

Twenty-first century palliative care: a tale of four nations

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Hospice and palliative care development, in terms of availability and services, occur to varying degrees in the developing world. In this paper, the evolution of palliative care practices in four developing nations (Nigeria, Georgia, Ethiopia and Tanzania) is described. By highlighting common problems as well as the unique individual perspectives of each country's practice, this paper aims at increasing global awareness of palliative care in the developing world. While the call for palliative care to become a fundamental human right is sustained, it is also hoped that this article will stimulate a global discussion on the best possible way to encourage the establishment and growth of palliative care services in other developing countries where hitherto it has not been in existence, with policymakers and healthcare professionals taking the lead through the institution of sound national policies to promote and provide palliative care to all citizenry.

Keywords: palliative care, developing nations, practice.

INTRODUCTION

Care of chronically ill patients and their families have come a long way from the days of Dame Cicely. While practice in developed countries has reached subspecialisation to ensure provision of care to all strata of society, palliative care in developing countries is still far from optimal. In Africa, less than 5% of people in need of palliative care are receiving it (Grant *et al.* 2011) and the demand for the latter continues to surpass service delivery especially with the rising burden of non-communicable diseases (NCDs). The Declaration of Venice (2006) has called for prioritisation of education and research as

means of promoting palliative care development in developing countries, taking into consideration cultural, geographical and socio-economic differences (IAHPC 2007). While there has been some increase in palliative care publications from all continents over the years, research from nations in Africa in particular remains sparse, with just 23 articles published in 2010 (Grant *et al.* 2011). While Harding *et al.* (2008) report a lack of cadre of African palliative care researchers, publication bias towards articles from African nations (O'Connor 2012) also contributes to the challenges in providing effective palliative care in these countries.

The idea for this article was birthed following the attendance of four of the authors to the 2012 Annual Assembly of the American Academy of Hospice and Palliative Medicine (AAHPM) in Denver, Colorado, USA. This article gives historical timelines and describes palliative care practice in four countries – Georgia, Nigeria, Ethiopia and Tanzania. It aims at increasing global awareness of the peculiar situations in these nations and at inspiring discussions on the way forward with palliative

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care practice in developing nations of the world, among healthcare professionals and policy makers. It is hoped that this discussion will spur on the development of effective models of palliative care for developing countries, which take into consideration the uniqueness and diversities of the various peoples embodied by these nations.

GEORGIA, EASTERN EUROPE

Georgia, also known to locals as 'Sakartvelo' is located at the intersection between Europe and Asia. According to Georgian folk medicine, the word 'Medicine' is said to be derived from the name of Medea, a Georgian sorceress who knew all curative and magical herbs and was said to have helped Jason steal the Golden Fleece and fled with him to Hellada (Salukvadze 2007). Georgia's independence from the Soviet Union was in 1991 (CIA 2012a). With a population of 4.5 million of which 1.2 million people live in the Tbilisi, the majority are rural dwellers (Kordzaia 2011). About 8500 new cases of cancer have been registered in Georgia in the last 10 years (Parliament of Georgia 2011). Mortality index is 9.9 per 1000 residents, which accounts for 42 000 deaths annually (Rukhadze *et al.* 2012). By April 2012, 3245 cases of human immunodeficiency virus (HIV) infection had been registered, with about 300 of them needing palliative care. Ischaemic heart disease and cerebrovascular disease rank highest of the 10 leading causes of death in the country (CDC 2012).

Palliative care in Georgia

Attempts at integrating modern palliative care into a national healthcare system that initially comprised of preventive medicine and curative medicine began in 2000. At present, palliative care is composed of separate initiatives and different pilot programmes, without a comprehensive national structure. Levels of services offered include inpatient practice, hospice and home-based services consisting of mobile teams/brigades and rural doctors and nurses. From the period of Soviet rule up till 2008, prescribing morphine for outpatients in need of the drug was the sole responsibility of a special commission set up within each outpatient clinic, consisting of head of internal medicine department as the chairman of commission, a family practice physician and an oncologist as members. Single prescriptions for morphine were made for a maximum of 3 days only. For inpatients, prescription of morphine had no formal barriers but its administration as well as pain management in general was far below professional standards.

