

COLOMBIA



Geography

Colombia covers an area of 1,141,748 square kilometres delimited by Panamá on the northwest, by Venezuela and Brazil on the east and by Perú and Ecuador on the southwest^{1,2}. The country has access to both the north Pacific Ocean as well as the Caribbean Ocean and is the natural bridge between South and North America³. Through



the western half of the country, three Andean ranges run north and south. The western half of the country is a low jungle-covered plain, drained by spurs of the Amazon and Orinoco Rivers inhabited mostly by isolated tropical-forest Indian tribes. The fertile plateau and valley of the eastern range are the most densely populated parts of the country.

PALLIATIVE CARE SERVICE PROVISION

Dr. Helena Restrepo who is a consultant physician in palliative care at the National Cancer Institute in Bogotá describes the situation of palliative care within the Colombian health care system as follows:

“ it [palliative care] is recognized within the health system; this means that people can access to palliative care. And there are different models for

palliative care provision, such as outpatient care, inpatient care and home care programmes [Palliative care] is also emerging in private clinics”⁴

On the other hand, another palliative care consultant at the Santa Fe Foundation in Bogotá, Dr Jairo Moyano remarks on existing barriers to the appropriate provision of palliative care within the Colombian health care organization:

“With no doubt one of the biggest obstacles for the development of palliative care is that from a political point of view within the national health system, palliative care does not exist. That means that although a legislation that contemplates the provision of palliative care to patients exists in practice there are neither suitable places nor palliative care specialists and no political intention of giving more importance to palliative care. The government has very few palliative care centres.”⁵

Current services

Palliative care is mostly provided by hospital palliative care teams operating as specialized services within pain clinics. In this sense, Dr. Rene Rodriguez, palliative care consultant at the Social Security Institute in Cali, points out:

“It is important to note that here in Colombia most pain clinics are mixed. We care for patients with chronic pain and palliative care patients with cancer pain. I understand that many clinics in Europe are exclusively palliative care clinics; but here in our area most of them are pain and palliative care clinics”⁶

Most consolidated palliative care teams exist in Bogotá, Cali and Medellín which are the biggest and most populated cities in Colombia. One of the most developed palliative care teams in the country functions at the National Cancer Institute in Bogotá. Another very active palliative care team operates within the private sector at the ‘Santa Fe’ Foundation, also in Bogotá. In Cali, one of the most recognized palliative care team exists at the Social Security Institute which provides care for free or at very low cost to a large proportion of people leaving outside the capital city. Another important palliative care service in Cali is the one at ‘del Valle’ University Hospital. In Medellín, palliative care is provided in the area of Antioquia.

Dr Moyano outlines some difficulties that may emerge as a result of most palliative care provision being only available in main cities:

“ It is probably worthwhile mentioning that the biggest and most important [palliative care team] is the Palliative Care Unit at the National Cancer Institute; but apart from this one, there are not many more. In fact, this unit receives patients from very distant places in the country, hundreds of kilometres away; and this can give you the idea that there are not as much resources as needed in the place the patient comes from. That is one of the big difficulties”⁷

Between late 1980s and early 2004, two palliative care organizations existed outside the public hospitals; they provided palliative care at home and inpatient care for underserved social sectors. These organizations were the palliative care programme called ‘La Viga’ in Cali and the ‘Omega’ Foundation in Bogotá. For reasons of financial constraints and structural and functional problems, both organizations have

had to close down their palliative care services (in 1997, the programme in La Viga and in 2004, the Omega Foundation)⁸.

Table 1 summarizes palliative care services that currently exist in Colombia.

Table 1: Palliative Care services currently available in Colombia

City	Palliative care services	Hospital palliative care team	Home palliative care programme	Hospice
Bogotá	National Cancer Institute (<i>public service</i>)	yes	only provided in very few circumstances	not currently available in Colombia (during the 1990s, hospice and home palliative care was provided by two organizations: the 'Omega' foundation that existed in Bogotá until 2004 and the programme in 'La Viga' that operated in Cali until 1997)
	'Santa Fe' Foundation (<i>private service</i>)	yes	no	
	'San Ignacio' Hospital (<i>private service</i>)	yes	no	
Cali	Social Security Institute (<i>public service</i>)	yes	no	
	'del Valle' University Hospital (<i>public service</i>)	yes	occasional	
	FUNDALIVIO (<i>private service</i>)	medical society for the relief of pain and for the provision of palliative care (private clinic)		
Medellín	'San Vicente de Paul' Hospital (<i>public service</i>)	yes	no	

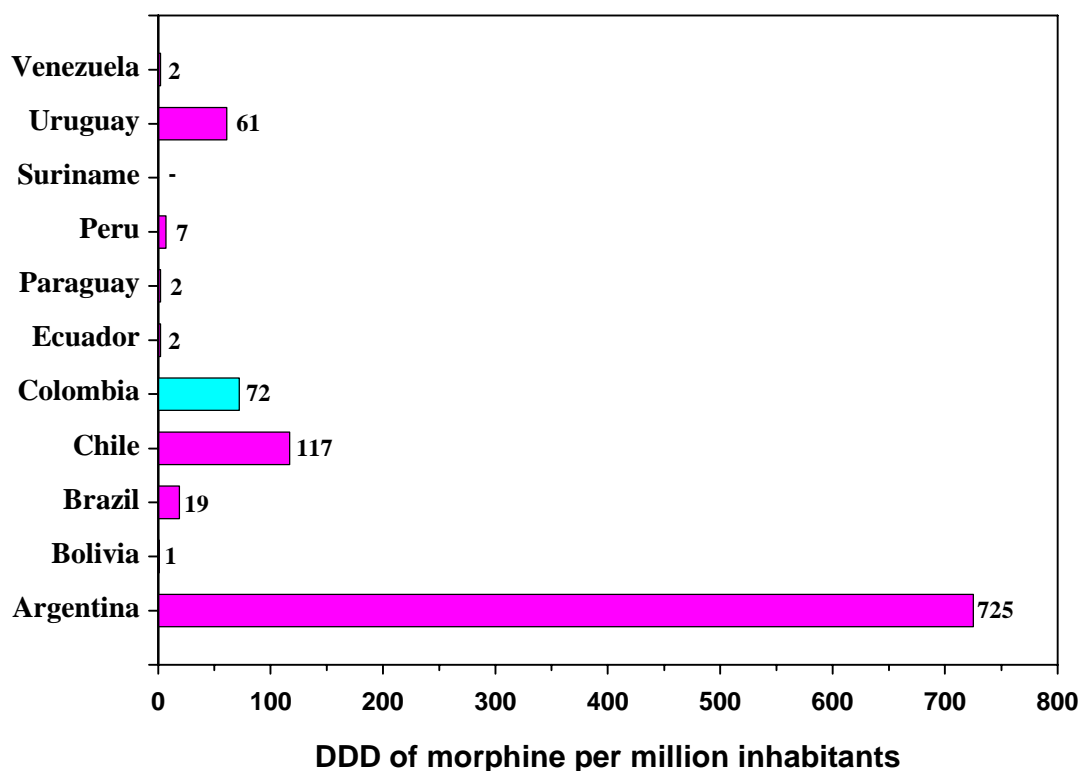
Reimbursement and funding for services

Dr Moyano gives an idea of the availability of funding for palliative care services within the Colombian health care system:

“Health insurances do not have adequate palliative care coverage, and when they do, palliative care services are very much underestimated. Although field research has demonstrated that palliative care is cost effective, health administrators’ blindness does not allow them to extend health coverage to include the provision of palliative care, including palliative home care. To give you an example, an inpatient admission to this Foundation may cost around three thousands dollars per day per patient because this is a very specialized hospital at the fourth level. When somebody shows them that the cost of three, four days of inpatient palliative care could be reduced to a tenth by providing home care, their response should be a “yes” immediately. But, the truth is different. The truth is that all health care is institutionalized.”⁹

Opioid availability and consumption

Graph 2 shows the average daily consumption of Defined Daily Doses (DDD)¹⁰ of morphine per million inhabitants during the years 1994-1998 for South American countries according to the world requirement estimates for 2000 of the International Narcotics Control Board (INCB) (Statistics for 1998)¹¹.



Graph 2. Average daily consumption of DDD of morphine per million inhabitants in countries of South America for the 1994/1998 period. Global consumption of principal narcotic drugs International Narcotics Control Board (2000) Narcotic Drugs: Estimated World Requirements for 2000. New York: United Nations.

According to these figures, Colombia is third in South America after Argentina and Chile on DDD of morphine. The average daily consumption of DDD of morphine per year has been suggested as an indicator of adequate pain relief and palliative care developments in the country¹².

