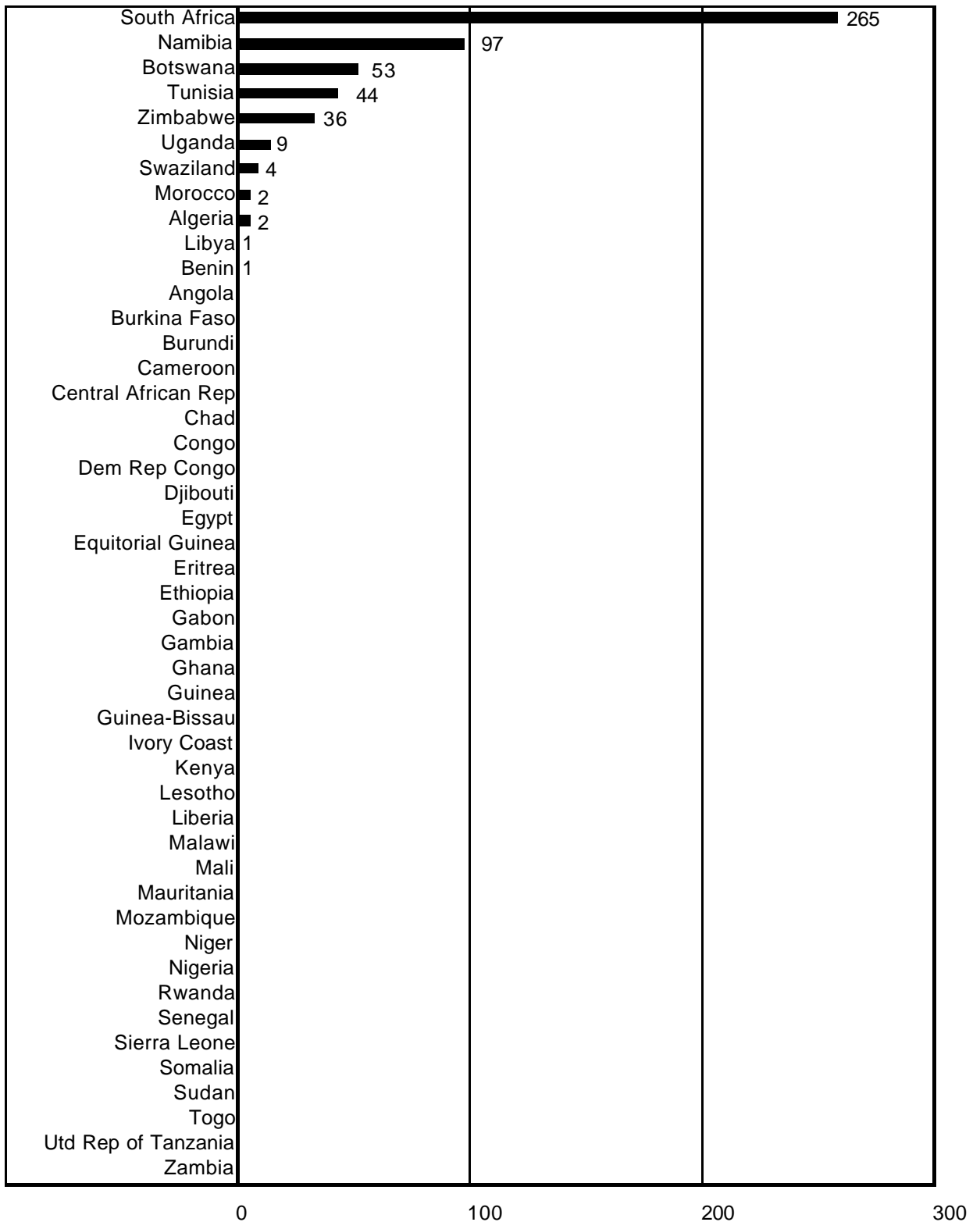
Source: Murray CJL, Lauer J, Tandon A, Frenk J. Overall health system achievement for 191 countries. Global Programme on Evidence for Health Policy Discussion Paper Series: No. 28. World Health Organization.

Appendix 6: Average defined daily doses of morphine: CEECAS (1994-1998)



Source: International Narcotics Control Board (2000) *Narcotic Drugs: Estimated World Requirements for 2000*. Statistics for 1998. New York: United Nations

Appendix 7: Average defined daily doses of morphine Africa (1994-1998)



Source: International Narcotics Control Board (2000) *Narcotic Drugs: Estimated World Requirements for 2000*. Statistics for 1998. New York: United Nations

Appendix 8:WHO definition of palliative care, 2002

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of care
- offers a support system to help patients live as actively as possible until death
- 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, and includes those investigations needed to better understand and manage distressing clinical complications

Source: Sepúlveda C, Marlin A, Yoshida T, Ulrich A (2002) Palliative care: the World Health Organization's global perspective. *Journal of Pain and Symptom Management* **24** (2): 91-6.

**Models of hospice and palliative care in
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