The years 2004–2010 saw the rapid development in the policy of palliative care in the fields of education, legisla-

tion, funding, the formation of the Georgian National Pain and Palliative Care Programme (Rukhadze & Kordzaia 2011), which was first implemented in the capital, Tbilisi and later, in other regions of the country. In addition, the Ministry of Labour, Health and Social Affairs (MLHSA) formulated a decree that included the following declarations: (1) a single opioid prescription of up to 7 days could be obtained; (2) all medical doctors (including rural doctors) would be able to prescribe opioids after passing special training course; and (3) the MLHSA, in preparation of request to the International Narcotics Control Board (INCB) for annual quota of opioids, must follow World Health Organisation (WHO) recommendation regarding ratio of different forms of morphine as well as their equi-analgesic abilities (Rukhadze & Kordzaia 2011). Fallout of this decree was the importation and availability of oral morphine with consequent improvement in and standardisation of pain management. In 2007, Georgia received funding from The Global Fund against Acquired Immune Deficiency Syndrome (AIDS), Tuberculosis (TB) and Malaria (Rukhadze & Kordzaia 2011). Within this programme, palliative care services for HIV/AIDS patients were developed and structured to cover four towns in Georgia (Tbilisi, Batumi, Kutaisi and Zugdidi) with enclosed regions.

Progress

Education has played a prominent role in advancing palliative care in Georgia (Kordzaia 2011). Prior to 2005 there was no palliative care education in the medical undergraduate and/or postgraduate programmes. In 2007, palliative care was officially approved as a subspecialty in four specialties: Internal Medicine/General Practice, General Surgery, Oncology and Critical Medicine. Between 2008 and 2010, two Georgian doctors have obtained international fellowships from the Institute of Palliative Medicine (San Diego Hospice, San Diego, USA) by the financial support of the Open Society Institute (OSI) New York, Open Society Georgia Foundation (OSGF) and the US National Institutes of Health (NIH) (Kordzaia 2011).

The present Georgian First Lady, Sandra Elisabeth Roelofs, has played a prominent role with regards to the development of palliative care in the country. In 2005, her charitable foundation, SOCO foundation, effectively funded the services of the first home-based palliative care mobile team in Tbilisi. It was this successful experience that stimulated the national organisation of both inpatients and home-based palliative care teams and their sustained financial support by government budget. The first Georgian Palliative Care Congress planned for 21–22

September 2012 in Batumi, Georgia and funded by OSGF will be held under the distinguished chairmanship of her Excellency, the First Lady of Georgia.

Currently, special courses in palliative care and pain management are implemented in the Universities for Medical education. The Education in Palliative and End-of-Life Care (EPEC) project curriculum for physicians is being translated into Georgian language. Short-term courses for general practitioners in pain and other symptom management as well as an initiative to involve psychologists and volunteers in multidisciplinary team work are being developed. Georgian-language handbooks and educational materials in palliative care are available. A new website of the Georgian National Association for Palliative Care (GNAPC) (<http://www.palliativecare.org.ge>) that includes links to online application forms to request palliative care services, access to ask-the-expert forum, online handbooks, manuals, guidelines and courses is currently updated.

Challenges and future prospects

At present, only 25% of Georgians are entitled to free palliative care services. Also several subspecialties of palliative care such as palliative care for the elderly, paediatric palliative care and palliative care for patients with resistant forms of tuberculosis, are yet to be developed. Perfection and liberalisation of legislation on drug availability, an increase in intensity and effectiveness of palliative care educational programmes for every category of healthcare worker involved as well as increase in government funding and development of palliative care in new institutions and other regions of Georgia are present concerns. A future in palliative care in Georgia is visualised where specialised palliative care services are available to everyone who needs it and consultation can be made through hotline telephone service and through the internet.

NIGERIA, WEST AFRICA

The most populous country in Africa, Nigeria is the seventh most populous country in the world with a population of approximately 170 million (CIA 2012b) and 250 ethnic groups. She also has the tenth largest oil reserve in the world of 25 billion barrels, producing over 2 million barrels per day (NAPIMS 2012). Nigeria has a rich history with its first inhabitants being the Nok people (500 BC to 200 AD) (Infoplease 2012), an annual health expenditure of about 5.8% of the gross domestic product (GDP) and a physician density of 0.395 per 1000 population (CIA 2012b).