In 2002, results of a nationwide survey conducted amongst Colombian medical practitioners during 1996 showed that 67% of the consulted doctors considered their education on cancer pain treatment to be insufficient; 46% identified pharmacies' poor availability of opioid as a problem for outpatients in need of the medicine; 34% found difficulties in achieving an adequate analgesic dose to control their patients'

pain; 18% considered opioid addiction to be a major problem amongst their patients and 93% judged the pain of their patients to be moderate or severe despite having received treatment¹³. According to this study, the following factors were the most influential in prescribing practices: postgraduate education, specialist training, basic medical education and personal clinical experience. In the same study, the availability of opioid for medical practice was acknowledged to be a particularly sensitive issue in a country highly affected by the illicit traffic and the black market of drugs.

Dr Restrepo describes progress made and barriers still to be overcome in making opioids more accessible to patients:

“In many cities it was very difficult [to obtain opioids] and from Bogotá [opioids] had to be sent [to other cities in the country]. But not all hospitals had the opportunity to make their opioid requests on time. In terms of opioid distribution, this has been improved. Unfortunately, concerns about illicit traffic and the misuse of these medicines have meant that suddenly we have to have further restrictions. Currently, for instance, each time a physician prescribes an opioid, the National Fund rings the doctor to confirm that such formulation was prescribed by such physician; and this makes things rather difficult for patients”¹⁴

Dr Moyano, on the other hand, describes patients’ preferences and attitudes towards the use of opioids:

“A big percentage of our patients are scared of opioid addiction despite explanations and educative campaigns. There are, for instance, and reaching almost one hundred per cent of patients, who are frightened of becoming addicted to morphine. There is a sort of “morphino-phobia” which is different from the general “opioid-phobia”. Other opioids are better tolerated, possibly because there is not much information and also because with them there is not the same historical legacy that exists with morphine. Definitively, fentanyl patches are much better accepted because they [patients] see them somewhat different, possibly because of its system of delivery”¹⁵

Dr Rene Rodríguez describes his experience as follows:

“Very often, as it is happening now, we have deficits on available opioids. At this moment, and for more or less three months now, we cannot get morphine in the city of Cali; neither hydromorphone or methadone which are the potent opioids we usually use. We have got legal problems. Morphine, for instance, can be prescribed for only ten days. And this is a very difficult issue when patients live far away from the health centre. Patients who live two or three hours from Cali have to send a relative every ten days to look for opioids”¹⁶

National and professional organisations

The Colombian Association for Palliative Care

(Asociación Colombiana de Cuidados Paliativos)

The Colombian Association for Palliative Care was created in 1996 by a group of *palliateurs*. It aims to formally represent their work in palliative care¹⁷ and to provide mutual support and encouragement amongst those working in palliative medicine. Ultimate goals of this Association are to encourage and further develop educative initiatives in palliative care for the medical community and the public in the country, and to undertake active participation in policies and governmental health care decisions. It has strong links with the Colombian Association for the Study of Pain and it has had a contributing role in developing recent governmental initiatives on the legislation of opioids.

Palliative care coverage

The most developed palliative care programmes exist in the main Colombian cities, such as:

- in Bogotá, at the National Cancer Institute. It provides outpatient and inpatient care. Members of the palliative care team also teach the principles of palliative care to undergraduate and postgraduate medical and nursing students at the private University of ‘La Sabana’
- also in Bogotá, at the ‘Santa Fe’ Foundation that provides outpatient and inpatient care

Both palliative care teams provide training opportunities for physicians and nurses

- in Antioquia, Medellin at the ‘San Vicente de Paul’ Hospital that also provides outpatient and inpatient care. It is linked to the University of Antioquia for academic support

- in Cali, at the Social Security Institute which provides outpatient and inpatient care. This clinic offers teaching and training support to medical students and training doctors

There are other palliative care services at

- the ‘San Ignacio’ Hospital, in Bogotá
- the ‘del Valle’ University Hospital and at FUNDALIVIO, in Cali

All these palliative care programmes operate as hospital palliative care teams (except for FUNDALIVIO that operates as a private clinic for pain control and palliative care).

Most palliative care teams are attached to the hospital pain clinic where palliative care is provided as another specialized service of the pain clinic. Palliative home care may be provided in very particular circumstances, but it is not formally recognized. There are no hospices in Colombia.

Dr Rodriguez describes how a hospital palliative care team works:

“We have not got a specific area for the admission of palliative care patients. Usually, cancer patients are admitted to the internal medicine ward and we are called in to act as advisors; and there are some patients who we follow during all their hospital admissions. Other types of patients are also admitted to the surgical ward, and we also go there to be [palliative care] advisors. But, we do not have a specific palliative care inpatient area”¹⁸

Table 2 shows the ratio palliative care services per million population in cities of Colombia in which the more consolidated palliative care services exist.

Table 2: Ratio palliative care services per million population

City	Ratio
Bogotá	1:2.279m
Cali	1:1.141m
Medellin	1:1.957m

Palliative care workforce capacity

Palliative care is mostly provided by medical specialists with a background in anaesthesiology, oncology or internal medicine. Nurses, psychologists, social workers and other health professionals constitute a smaller percentage. As palliative care has not been fully recognized by health care organizations, most palliative care professionals are not paid for their work in palliative care, but they do receive reimbursement for the work they do in other specializations.

Dr Restrepo gives some insight into the Colombian palliative care workforce capacity:

“At different hospitals, the possibility exists that the physician would care for the patient according to his or her medical background. Specialist palliative care is provided by specialist doctors at the National Institute which is the central model, with high complexity. Each [health professional] has her or his medical specialty at the Institute. For instance, there is an anaesthesiologist,

therapists, oncologists, family physician, clinician. We all have a basic specialization, but also we have a specialization [in palliative care]. Most palliative care, in this country at least, has emerged around the cancer patient. But we have had to make our care also available to AIDS and other chronically ill patients who have not had a definitive cure”¹⁹.

Although it has changed slightly during the twelve years of its lifespan, Dr Rodriguez describes how his palliative care team is made up:

“We have got a general physician, a psychologist, a volunteer lady. And we have the collaboration of a neurology physician and of a physician specialized in physical therapy and rehabilitation. We also have two auxiliary nurses”²⁰.

Education and training

Dr. Moyano describes the situation of palliative care education in Colombia as follows:

“[education] opportunities are scarce. There are basically ... in the big cities ... probably two ... or three places in the whole country where training in palliative care can be obtained. These are one-year programmes targeted on medical specialists in different areas; usually, most people who decide to do palliative care are anaesthesiologists or family care physicians or oncologists. Training centres in palliative care for nurses, for instance, do not exist in the country. Most of the time nurses that want to be trained in palliative care are incorporated [to the palliative care team] and in an empirical way we train

them by working alongside us. But, there is a great deficiency in specialized palliative care training centres. The two biggest programmes are ours; this is the Santa Fe de Bogotá Foundation programme; it is a one-year programme. We train two people per year: one during the first semester and the other one during the second semester. And the other programme is the one at the National Cancer Institute, which is also a one-year programme that trains two people per year, one person per semester. Undergraduate education in palliative care is also extremely poor. Some time ago we worked towards including some palliative care experience in the curriculum of advanced medicine and nursing students, but our efforts did not have any impact”²¹

HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

Narrative history of palliative care

The development of palliative care in Colombia started during the 1980s. It developed as a result of a growing interest in end of life care and in adequate pain control programmes amongst active physicians. It emerged out of two main types of initiatives: 1) private, non-profit, charitable foundations 2) hospital pain clinics.

The earliest non-profit initiatives were led by highly motivated psychologists, such as Ms Isa Fonnegra de Jaramillo who created the Omega Foundation in Bogotá, and Ms Liliana De Lima who established a palliative care programme in La Vega in Cali during the late 1980s. Both foundations aimed at providing end of life care, adequate

pain and other symptom control, as well as bereavement support to a social sector that could not access to appropriate medical care in the country at the time.

During the 1980s and 1990s, hospital pain clinics and palliative care services proliferated in Colombian main cities. Overall, they aimed to improve the management of chronic pain and the support provided to chronically ill, cancer and dying patients²². For instance, Dr Tiberio Alvarez and his team provided care for low-income patients at the pain clinic at the ‘San Vicente de Paul’ Hospital in Medellin - a teaching hospital for medical students with close links to the local private university. Dr Tiberio Alvarez established an educative programme that included a course on pain relief and palliative care for undergraduate students and published a monthly pamphlet on the treatment of terminally ill patients.

In 1986, a pain clinic at the ‘del Valle’ University Hospital emerged in Cali²³. Initially, it aimed to provide training opportunities to advanced students of psychology and to offer emotional support to chronic pain patients. Over the following five years, the demand for care increased to include terminally ill cancer patients and anaesthesiologists, pain and palliative care specialists were appointed. Since 1990, Dr Jorge Alvarez, together with other health professionals, forms a multidisciplinary team that provides palliative care to terminally ill patients referred to the pain clinic. He has also developed educative programmes on pain control and palliative care for undergraduate students of medicine, psychology and social work; for junior doctors and for geriatricians.

In 1991, Dr. Rene Rodriguez alongside other professionals formed the Pain and Palliative Care Clinic at the Social Security Service also in Cali. This service provides care and support to chronic pain and cancer patients, and to their families. It is linked to the 'Universidad Libre'. Since 1993, it provides teaching support to undergraduate students, and training opportunities to postgraduate students of anaesthesiology at the 'Universidad del Valle'. It also holds a national symposium on pain medicine and palliative care once a year.