The burden of chronic diseases like tuberculosis, sickle-cell anaemia, malaria and HIV/AIDS is enormous. In 2007, Nigeria had the fourth largest tuberculosis burden in the world (Ibrahim *et al.* 2012) and about 730 000 HIV-infected babies are born yearly (USAID 2012). Projections have been made that eight million Nigerians could have HIV/AIDS by 2012, an alarming increase from the four million citizens estimated to have been affected by the disease in 2002 (NigeriaHIVinfo.com 2006). The cancer burden is unknown majorly due to poor record-keeping and under-reporting. This is also a country with the largest unmet pain relief need in sub-Saharan Africa (Pallium India 2012) and is unable to provide enough opioids for treatment of up to 1% of its population of terminal cancer and HIV/AIDS patients (Human Rights Watch 2012). Nearly 60–70% of patients with cancer present late and more than 50% have severe pain at presentation (Adenipekun *et al.* 2005). It has been projected that by 2020, 42 million cancer cases would be in existence in the country.

Palliative care in Nigeria

This is a new and evolving practice, which, for several years prior to 2003, was powered solely by non-governmental organisations (NGOs) and missionary institutions like the Centre for Palliative Care, Nigeria (CPCN) and Hospice Nigeria, Lagos respectively. Presently, these NGOs continue to encourage government involvement in palliative care development through capacity building, advocacy, training and community development. Current palliative care services are mainly hospital-based, offering adult and paediatric inpatient and outpatient consultations, pain management, home visits and bereavement support. The major palliative care units are found in six tertiary health institutions in the country. In January 2007, the Hospice and Palliative Care Association of Nigeria (HPCAN) was formed to promote the practice of palliative care and ensure the provision of affordable and accessible palliative care to all Nigerians. Presently, HPCAN has commenced the inauguration of local chapters of the association in all the tertiary health institutions in the country to facilitate the dissemination of palliative care services in the nation. At present, there are no national policies or programmes on cancer pain relief and palliative care. Every year, a low allocation of the national budget is made to healthcare, in which there is no consideration for palliative care. There is no system in place to monitor constant opioid availability and accessibility to patients. Strict regulation on the importation of opioids exists with the National Agency for Food and Drug Administration (NAFDAC) and the Federal

Ministry of Health (FMOH) being responsible for such regulation.

Challenges

The trend of 'death denial' exists and in many tribes it is considered a taboo to speak of impending death (Onyeka 2011). In south-west Nigeria, there exist some beliefs and attitudes that encourage secrecy when illness occurs in a family (Otegbayo *et al.* 2010). Many see the origin of illness as being 'spiritual', hence they seek help with spiritualists and churches before getting proper medical care, giving rise to late presentation (Ezeome & Anarado 2007). Widespread use of traditional remedies and herbs among cancer patients in Eastern Nigeria has been established (Ezeome & Anarado 2007) and contributes to late presentation. Expression of pain varies within Nigeria. For example, parturients from the east and south of Nigeria have emotional and public display of pain during labour as opposed to the stoic northern parturient. Also, segregation of sexes in northern Nigeria owing to religious inclinations demands female patients to be seen by female doctors and this practice may pose a limitation to care of the female cancer patient in an environment without a female palliative care physician or health worker.

National medical or nursing academic curriculum for palliative care at both undergraduate and postgraduate levels is lacking and palliative care research is nascent. Significant lack of awareness of palliative care, cancer pain relief and opiophobia among health workers, policy makers and public exists (T.C. Onyeka, H.A. Ezike and E.C. Onuorah, 2013, unpublished studies). Problems of opioid unavailability, infrastructure lack and ill-equipped health-care facilities also militate against palliative care growth. The ratio of about 40 Nigerian urologists serving a 155 million population is disturbing (Beishon 2010). Oncology services are few and poorly developed, with only 10 hospitals as designated cancer centres. Seven radiotherapy centres and one brachytherapy unit, at various operational levels, serve this large population. Radiotherapy remains a costly venture for cancer patients, amidst high rates of unemployment and poverty. Influx of fake medications like anti-retroviral (ARV) drugs (Chika *et al.* 2011; PlusNews 2012) continues to be a challenge. Many essential anti-cancer drugs, modern chemotherapy treatments and consumables like parenteral nutrition continue to be either unaffordable or unavailable.

Progress

In 2008, the Consultative Committee on National Cancer Control was formed by the FMOH to create policy guide-

lines for prevention and management of cancer in Nigeria, through establishment of a 5-year Cancer Control Plan. Nigeria has an 8-year partnership with the International Atomic Energy Agency (IAEA) to ensure procurement of equipment for cancer diagnosis and treatment and training of relevant personnel. In 2011, on the World Cancer day, a pilot scheme of free human papilloma virus (HPV) vaccination of young girls against cervical cancer was launched.

Organisations like the Nigerian Cancer Society, Society of Oncology and Cancer Research of Nigeria (SOCRON), Society for the Study of Pain (SSPN) and Centre for Palliative Care Nigeria (CPCN) are in the forefront of advocacy, organising workshops, trainings and conferences in pain management and palliative care. Nigeria is currently involved in the International Haplotype Mapping Project together with other nations. Several collaborations exist between Nigerian palliative care institutions and prominent cancer bodies and institutions like the International Breast Cancer Research Foundation, Roswell Park Cancer Institute, USA (Nwogu *et al.* 2010), and MD Anderson Cancer Centre, Texas, USA. The University of Kent, UK and its sister hospices has fostered collaboration with Federal Medical Centre, Abeokuta (FMCA), which encouraged development of palliative care practice in the former, despite cultural, educational and healthcare differences (Oliver *et al.* 2011). The University College Hospital, Ibadan has just successfully introduced palliative care into its undergraduate curriculum, and other tertiary institutions are in the process of following suite. In February 2012, a 3-year collaboration between the Union for International Cancer Control (UICC) and the American Cancer Society's Global Access to Pain Relief Initiative (GAPRI) and Nigerian government to ensure provision of opioids for all Nigerians in need of it was signed and an emergency procurement of 26 kg morphine was ordered to initiate the programme (two pounds was last procured in 2008) (McNeil 2012). There is also hope for construction of 10 new cancer centres across Nigeria.

ETHIOPIA, EAST AFRICA

As the second most populous nation in sub-Saharan Africa and with a population of 80 million, Ethiopia has 82.4% of her people living in the rural areas. In addition, her health-care system is among the least developed in sub-Saharan Africa (CNHDE 2012). The FMOH of Ethiopia is poised to ensure the control and prevent NCDs and their common risk factors, and to establish a structure for effective and efficient co-ordination of activities and resource mobilisation (ICAP 2010). Widespread poverty, poor nutritional

status, low education levels and poor access to health services have contributed to the burden of ill health in Ethiopia. In addition, significant proportions of beds located within urban hospitals are occupied by AIDS patients (Alemu *et al.* 2012). In 2008, the Ethiopian FMOH conducted a situational analysis and revealed that cardiovascular disease, cancer, diabetes mellitus, renal diseases and chronic obstructive pulmonary disease in particular produce the highest burden (ICAP 2010). While chronic NCDs were originally thought to be associated with affluent societies, the epidemiological shift has given rise to an increase in NCDs in developing countries. Contrary to common perception, 80% of chronic disease deaths occur in lower- and middle-income countries where chronic diseases affect younger populations and lead to premature mortality due to lack of prevention or effective management of the diseases or their risk factors. However, the growing burden of NCDs is gaining recognition worldwide, including in Africa. In the African region, it is projected that NCDs will account for more than one-quarter of all deaths by 2015 (ICAP 2010).

Palliative care in Ethiopia and progress

Ethiopia with four other African countries was included in a WHO palliative care project in Africa between 2001 and 2002. The number of people needing palliative care was estimated to be at least 0.5% of the total population of each country based only on people needing care in the terminal stage of HIV/AIDS or cancer (Sepulveda *et al.* 2003). A preliminary estimate arrived at then showed that about 1% of the Ethiopian population needed some level of palliative care each year (Sepulveda *et al.* 2003), and this figure is expected to rise with the increasing burden of NCDs.

In 2006, palliative care was included in training for physicians in a basic ARV programme. Subsequently in 2007, a HIV-palliative care training package and pain management training package for physicians was approved by the FMOH and has commenced. Hospice Ethiopia also offers palliative care services. Also, a home- and community-based care programme, which is affiliated to local hospitals, utilises traditional burial societies known as 'idirs', volunteer caregivers and family members trained in basic nursing skills, is used to ensure the provision of palliative care to patients in their homes (Sepulveda *et al.* 2003). This programme has resulted in numerous successes including reduction of discrimination of people living with HIV/AIDS (PLWHA) and an increase in use and acceptance of voluntary testing and counselling, among others (Wube *et al.* 2010).