In the early 1990s, a group of oncologists encouraged the creation of a hospital palliative care team at the pain clinic of the 'Instituto Nacional de Cancerología' (National Cancer Institute) - one of the most influential cancer centres in the country and more recently a palliative care team led by Dr. Jairo Moyano operates from the 'Fundación Santa Fe' (Santa Fe Foundation), within the private health sector²⁴.

Similar pain and palliative care initiatives emerged at the Pain Medicine section of the 'Valle del Lili' Foundation in Cali, and at the pain clinic of the 'San Ignacio' private Hospital, in Bogotá.

The first Colombian Palliative Care Congress took place in 1987 in Bogotá and it was organized by the Omega Foundation²⁵. Although the congress was successful in terms of raising medical interest, it was never repeated. Dr Sanchez Torres, a retired gynaecologist, academic and bioethicist very much involved in end life care issues in Colombia, refers to this event as follows:

“Towards the end of that year ... Omega organized the first Colombian Palliative Care Congress; its development was a complete success. However, a second congress was never organized. Why? It was because Dr. Fonnegra’s initiative was never welcomed. Probably not within the medical community, but within those [private sectors] that could use this service because it is expensive, isn’t it? For this reason, the provision of palliative care, in a holistic way, could never be consolidated”²⁶

International opportunities for training as well as moral support were crucial for starting the development of palliative care in Colombia. Dr Retrepo describes the process as follows:

“Towards the year 1994, Dr. Jairo Moyano went, for instance, to Canada [to gain palliative care knowledge]; Dr Rene Linares gained experience in Paris; Carlos Rodriguez was in Milan with Dr Ventafridda; and I myself gained knowledge at the Gregorio Marañón at the Pain and Palliative Care Unit directed by Juan Manuel Núñez Olarte [in Madrid]. As a result, we all had different experiences: Jairo came with experience gained with Eduardo Bruera, the other doctor with experience gained with Ventafridda and this group arrived in Bogotá to consolidate these experiences. There were other people working in Bogotá; in Cali [there was] Liliana De Lima and it was [as if] many things were happening at the same time. It was a movement that was emerging from more or less 1990. There are many pain units, palliative care units at the primary and secondary levels of attention in our country. And a

network has been consolidated in what we think is the way palliative care should develop in our country”²⁷

Palliative care programmes emerged mostly with very little or no support from the government. The situation of palliative care, however, seemed set for improvement following the approval of the “Ley 100” (100 Law) in 1993. According to this law, the Colombian health care system would be reformed to guarantee that the country’s entire population would perceive the benefits of adequate health care by the year 2000 and pain control was considered a patient’s right in legal terms for the first time²⁸. But, palliative and end of life care issues were very poorly defined in the documentation and strategies for practices and education on palliative care across the country failed to be established.

In 2004, palliative care is mostly provided in hospitals and exists as a specialization within pain clinics. Following the disappearance of some palliative care programmes, such as ‘La Viga’ and the ‘Omega’ Foundation that provided home care and bereavement support, most current services care for hospital palliative care out- and in-patients. In this sense, Dr Sanchez Torres observes:

“A few days ago, exactly on April 21st [2004], Omega was closed down. That means that we haven’t got palliative care services to provide holistic care in the country. When I mention ‘holistic palliative care’, I refer not only to medical care, but also to the psychological and spiritual care of patients and families. This implies specialized teams and an adequate place or centre for care. And as I said before, these types of services are expensive. ‘Holistic palliative care’ is not

included in the Colombian health care schedule. Only symptom control is offered; that is, particularly pain control²⁹

Hospice success stories /case studies

The Omega Foundation

The Omega Foundation was created by Ms. Issa Fonnegra de Jaramillo in the late 1980s as a non-profit entity to care for terminally ill patients and their families throughout the disease process and into bereavement³⁰. Motivated by a great interest in matters of dying and death, Ms Fonnegra established international links to encourage and support the creation of a multidisciplinary palliative care team at an already existing foundation named 'Pro al derecho a morir dignamente' ('For the right to die with dignity'). The Omega Foundation was established with private funds in Bogotá to look after cancer and AIDS patients in their own homes. It functioned as a palliative home care programme led by a group of psychologists very much involved in bereavement support as well as circumstances of catastrophic and violent loss. Their palliative care work was supported by medical and nursing staff.

The Omega Foundation provided free support and care to a sector of seriously ill patients that could not afford medical assistance at a time when better quality analgesia and end of life care was the privilege of only the most prosperous social sectors in Colombia. However, in order to support the continuity of the palliative care service, small fees were applied to those who could afford them and also for educative activities undertaken by the Foundation. During the 1990s and until 2000, the members of the Omega Foundation pioneered the development of a palliative care

culture in Colombia, providing knowledge and training opportunities for interested physicians, nurses and psychologists.

As a result of the 1993 law that entirely reformed the Colombian health system, the Omega Foundation was seen as a private organization outside the newly created public medical system. With no governmental support, the Foundation suffered progressive financial constraints that led to the closure of its palliative care service on April 21st 2004. It continues to provide bereavement support to families and relatives of those dying from violence and other traumas.

The palliative care programme in La Viga, Cali

This palliative care programme was created in 1989 with the aim of providing adequate symptom control and psychosocial care for cancer patients who for financial reasons were not cared for in other health care institutions in Colombia³¹.

La Viga was situated in a large green area on the periphery of the city of Cali. After 1979, it was known as the 'House of Recovery La Viga' and it was run by a congregation of Catholic nuns who looked after old people as well as tuberculosis and cancer patients. La Viga was a charity service providing humanitarian non-professional support to poor patients either while they were waiting for medical treatment at nearby hospitals or when they were dying.

In 1989, Ms Liliana De Lima together with Dr Pedro Bejarano led the development of a palliative care programme in La Viga³². Health professionals were appointed to form a multidisciplinary team to care for terminally ill cancer patients and for other

seriously ill cancer patients who were on some oncological treatment at the local university hospital. The poorest patients were looked after free of charge while most income to the programme came from charity and from those who could afford the cost of their care either privately or through their social insurances.

Over a period of seven years from its creation, the palliative care programme in La Viga looked after around 7,300 patients a year either at their home or as inpatients. It also gained recognition as a place for gaining knowledge on palliative care for undergraduate and postgraduate students in the country.

In 1994, the main difficulties faced by the programme were³³:

- financial constraints
- prejudice and misunderstandings amongst health professionals and in the community, about caring for the terminally ill
- deficient opioid availability due to severe legal restrictions
- long distances between La Viga and the city of Cali that made access to the programme difficult for families

In 1997, Ms De Lima resigned as the programme coordinator because of disagreements with managerial decisions made by the administrators of the programme. Following her departure, other professional staff also resigned, leaving the programme seriously debilitated and it was closed down some time later.^{34, 35}

The Hospital Palliative Care Team at the National Cancer Institute

This team was created in 1997 as part of the hospital pain clinic and was supported by the hospital authorities as well as by international encouragement. It constituted the first palliative care service to be available at a main public hospital that cares for most people known to suffer from cancer in the country³⁶. A group of anaesthesiologists, an oncologist, a neurosurgeon, nurses, a psychiatrist, a psychologist, a social worker and administrative staff constituted the early palliative care team that undertook clinical as well as educative duties to promote palliative care. Being a main public hospital supported by the government, this palliative care initiative was crucial in influencing more favourable policies at the Colombian Ministry of Health and due to its position as a third level reference hospital with high complexity, the palliative care team could promote pain relief and palliative care in hospitals with lower complexity and at the regional level³⁷. The development of primary and secondary regional centres was encouraged to enhance the attention given to palliative care. The main difficulties faced by this pioneering group on establishing palliative care as a medical discipline were the widespread lack of knowledge about palliative medicine amongst the medical community, patients and the public; insufficient interest in palliative care development on the part of the hospital administrators; and the absence of national political and legal frameworks for practice, leading to scarce financial, human and pharmacological resources. The hospital palliative care team at the National Cancer Institute constitutes, however, one of the most consolidated and well-recognized palliative care initiatives in the country.

Life/oral histories

The following Colombian '*palliateurs*' have been interviewed in accordance with the International Observatory on End of Life Care history programme protocol:

a) Liliana de Lima: interviewed by Silvia Paz on February 6th 2004. Interview length: 53 minutes 40 seconds.