Challenges

Some of the greatest unmet needs of terminally ill Ethiopians are pain relief, symptom relief and drugs (Sepulveda *et al.* 2003). There are no opportunities for surgical palliation for patients in need of the latter (Gleysteen 2011). Apart from late disease presentation, stigma and discrimination of the cancer patient also limit development of the discipline. Culturally, distrust of western medicine exists in some areas. Many people and healthcare personnel such as Ethiopian doctors are unenthusiastic when it comes to discussing poor prognosis and death and therefore avoid the chronically ill and very sick patients (Sepulveda *et al.* 2003). Bearing bad news could be seen as cause of a terminal illness and labelling patients as 'terminally ill' may have harmful consequences on the patient such as isolation, and denied access to care. HIV/AIDS patients are stigmatised and many times are driven from their homes. There are limited healthcare infrastructure as well as knowledge and skills, in addition to scarce human resources (e.g. few doctors). Chemotherapy and radiotherapy are expensive ventures, access to opioids is difficult and prescribing opioids requires a special licence and a special prescription form (Human Rights Watch 2012).

Future of palliative care in Ethiopia

To improve the quality of life for Ethiopian patients with chronic debilitating illnesses, the promotion of home- and community-based care programme that addresses palliative care needs at all stages of disease and the development of simple protocols for lay people to help deliver palliative care are in progress. Advocacy for drug access and funding as well as for laws and policies relating to palliative care is greatly desired. Integration of palliative care training into curriculum (medical, residency, fellowship and nursing) is a long-term plan.

TANZANIA, EAST AFRICA

The East African nation of Tanzania covers 384 898 square miles and has 44.9 million people (TNBS 2012) with a life expectancy at birth of 53 years and 58 years for men and women respectively (WHO 2012). The burden of NCDs in Tanzania (diabetes, cancers and cardiovascular illnesses), have persistently increased partly due to the changes of the social lifestyle (WHO 2005) and are significantly fuelled by HIV/AIDS pandemic (Dagogo-Jack 2008). The WHO estimated a 40% prevalence of elevated blood pressure among Tanzanians aged 25 years and older (WHO 2012), with stroke being one of major sequelae of hypertension in

developed countries. Studies have shown similar statistics in various parts of Tanzania (Walker *et al.* 2010) and age-standardised incidences of stroke in Dar es Salaam, its capital city, is strikingly higher than most of developed countries (MOH & AMMP 1997). About 20 000 new cancer cases are seen per year (WHO 2012). The high prevalence of NCDs has put additional stress to a health-care system, which is already overstretched by relentless rising of incidences of infectious diseases. The HIV epidemic has also led to an increased prevalence of certain cancers (cervical cancers, Kaposi's sarcoma) (ter Meulen *et al.* 1992). Extensively hit by HIV and AIDS, it has been established that in 2009, 1.4 million Tanzanians had HIV/AIDS (WHO 2012) and that the prevalence rate was 5.7% in 2010 (TACAIDS 2012). The need for palliative care has also been established among 53% of Tanzanians on ARV (Collins & Harding 2007).

Palliative care in Tanzania

In 1999, the government of Tanzania realising the sufferings resulted from the double burden of both communicable and NCDs thus established the Home-based Care Services (HBCS) as a way of responding to this burden. Following the second National Multisectoral Conference on HIV/AIDS held in December 2002, Tanzania passed a resolution stating that palliative care was to be a core component of all HBCS for people living with HIV/AIDS in Tanzania and by the end of 2005, palliative care services in Tanzania were offered by four facilities throughout the country including: Selian Lutheran Hospital, Pastoral Activities and Services for People with AIDS in Dar es Salaam Archdiocese (PASADA), Ocean Road Cancer Institute (ORCI) (which happens to be the only cancer hospital in the country) and Muheza District Hospital (TPCA 2012).