Liliana de Lima was born in Cali, Colombia. In this interview, she describes those events in her early life that influenced her decision to get involved in palliative care and pain relief: the distress suffered by her uncle dying from a sarcoma, her sister's death in a fatal accident and her grandmother's progressive health deterioration and death from a degenerative neurological condition. Ms de Lima decided to become a psychologist and to get experience in the contribution of psychology to the control of severe acute and chronic pain. During the 1980s, she got to know about other groups of people that were working on matters of dying, death and end of life care in Colombia, such as the 'Omega' Foundation, and became very interested in further developing these ideas. She travelled to the UK to learn about hospice care. There, she found out that the programme in La Viga, in Cali, was a recognized palliative care initiative. Back home, she decided to present a more comprehensive palliative care programme to the La Viga authorities. La Viga was at that time a place run by nuns where severely ill cancer patients could stay while they were waiting for a medical appointment or if they were very close to death. In 1989, Ms de Lima's palliative care programme was accepted formally and established in 'La Viga'. The palliative care programme at 'La Viga' worked well for eight years. More than 3,300 patients per year were looked after by the programme as either inpatients or outpatients. Its further development was, however, stopped due to poor management strategies.

Ms de Lima describes aspects of the availability and accessibility of strong opioids in Colombia and in 'La Viga' at the time she was part of the palliative care team there. She also speaks about the perception of other health professionals, particularly of physicians, with regard to this palliative care initiative, and about her experience as a psychologist undertaking this challenge. She remembers that most palliative care teams in Colombia emerged out of pain clinics led by anaesthesiologists interested in pain control. Exceptions to this phenomenon were the 'Omega' Foundation and the 'La Viga' programme.

In the 1990s, Ms de Lima moved to the USA where she developed several academic activities in health care administration and in 1996, she became a member of the Pan-American Health Organization (PAHO) and worked as a research fellow at the MD Anderson Cancer Hospital in Houston, Texas. She goes on to describe the relationship between the World Health Organization (WHO) and PAHO and how the WHO's cancer pain control plan has been introduced into the PAHO programme. She also describes the circumstances in which she was appointed the executive director of the International Association for Hospice and Palliative Care (IAHPC); she mentions some activities of international relevance developed within this project, and describes other consultancy jobs in health administration which she undertakes in Colombia for a university hospital and a community care institution.

Liliana de Lima considers the allocation of resources for end of life care as well as the cost of palliative care medicines as key ethical dilemmas. Finally, she suggests that a strategy based on three aspects needs to be put in place to guarantee the future development of palliative care in Latin America: 1) comprehensive health policies, 2)

legislation for the adequate availability of opioids and 3) the insertion of palliative care as a discipline within all health organizations. She concludes with an overview of regional palliative care developments, remarking, for instance, on the progress made in Argentina and Chile and mentioning the lack of coherent effort as a crucial drawback for the development of palliative care in Colombia.

b) Issa Fonnegra de Jaramillo: interviewed by Silvia Paz on February 29th 2004. Interview length: 67 minutes 40 seconds.

Ms Fonnegra starts this interview by describing her experience working as a psychologist with children, adults and families with depression due to catastrophic situations, such as violent and accidental deaths or deaths due to natural tragedies since 1970. Looking after a dying relative in the early 1980s, Ms Fonnegra recognized a need for skills and knowledge to support patients in this situation as nobody seemed to provide this type of care in Colombia at the time. She contacted Dr Elizabeth Kübler Ross, the author of some well known books on death and dying, and spent some time with her in the USA learning about supporting dying patients. This was the start of Ms Fonnegra's involvement in palliative care. In the interview, she also speaks about her family and the way they cope with her job caring for dying people.

Ms Fonnegra describes the emergence of the 'Omega' Foundation: how the idea for the foundation emerged, the supporters and contributors to the idea, the international and local contacts, the early period in the development of the Foundation as a non-profit organization seeking to look after dying patients at home, supporting their

families throughout the disease process and afterwards, the educative role of the foundation, and its main achievements and challenges. In describing this endeavour, Ms Fonnegra gives details about Colombian social attitudes towards dying and death, and caring for the dying love one, as well as health professionals' attitudes towards multidisciplinary team work. During the 1990s, the 'Omega' Foundation had a pioneering role in bringing forward the discussion on matters of dying and death within the medical community in the country and within other health care organizations elsewhere in Latin America. However, the 'Cien' law enacted to make health care available to all social sectors in Colombia in 1993 represented a major burden to the 'Omega' Foundation which began to suffer progressive financial constraints and had to be closed as a palliative care organization in 2004. It continues to exist as a foundation orientated towards providing bereavement support to people who have suffered major losses in catastrophes and violent events.

Ms Fonnegra mentions a number of ethical dilemmas: most physicians' lack of ability to discontinue active treatments for dying patients; poor education on the ethics of end of life care for health professionals, and the lack of guidelines on caring for and on stopping treatments when appropriate, in incompetent patients. She mentions that Colombia, despite being a very Catholic country, has pioneered initiatives towards legalizing euthanasia for terminally ill patients in uncontrollable distress in Latin America. Ms Fonnegra also describes a prevailing theme concerning attitudes towards end of life communication issues among physicians: while some are capable of maintaining an open dialogue with their patients and families, many others maintain a very paternalistic attitude and tend to mistakenly identify palliative care initiatives as 'pro-euthanasia' practices.

Ms Fonnegra thinks that the adequate provision of palliative care and pain relief is very limited in Colombia, existing only among groups of interested people. Concerns about the use of morphine and other strong opioids, and Colombian society's continued exposure to violence are main barriers to palliative care developments. Finally, she mentions that palliative care is contemplated within the health sector, but because the discipline is not offered in the clinic, patients and families do not demand this type of care. She concludes by saying that her story is one of victories and disappointments (as is life) and that she carries on caring for people suffering from many losses in her clinic and doing some sort of palliative care, but not in the way that she would wish.

c) Jairo Moyano: interviewed by Silvia Paz on April 7th 2004. Interview length: 41 minutes 21 seconds.

In this interview, Dr. Moyano describes how he became a medical student, an anaesthesiologist and then a palliative care specialist, undertaking his specialist training in palliative care in Alberta, Canada. Dr Moyano reflects on his early years trying to apply his palliative care knowledge back in Colombia at a time when very little was known about the discipline in the country and many approaches were overlapping, including: acute pain control, chronic pain management and palliative care.

Dr Moyano describes major barriers to the implementation of palliative care in Colombia: the discipline is not established within the health care organization;

medical security systems do not cover the cost for the provision of palliative care; opioids are poorly accessible and available; and opportunities for palliative care education are scarce. Formal palliative care education for nurses, for instance, does not exist yet. He also describes popular and professionals' attitudes towards the use of morphine as a barrier to appropriate palliative care.

Dr Moyano mentions two main ethical dilemmas in end of life care in Colombia: first, terminal sedation is very frequently associated with the practice of euthanasia among health professionals; second, it is usually very difficult to discuss the discontinuation of artificial feeding or hydration in dying patients. He briefly describes: the debate on euthanasia and the place of palliative care within this debate in Colombia; the relevant role of the family and of religion at the end of patients' lives; the use of alternative medicines in more than 70% of palliative care patients; and difficulties in informing patients about their diagnosis and prognosis. He concludes with a positive view of the future development of palliative care in the country and in Latin America, although there is still a great need for functional and structural policies to be implemented by the relevant governments.

d) Helena Restrepo: interviewed by Silvia Paz on April 3rd 2004. Interview length: 64 minutes 22 seconds.

Dr. Restrepo studied Medicine at the University of Antioquia in Medellín in Colombia. Since her undergraduate education, she has been motivated by different aspects of cancer prevention, education and rehabilitation. Dr Restrepo describes several activities she developed in the community and with non-governmental

organizations in the area of cancer care whilst a medical student. She became an oncologist, later devoted to palliative care. Working at the Instituto Nacional de Cancerología, she found it difficult to deal with dying patients and the burden of the process in their families and decided together with other colleagues to look for training opportunities in palliative care in countries such as Canada, Italy and Spain. She describes her experience in bioethics, some educative activities she undertakes in bioethics and in end of life care ethics at the University de 'La Sabana' in Bogotá, Colombia and her role as the president of the Colombian Association for Palliative Care.

Dr. Restrepo observes that the palliative care team was formed in the mid-1990s within the pain section of the Instituto Nacional de Cancerología and that it represents one of the most consolidated palliative care teams working in public hospitals in Colombia. She outlines how the team works, its organization, challenges and achievements, and how other medical disciplines, patients and families perceive the palliative care initiative.

Dr Restrepo speaks about the provision and availability of opioids in Colombia; health authorities' attitudes towards opioid legislation and bureaucracy, and physicians', patients' and families' attitudes towards the use and the prescription of opioids. She also discusses the provision of palliative care within the health care system and a pilot project designed to provide education on palliative care to health professionals that was developed with support of the Pan-American Health Organization's (PAHO) and with national funding. However, most public hospitals where these health professionals seek to apply their skills do not have the necessary

infrastructure to provide adequate palliative care. She also describes her team's attitudes towards the use of alternative medicines by patients.

Dr Restrepo outlines her viewpoint on the euthanasia debate in Colombia and the place of palliative care in this debate. She describes the following main ethical dilemmas in end of life care in Colombia: patients' lack of accessibility to opioids; the use of patients with advanced diseases in research projects; physicians' lack of ability to determine when to stop active treatments; poor pain control education; the withholding of information from patients; and inappropriate prescription of terminal sedation. She sees religion and the family as providers of spiritual and affective support at the end of patients' lives. She concludes with a positive view on the future of palliative care in the country and the region, suggesting that major achievements have been made on the clinical and academic sides, although governmental support and strategies for implementation and education still remain very poor.

e) Rene Rodriguez: interviewed by Silvia Paz on April 26th 2004. Interview length: 37 minutes 18 seconds.

Dr Rodriguez starts this interview describing how he decided to study medicine and to become a pain and palliative care specialist. He was born in a family with very limited financial resources and it was his father's idea that his two sons should study medicine. Later, Dr Rodriguez came to see medicine as an attractive career and after completing his studies at the School of Medicine at the 'Universidad del Cauca' in Popayán, he became an anaesthesiologist at the 'Universidad del Valle' in Cali. He decided to travel to Brazil to study pain control and palliative medicine at the

‘Universidad Federal de Rio Grande do Sul’ in Porto Alegre where he obtained his specialization in palliative medicine.

Dr. Rodriguez goes on to describe his current pain and palliative care team at the Social Security Institute in Cali, looking after low income cancer patients and other adult outpatients and inpatients suffering from severe or chronic pain. This pain and palliative care service was formed in 1992 and although its structure has changed slightly over time, most of its current members have been part of the service for several years.

Dr Rodriguez describes the situation of palliative care in Colombia. In his view, lack of adequate opioid availability; insufficient physicians’ and nurses’ knowledge on the use of strong opioids, and myths on the use of morphine are major barriers to the appropriate provision of palliative care and pain control. He also thinks that governmental initiatives to overcome these problems are too scarce. As a result, the development of palliative care appears still very preliminary in the country.

He also speaks about opioid prescription and health professionals’, patients’ and families’ concerns about using opioids, in a context where fears of addiction and of speeding up death are the commonest worries. He says that the breaking of information on diagnosis and prognosis to patients and families has slightly improved since the early 1990s. In 2004, 30-40% of patients referred to palliative care know about their diagnosis and treatments.

Dr Rodriguez acknowledges the important role that religion plays at the end of patients' lives. Most patients are Christians, most of them Catholics and, for the vast majority, he finds that suffering represents a way of offering their sacrifice to their faith. He goes on to speak about the role and significance of folk medicines for patients with incurable diseases and at the end of their lives. In rural and in most underserved areas where poverty and poor education prevail, products from plants and animals are frequently used alongside orthodox medicines by the vast majority of patients.

Dr Rodriguez speaks about terminal sedation and euthanasia as issues to be discussed from an ethical perspective at the end of life and in palliative care. He says that many physicians and medical students may question the sedation of a patient in distress and suffering may result, because sedation is considered to be a practice very close to euthanasia and therefore to be avoided. The practice of euthanasia, on the other hand, has been deeply condemned in society from a Christian viewpoint although attempts to legalize it have been made in Colombia. Palliative care should be considered an alternative to euthanasia however as it seeks to relieve patients from suffering unbearable pain and other physical and emotional symptoms which are usually principal reasons for requesting euthanasia. Dr Rodriguez remembers only three patients in twelve years that have asked him for euthanasia. He finds that the discontinuation of life sustaining measures, such as hydration, nutrition and oxygen in dying patients have represented major ethical dilemmas in his experience.

Dr Rodriguez considers the future of palliative care in Colombia to be promising. He remarks on the importance of educative initiatives recently undertaken in Medellín

and in Bogotá. Although most of them are directed to medical doctors, training activities in Medellín have included psychologists and social workers as well. He also mentions the important contributions of the Colombian Association for Palliative Care and of the Latin American Association for Palliative Care to the future development of the discipline in the country and in the region. In conclusion, he suggests that international collaboration through grants, fellowships or educational visits would be extremely helpful to support education and research in palliative care in poorly resourced regions, such as Latin America.

f) Fernando Sánchez Torres: interviewed by Silvia Paz on April 30th 2004. Interview length: 34 minutes 22 seconds.

Dr Sanchez Torres was born in Bogotá. He is seventy-four years old, married for forty years and he has six daughters. He enjoys reading and painting in his free time. He mentions that the death of his mother when he was ten encouraged him to study medicine. He became a medical specialist in obstetrics and gynaecology. He focused on problems of hypertension during pregnancy and saw many female patients with cerebral-vascular accidents that became severely disabled or terminally ill. This job confronted him with many ethical dilemmas at the end of life and fostered his interest in bioethics. He has written many documents on these topics and because of his publications, he was awarded the National Medicine Prize in 1973. He has also published around one hundred scientific articles in national and international journals and eight books, two of them on medical ethics. He was Dean of the School of Medicine at the National University in 1980 and Head of the same university in 1982. He has also been a member of several national and international medical associations.

In 2000, he retired as a medical practitioner and he is currently devoted to academic activities and to his hobbies.

Dr Sanchez Torres describes how Bioethics started as a discipline in Colombia during the 1980s. As a result of the publication of a book *Bioética: puente hacia el futuro* (Bioethics: a bridge to the future) by the author Potter and of the '23 law' enacted to regulate the practice of medicine in Colombia in 1981, discussion on medical ethics was encouraged. The '23 law' was part of the Colombian Code of Medical Ethics. At that time, he became a member of an already existing foundation named *Pro Derecho a Morir Dignamente* (For the Right for Dying with Dignity) that he perceived as the appropriate scenario in which to discuss end of life issues from an ethical perspective.

The 'For the Right for Dying with Dignity' Foundation aims to protect terminally ill patients' rights, wishes and choices at the end of their lives. End of life options, such as palliative care, assisting suicide and euthanasia are frequently addressed by the foundation's members. The foundation also plays an important educative role in these issues for patients and health professionals, providing documents and guidelines for discussion and practice.

Dr. Sanchez Torres also describes the earliest palliative care activities carried out in Colombia to attract public interest in end of life care matters, such as the first Colombian Palliative Care Congress organized by the Omega Foundation in 1987. He remembers that, although, the congress was very successful because of the medical interest it promoted, the provision of *integral* [or holistic] palliative care was never supported because it implied high costs to private interested sectors. A second

congress was never encouraged. He briefly mentions that, with the disappearance of the Omega Foundation, the provision of palliative care outside hospital institutions has also disappeared.

Dr Sanchez Torres went on to describe issues related to the practice of euthanasia in Colombia. He mentions, for instance, that in 1997 the Colombian Constitutional Court declared itself in favour of euthanasia if it was practiced by a physician to a terminally ill patient suffering incontrollable pain. This law has yet to be approved by the Colombian Parliament, but the practice of euthanasia could be considered a legal act by particular juries in certain circumstances. This has caused intense discussions amongst religious and lay groups as well as within the medical community and the public. He finds that there is a growing interest in these matters and a more questioning attitude in society about life prolonging treatments and prolonged suffering.

Dr Sanchez Torres speaks about the relationship between palliative care and euthanasia as possible options at the end of life and mentions that in Colombia, palliative care is accepted and recognized as the best and ideal option in this situation. He also speaks about the lack of attention given to matters of dying and death in the medical curriculum at *all* Colombian Schools of Medicine. However, most postgraduate participants of courses at the Instituto Colombiano de Bioetica (Colombian Institute of Bioethics) have shown great interest in these issues.

Dr Sanchez Torres thinks that the demand for palliative care will grow in the future because of an increasingly older population, and its development could be

strengthened by its close links to Bioethics. In this way, a more humanitarian approach to end of life care could be achieved. He also describes issues around withholding of information to patients and the use of folk medicines at the end of life. Finally, he welcomes research activities undertaken to explore palliative and end of life care issues.

PUBLIC HEALTH CONTEXT

History

Before the arrival of the Spanish conquerors in XVI century, Colombia was inhabited by various Indian tribes^{2,3}. After a 14-year struggle with the Spanish authority, Simón Bolívar's Venezuelan troops won the battle of Boyacá in August 7th 1819. This victory led the way to the independence of Colombia from Spain in 1824.

Since its independence and throughout the first half of the 19th century, Colombia went through periods of insurrections, revolutionary pressures and brutal civil wars. In the 1950s, military governments took power aiming to restore the order in society by imposing repressive measures. During the 1960s and 1970s, Marxist groups, such as the May 19th Movement (M-19), the National Liberation Army (ELN), and the Revolutionary Armed Forces of Colombia (FARC) were organized as revolutionary forces to react against military repression and poverty.

Due to its strategic geographical position, its favourable conditions for the cultivation of opium poppies and cannabis and its increasing levels of poverty, corruption and

marginalization, Colombia became one of the international centres for illegal drug production and trafficking in the 1970s and 1980s. Drug cartels, such as the Medellín and the Cali cartels virtually controlled the country at times³⁸. In the 1990s, drug traffickers and landowners formed several paramilitary groups making of the country a public battleground sowed of bombs, killings and kidnappings. Despite being a democratic republic, Colombia's subsequent presidents have failed to control drug trafficking and corruption and to fully restore its social order³⁹.