Establishment of the Tanzania Palliative Care Association (TPCA) in 2004 has been a key step towards unification and strengthening of various efforts of integrating palliative care services in the Tanzanian healthcare system. Numerous efforts for expanding palliative care services were achieved through institutions' initiatives and support from various national and international agencies. In 2006, the Foundation for Hospices in sub-Saharan Africa (FHSSA), a non-profit, non-governmental organisation based in the USA received a 3-year grant 'Continuum of Care for People Living with HIV/AIDS in Tanzania' (CHAT) and more funding from the US government's President's Emergency Response to AIDS Relief (PEPFAR)'s New Partners Initiative programme (Owens 2012). FHSSA was tasked with ensuring the provision of palliative care services using rural HBCS.

Establishment of the Family-Centred Palliative Care at PASADA, decentralisation of palliative care services to 19 Evangelical Lutheran Church of Tanzania by Selian Lutheran Hospital, establishment of post graduate diploma course in palliative care at International Medical Technology University and endorsement of the palliative care policy by the government of Tanzania collectively demonstrate a clear advancement in palliative care initiatives in Tanzania. However, it is critical for these palliative care initiatives in Tanzania while evolving to adopt strategies that address the burden of both infectious and non-infectious illnesses and accounting for scarcity of resources.

Challenges

Opiophobia exists among health workers and the public. Getting a licence to administer morphine and having access to the drug remain problematic. This is worsened by the weak morphine chain supply that involves health personnel travelling long distances to collect oral morphine (Human Rights Watch 2012). Palliative care to cancer patients still remains largely unaddressed, as most funding is for HIV/AIDS. Stigma to cancer patients and PLWHA continue to exist. Poverty still remains a significant challenge to palliative care in Tanzania. Hospice and palliative care services are still largely run by missionary and non-governmental organisations.

Future of palliative care in Tanzania

Strategies that reinforce community participation have been embraced and are strongly encouraged in this context where most of the patients' families and the healthcare system are already overwhelmed by the diseases burdens. The Family-Centred Care, a PASADA palliative care initiative demonstrates the feasibility of engaging families and integration of palliative care services at all stages of patients' care. This integration allows collaboration with family members in developing an effective patient care plan. While there are still huge unexplored resources at the community level, it is anticipated that the sustained and concerted efforts of individuals, the TPCA, missionary and non-governmental organisations will propel the growth of palliative care.

CONCLUSION

Palliative care for the terminally ill patient or the patient with chronic disease condition involves a holistic approach that ensures the patient and his/her family

receives medical, psychological and spiritual care. Its practice in developing nations is hindered by several common factors. However, there are many valuable lessons that can be learned from these four nations. The efficacy of Ethiopia's home and community-based care and involvement of 'idirs', the pioneering initiative of NGOs partnering with government in Nigeria, the active involvement of family members in patient care as exemplified in Tanzania's family-centred care as well as the mobile teams for home care and the pivotal role of education as seen in Georgia are significant catalysts to the sure and steady growth of palliative care in these and other developing countries. These variations in palliative care services within these four nations, for example available resources and levels of provision, make it imperative that they and similar developing nations embrace the Budapest Commitments. The concept of the Budapest Commitments, birthed by the European Association for Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Palliative Care Alliance (WPCA) during the 10th EAPC Congress in Budapest in 2007, was developed primarily to boost development of palliative care practices in European countries but encourages the involvement of other nations outside the European continent (Fürst *et al.* 2009). It involves the

building of research networks and databases, development and implementation of courses, trainings and curricula at all levels of education, the creation of public awareness as well as funding and recognition of palliative care in the healthcare system (Fürst *et al.* 2009). This plan is committed to helping each nation define its priorities and goals for palliative care practice each year and assess successes achieved in relation to the set goals. In addition, the authors refer policymakers in developing countries, especially on the African continent, to a white paper by EAPC on the standards and norms for hospice and palliative care in Europe, which is based on recommendations for consensus over palliative care practices and standards in over 20 European countries with different healthcare systems and different cultures (Radbruch & Payne 2009, 2010), as obtains in the USA and Canada (von Gunten 2007). It is hoped that in future, through more determined and resourceful efforts from the national and international communities to develop palliative care and the collaborative effort of policymakers, healthcare professionals and all involved, a wider and more accessible palliative care coverage will be in place in all developing countries and the large disparities in palliative care provision as observed throughout the developing world would be eliminated.

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