In May 2004, the United Nations announced that Colombia's 39-year-long drug war had created a humanitarian crisis⁴⁰. Known as Internally Displaced People (IDPs), more than 2 million Colombian inhabitants had been forced to leave their homes due to violence, and several indigenous tribes were close to extinction. According to the Under-Secretary-General for Humanitarian Affairs and Emergency Relief Coordinator for the United Nations, these figures give Colombia the third biggest internally displaced crisis in the world after Congo and the Sudan⁶.

Population

Colombia is a Roman Catholic country with a population of 43,034,395 inhabitants (2001 estimates)⁴¹. The ethnicity⁴² of its population is rather diverse with mestizo (58%), white (20%), mulatto (14%), black (4%), zambo (3%) and indigenous (1%) origins. The literacy rate is 93% (2003 estimates). Spanish is its official language. Santa Fe de Bogotá (6,837,800 inhabitants) is the country's capital and largest city. Other big cities are Cali (2,283,200 inhabitants), Medellín (1,957,800 inhabitants), Barranquilla (1,330,400 inhabitants) and Cartagena (901,500 inhabitants)⁴³.

Most people live in urban areas (table 3) and the 2001 estimated growth of the Colombian population was 1.9% (table 4)

Table 3: Population structure⁴⁴ (2001 estimates)

Total population	43,034,395
(a) urban population	30,693,455
(b) rural population	12,341,939

Table 4: Population demography (%) (2001 estimates)

Annual growth rate	1.9
Crude birth rate	21.7
(a) urban area	21.6
(b) rural area	25.6
Life expectancy at birth	70.6
(a) for men	69.2
(b) for women	75.3
Crude death rate	5.9
Number of inhabitants that left their homes due to violence in 2000	308,000

According to the United Nations Development Report for 2003, Colombia is ranked 64/175 countries, with a Human Development Index of 0.779⁴⁵. This places Colombia in the medium human development ranking.

Epidemiology

Social unrest and violence in Colombia have profoundly influenced the epidemiology as well as the health indicators of the Colombian population⁴⁶.

In 1998, there were 419.9 registered deaths per 100,000 inhabitants (509.5 male and 331.4 female deaths per 100,000 inhabitants). Cardiovascular diseases represented the first cause of death (113.4) followed in second place by violence including homicide, accidents and suicide (97.0). Homicide constitutes the most important cause of death among young adults (age 15-49). Malignant diseases were in third place (61.3) and infectious diseases represented the fourth most important cause of death (37.4)⁴⁷. The 1998 mortality rate for children under the age of 5 was 336.8 per 100,000 inhabitants and acute infectious conditions represented a significant cause of death within this social sector (9.4% of these deaths were due to acute respiratory diseases and 8.9% were due to acute diarrhoea).

Over the last 50 years, Colombia has experienced a significant demographic transformation⁴⁸. Fertility, birth and child death rates have steadily decreased, life expectancy has increased and inhabitants have increasingly established in urban areas. A similar trend is observed in other Latin American countries.

Despite a growing older population and an already high incidence of malignant conditions, the provision of palliative care does not seem to represent a priority for within the Colombian health care system⁴⁹.

Health care system

In 1993, Colombian health care organization was profoundly changed as a consequence of a parliamentary law called 'Ley 100' (the '100 Law')^{50, 51}. Based on a radical alteration in the way support for health care is generated and administered, this law aimed, by 2000, to guarantee equal access to health services for the entire population independently of individuals' financial and social circumstances. According to this law, all active workers pay a standard contribution of 12% of their monthly salary (1/3 of this percentage is usually paid by the employee and 2/3 by the employer); this contribution is administered by private non-governmental decentralized organizations.

It has been reported, however, that poor communication systems, inadequate distribution of health services which are mostly concentrated in urban sectors, a low physician/inhabitant ratio of 1/1350, prohibitive costs of medicines, and a health care organization very much orientated towards cure with scarce preventive strategies have contributed to the disadvantageous situation of the poorest and the rural sectors in society that remain unable to access basic health care^{52, 53}. It has also been suggested that, as a consequence, alternative and indigenous medicines are frequently used by the more disadvantaged social groups¹⁹.

Table 4 shows total health expenditures as percentages of GDP for South American countries in 2001. Colombia is the lowest fourth after Ecuador, Perú and Bolivia.

Table 4: Total health expenditure as a percentage of GDP: countries of South America for 2001

Country	Total health expenditure as % of GDP (2001)
Uruguay	10.9
Argentina	9.5
Suriname	9.4
Paraguay	8.0
Brazil	7.6
Chile	7.0
Venezuela	6.0
Colombia	5.5
Bolivia	5.3
Peru	4.7
Ecuador	4.5

Source: WHO statistics 2000-2002

Table 5 shows the principal sources for public and private health expenditure in the country.

Table 5: Selected national health accounts indicators (2001 estimates)⁵⁴

Indicator	Value
Per capita GDP in international dollars	6,519
Total health expenditure	
Total expenditure on health as % of GDP	5.5
Public health expenditure	
General Government expenditure on health as % of total expenditure on health	65.7
Per capita government expenditure on health in international dollars	234
Sources of public health expenditure	
Social security expenditure on health as % of general government expenditure on health	25.0
Private health expenditure	
Private expenditure on health as % of total expenditure on health	34.3
Sources of private health expenditure	
Prepaid plans as % of private expenditure on health	34.8
Out-of-pocket expenditure on health as % of private expenditure on health	65.20

Source: WHO statistics 2000-2002

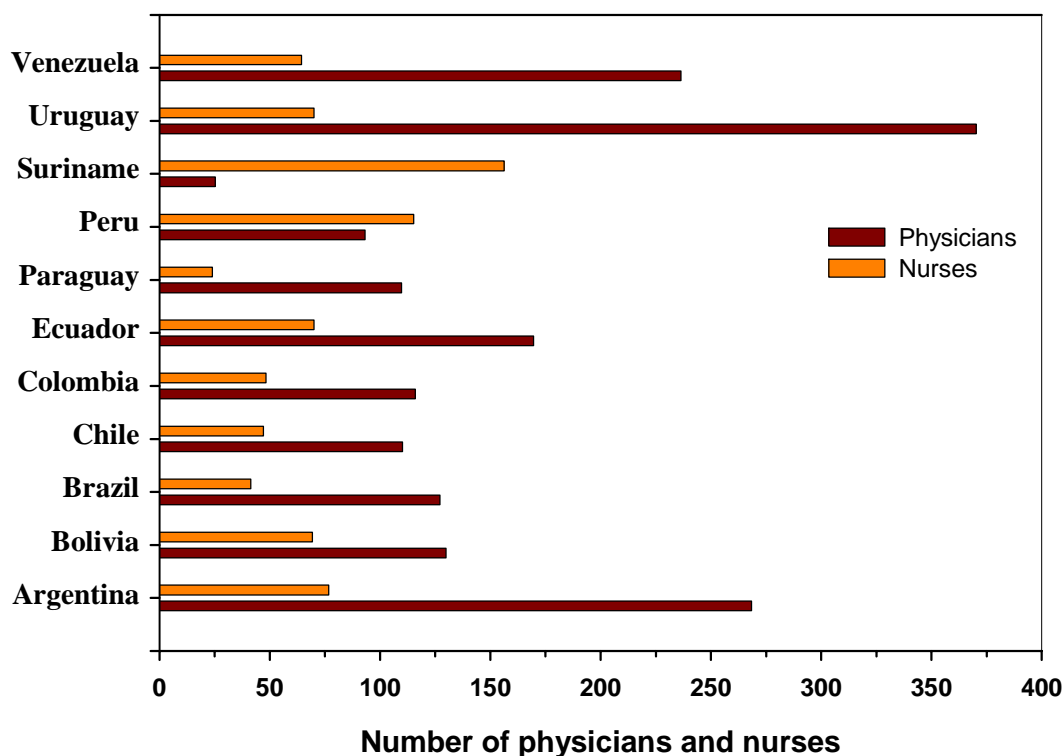
Table 6 shows that, in 2001, Colombia expended 356 Intl \$ per inhabitant on health. This figure is the seventh highest amongst eleven South American countries.

Table 6: Total health expenditure capita (Intl \$) in countries of South America, 2001

Country	Total health expenditure per capita (Intl \$, 2001)
Argentina	1,130
Uruguay	971
Chile	792
Brazil	573
Suriname	398
Venezuela	386
Colombia	356
Paraguay	332
Peru	231
Ecuador	177
Bolivia	177

Source: WHO statistics 2000-2002

In Graph 1, it is shown that there are significantly more physicians than nurses in Colombia, as in most South American countries⁵⁵. Figures for other health professionals relevant to palliative care, such as pharmacists or social workers are scarcely reported.



Graph 1. Rate of physicians and nurses per 100,000 population per year in South American countries. Source: The World Health Report 2003, WHO statistics 2002-2003

Political economy

High rates of inflation and of unemployment are major burdens to Colombia's economy (table 7)

Table 7: Summary of Colombian economic profile⁵⁶ (2002 estimates)

GDP/PPP	\$251.6 billion
GDP per capita	\$6,300
Inflation	6.2%.
Unemployment	17.4%.
Labor force (1999 estimation)	18.3 million
Natural resources:	petroleum, natural gas, coal, iron ore, nickel, gold, copper, emeralds, hydropower.
Agriculture (40%)	coffee, cut flowers, bananas, rice, tobacco, corn, sugarcane, cocoa beans, oilseed, vegetables; forest products
Industries (24%)	textiles, food processing, oil, clothing and footwear, beverages, chemicals, cement; gold, coal, emeralds

ETHICS AND ETHNOGRAPHY

Ethical issues

The following ethical concerns have been mentioned in the interviews or they can be found in the literature:

- a) lack of adequate availability, accessibility and provision of opioids to patients
- b) lack of medical skills for establishing the therapeutic or palliative scope of treatments at the end of patients' lives
- c) insufficient medical skills for adequate pain management
- d) physicians and families' conspiracy of silence and the withholding of diagnostic or prognostic information from patients
- e) the futility of medical treatments prescribed to terminally ill and dying patients
- f) lack of general agreement for prescribing palliative sedation at the end of life
- g) lack of public discussion and misunderstandings on end of life care
- h) poor legal and political frameworks and a lack of standards for practice and education at governmental levels - making for inadequate accessibility to health resources for palliative care providers
- i) lack of interest and support from local health authorities, leading to a poor recognition of the discipline and weak structures for practice and education

Issues and priorities

Dr Restrepo summarizes key priorities for the further development of palliative care in Colombia as follows:

“...there are many things that need to be changed simultaneously: on the one hand, medical education and training need to be improved; physical infrastructure as well as logistic and structural strategies to allow team work and the development of palliative care units are needed in health care institutions. On the other hand, at the governmental level, formal policies are needed to guarantee the recognition of palliative care as a medical specialization as well as the availability and accessibility of palliative care to patients”⁵⁷

Other priorities have also been suggested such as⁵⁸:

- education for pharmacists in opioid analgesia and general principles of cancer pain treatment
- drug policies to guarantee the distribution and availability of opioids and other medicines needed in palliative medicine in the countryside and small towns
- education for general practitioners and other specialties on opioid addiction, tolerance, side-effects and dependence
- education on the philosophy of palliative care for medical students

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² <http://www.infoplease.com/ipa/A0107419.html> visited in June 2004

³ <http://www.nadir.org/nadir/initiativ/agp/free/colombia/colombia.htm> visited in June 2004

⁴ IOELC interview: Helena Restrepo–3 April 2004- Length of interview minutes: 64 minutes 22 seconds

“está reconocida dentro del sistema de salud, o sea que la gente puede acceder. Y existen diferentes modelos: la atención ambulatoria, la atención hospitalizada, y los programas de atención domiciliaria.también en las clínicas privadas va existiendo”

⁵ IOELC interview: Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

“Sin duda,uno de los mayores obstáculos para el desarrollo del cuidado paliativo, es que dentro de el punto político (digámoslo así), y es que dentro de las prioridades del Sistema Nacional de Salud, el cuidado paliativo no se encuentra. Es decir, que a pesar de que haya una reglamentación, y que de cierta cabida al cuidado paliativo, en la práctica no hay ni los sitios, ni los especialistas, ni la intención política para darle mayor importancia al cuidado Paliativo...el gobierno tiene muy pocos centros de cuidados paliativos”.

⁶ IOELC interview: Rene Rodriguez–26 April 2004- Length of interview minutes: 37 minutes 18 seconds

“Es importante anotar que acá en Colombia las clínicas para alivio del dolor la mayoría son mixtas. Nosotros tratamos pacientes con dolor crónico, y tratamos pacientes con dolor por cáncer y cuidados paliativos. Tengo entendido que muchas clínicas en Europa sólo son de cuidados paliativos; pero acá en nuestra área la mayoría son de clínicas del dolor y cuidados paliativos”

⁷ IOELC interview: Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

“Valdría la pena mencionar que el más grande y el más importante es la Unidad de Cuidados Paliativos del Instituto Nacional de Cancerología, pero aparte de ese no tiene más. De hecho esta unidad ve remisiones de grandes, de sitios muy distantes del país, de centenares de kilómetros, y eso le puede dar a usted una idea de cómo no, no hay el recurso necesario en el sitio de donde proviene la persona. Esa es una de las dificultades grandes.”

⁸ IOELC interviews:

Issa Fonnegra de Jaramillo – 29 March 2004 - Length of interview 67 minutes 40 seconds

Liliana De Lima- 6 February 2004- Length of interview 53minutes 40 seconds

⁹ IOELC interview: Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

“los seguros médicos pues no tienen una cobertura adecuada, y cuando la tienen, el valor de los servicios de cuidados paliativos es muy bajo. A pesar de que ha habido... varios estudios de campo digámoslo demostrando cómo el cuidado paliativo es costo efectivo, la ceguera, por decirlo así, de los administradores de salud, no les permite ampliar la cobertura de servicios de salud al cuidado paliativo, incluyendo el cuidado paliativo domiciliario. Por decirle algo, una estancia en un hospital como la Fundación, puede costar alrededor de unos, una cama puede costar alrededor de unos tres mil, más o menos unos tres mil dólares, unos tres mil dólares diarios, ¿sí?, porque es un hospital muy especializado de cuarto nivel. Cuando uno les muestra que un paciente va a gastar uno, o dos, o tres, o cuatro días en tratamientos paliativos hospitalizados, y cómo puede reducirse a una, probablemente a una décima parte el cuidado domiciliario, pues la respuesta debería ser inmediatamente sí, hagamos cuidados paliativos, pero la verdad es otra, la verdad es que todo el cuidado está institucionalizado...”

¹⁰ Drug consumption figures are presented as numbers of DDDs per population per day for comparative purposes in drug utilization studies. In the INCB technical publications, DDD figures were calculated as the annual average dose of drug consumed, computed over 5 years, per million inhabitants in a given country’ World Health Organisation. *Achieving Balance in National Opioids Control Policy*. 2000:30

¹¹ available at <http://www.who.int/medicines/library/qsm/who-edm-qsm-2000-4/Annex%204.pdf> visited in June 2004

¹² De Lima L et al (2001) Legislation analysis according to WHO and INCB criteria on opioid availability: a comparative study of 5 countries and the state of Texas. *Health Policy* 56:99-110

¹³ Moyano J, Ruiz F, Vainio A (2002) Cancer pain management in Colombia. *European Journal of Palliative Care* 9(3): 98-101

¹⁴ IOELC interview: Helena Restrepo–3 April 2004- Length of interview minutes: 64 minutes 22 seconds

“En muchas ciudades eran muy difícil la consecución y desde Bogotá había que mandarlos. Pero no todos los hospitales tenían la posibilidad de hacer el trámite en forma oportuna. Eso es lo que se ha ganado en cuanto a distribución. Lamentablemente los temores un poco de restricciones que tiene el país como lo llamamos entre comillas, entre el narcotráfico y el mal uso de los medicamentos, han hecho que de un momento a otro tengamos que tener restricciones. En este momento por ejemplo, cada vez que un médico formula el opioide, el fondo nacional llama a verificar si esa fórmula fue expedida por el médico, lo cual dificulta enormemente a los pacientes.”

¹⁵ IOELC interview: Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

“Nuestro gran porcentaje de pacientes tienen mucho temor a la adicción a los opio-ideas, a pesar de las explicaciones y a pesar de las campañas educativas... Yo le pudiera comentar que por ejemplo hay temor a la adicción al tramadol, hay temor a la adicción a la codeína...Podría subirse muchísimo más el porcentaje llegando casi al cien por cien de los pacientes que tienen temor a la adicción a la morfina...hay una cierta morfínofobia que es diferente opio fobia en general...Otros opioides son mejor tolerados, posiblemente porque no, no hay el conocimiento o no hay la novela histórica que hay con la morfina...definitivamente los que si tienen mucha mejor aceptación, son por ejemplo los parches de fentanil, porque los ven como un poco diferentes, posiblemente por el sistema de administración.”

¹⁶ IOELC interview: Rene Rodriguez–26 April 2004- Length of interview minutes: 37 minutes 18 seconds

Nosotros tenemos con mucha frecuencia, como sucede en este momento, un déficit de disponibilidad de opioides. En este momento y desde hace más o menos unos tres meses no se consigue morfina aquí en la ciudad de Cali; tampoco hidromorfona, metadona tampoco, que son pues los opioides potentes con los que generalmente nosotros trabajamos...tenemos problemas legales como por ejemplo el de que se puede formular morfina por solamente diez días. Y esto es un punto de mucha dificultad cuando los pacientes viven muy distantes de la cabecera municipal, pacientes que viven a dos, tres horas de la ciudad de Cali, y tienen que estar enviando familiares cada diez días a que les consigan los opioides”

¹⁷ IOELC interview: Helena Restrepo–3 April 2004- Length of interview minutes: 64 minutes 22 seconds

¹⁸ IOELC interview: Rene Rodriguez–26 April 2004- Length of interview minutes: 37 minutes 18 seconds

“Nosotros no tenemos un área específica para hospitalizar pacientes de cuidados paliativos. Generalmente los pacientes que tienen cáncer son hospitalizados en el área de medicina interna, y a esta área es a donde nos llaman a nosotros como inter-consultores, y hay algunos pacientes que los seguimos a través de todas sus fases hospitalarias. Otro tipo de paciente, también son hospitalizados en el área quirúrgica, y pues allá también vamos como inter-consultores. Pero no tenemos un área específica de hospitalización de cuidados paliativos”.

¹⁹ IOELC interview: Helena Restrepo–3 April 2004- Length of interview minutes: 64 minutes 22 seconds

“Están en los diferentes hospitales la posibilidad de que el médico, en su diferente formación atiende al paciente. En cuidado paliativo está, por lo menos como el modelo central, el del Instituto Nacional, de alta complejidad, está con médicos especializados, cada uno tiene... En el Instituto por ejemplo está el anestesiólogo, rehabilitadores, oncólogos (como soy yo), médico familiar, médico internista... Todos tenemos una especialización de base, pero además tenemos la especialización...la mayoría del cuidado paliativo, en este país por lo menos, se ha ido formando alrededor de la patología del paciente con cáncer. Perotambién tengamos que abordar el paciente con SIDA, o el paciente con una enfermedad crónica que definitivamente no tiene una salida”.

²⁰ IOELC interview: Rene Rodriguez–26 April 2004- Length of interview minutes: 37 minutes 18 seconds

“Tenemos un médico general, tenemos una psicóloga...una dama voluntaria.... Y tenemos la colaboración de un médico internista neurólogo, y de una médica especialista en medicina física y de rehabilitación...además tenemos dos auxiliares de enfermería.”

²¹ IOELC interview: Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

“Las opciones son pocas. Hay básicamente, digamos en las grandes ciudades hay sitios, vamos a decir que hay alrededor de unos, probablemente dos, o si acaso tres sitios en todo el país donde se pueda adquirir la formación en cuidados paliativos. Son programas de un año y son programas diseñados para especialistas de diferentes áreas; casi siempre las personas

que optan por cuidados paliativos son especialistas o en anestesia, en medicina familiar o en oncología. Centros para formación de cuidados paliativos, para enfermeras por ejemplo no tenemos, no hay en el país un solo sitio que esté diseñado para entrenamientos en cuidados paliativos para las enfermeras. Casi siempre lo que hacemos es que las enfermeras que quieren entrenarse las vinculamos, y en forma un poco empírica las vamos entrenando a nuestro lado. Pero hay una carencia grande de centros especializados de enseñanza en cuidados paliativos. Los dos programas más grande son el programa nuestro, que es el “Programa de la Fundación Santa Fe de Bogotá”, es un programa de un año... formamos dos al año, uno por cada semestre. Y el otro programa es el del Instituto Nacional de Cancerología, que forma también dos personas al año, uno por cada semestre....En pregrado es excesivamente pobre la información que hay. En algún tiempo nosotros tratamos de, de que se incluyera, al menos una rotación muy corta cuando ya el estudiante de medicina, o la estudiante de enfermería estuvieran un poco avanzados, en una unidad de cuidados paliativos, pero realmente no tuvo ningún eco.”

²² De Lima L (1993) Colombia: Status of cancer pain and palliative care. *Journal of Pain and Symptom Management* 8(6):404-406

²³ Universidad Libre de Cali (editor) (1998) *Medicina del Dolor y Cuidados Paliativos*. Chapter: *Reseña Histórica de las Clínicas para alivio del Dolor y Cuidados Paliativos en Cali*. Cali, Universidad Libre.

²⁴ IOELC interview: Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

²⁵ IOELC interview: Fernando Sanchez Torres–30 April 2004. Interview length: 34 minutes 22 seconds

²⁶ IOELC interview: Fernando Sanchez Torres–30 April 2004. Interview length: 34 minutes 22 seconds
“A finales de ese mismo año, el año ochenta y siete Omega organizó el “Primer Congreso Colombiano de Cuidados Paliativos”, el cual se realizó con un completo éxito. Sin embargo nunca se convocó a un segundo congreso. ¿Por qué?, porque realmente esta iniciativa de la doctora Fonnegra no tuvo buen recibo. Quizás no dentro del cuerpo médico, sino de los particulares que podían utilizar este servicio, ya que se trata de algo que es costoso, ¿no? Por eso la cultura de los cuidados paliativos, suministrados en forma integral no ha logrado consolidarse.

²⁷ IOELC interview: Helena Restrepo–3 April 2004- Length of interview minutes: 64 minutes 22 seconds

“Hacia el año noventa y cuatro el doctor Jairo Moyano, se fue por ejemplo a formar a Canadá, el doctor René Linares tuvo una formación en París..., Carlos Rodríguez estuvo en Milán con el doctor Ventafrida, y yo me formé en el Gregorio Marañón en la Unidad de

Dolor y Cuidados Paliativos bajo la dirección...en ese momento estaba Juan Manuel Núñez Olarte.. Entonces fijate que teníamos como una diferente formación: Jairo venía con la formación de Eduardo Bruera, el otro con la formación de Ventafrida. Y llegó este grupo pues en lo que es en la parte de Colombia, en Bogotá, a consolidar estas experiencias. Ya habían otras personas en Bogotá trabajando. En Cali, Liliana De Lima...Y fue como una cantidad de cosas que se fueron dando... fue como un movimiento que se fue creando más o menos desde el año noventa, Existen muchas unidades de dolor, de cuidado paliativo en el nivel primario y secundario de atención en nuestro país. Y ahí se ha ido consolidando la red de lo que creemos debe ser el desarrollo del cuidado paliativo en nuestro país”

²⁸ Moyano J (1996) Colombia: status of cancer pain and palliative care. *Journal of Pain and Symptom Management* 12(2):104-105

²⁹ IOELC interview: Fernando Sanchez Torres–30 April2004. Interview length: 34 minutes 22 seconds
Hace pocos días, exactamente el veintiuno de abril se cerró Omega. Es decir, en este momento no tenemos en el país ninguna institución que ofrezca unos cuidados paliativos integrales cuando menciono “Cuidados Paliativos” integrales me refiero no sólo a la atención médica propiamente dicha, sino también a la asistencia psicológica y asistencial del enfermo y sus familiares. Entonces esto requiere conformar equipos, equipos especializados y contar con un lugar o un centro adecuado para darles asistencia. Y ya lo dije que este tipo de servicios se hacen costosos. A ver, del esquema de salud o asistencia en Colombia, no se contempla la atención paliativa integral. Sólo se ofrecen cuidados sintomáticos, es decir, particularmente en dolor.

³⁰ IOELC interview: Issa Fonnegra de Jaramillo – 29 March 2004 - Length of interview 67 minutes 40 seconds

³¹ De Lima L and Bruera E (1994) Palliative Care in Colombia: Program in “La Viga” *Journal of Palliative Care* 10(1): 42-43

³² IOELC interview: Liliana De Lima- 6 February 2004- Length of interview 53minutes 40 seconds

³³ De Lima L and Bruera E (1994) Palliative Care in Colombia: Program in “La Viga” *Journal of Palliative Care* 10(1): 42-43

³⁴ IOELC interview: Liliana De Lima- 6 February 2004- Length of interview 53minutes 40 seconds

³⁵ Universidad Libre de Cali (editor) (1998) *Medicina del Dolor y Cuidados Paliativos*. Chapter: *Reseña Histórica de las Clínicas para alivio del Dolor y Cuidados Paliativos en Cali*. Cali, Universidad Libre.

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- ³⁶ Moyano J (1999) Colombia. Letter from Colombia. *Progress in Palliative Care* 7(2): 98-99
- ³⁷ De Lima L (1993) Colombia: Status of cancer pain and palliative care. *Journal of Pain and Symptom Management* 8(6):404-406
- ³⁸ For some historical information on cocaine, a chronological review of the illegal trade of cocaine and the involvement of Colombia into this drug black market, see for instance Durlacher J (2000) *Cocaine* London, Carlton Books.
- ³⁹ <http://www.nadir.org/nadir/initiativ/agp/free/colombia/colombia.htm> visited in June 2004
- ⁴⁰ United Nations (May, 2004) *Press briefing on Colombia by emergency relief coordinator* available at <http://www.un.org/News/briefings/docs/2004/OCHABrf.doc.htm> visited in June 2004
- ⁴¹ *Situación de Salud en Colombia. Indicadores Básicos, 2001* available at <http://www.gerenciasalud.com/art42.htm> visited in June 2004
- ⁴² Some definitions:
- White*: the child whose both parents were of European origin
 - Mestizo*: the child born from a white father and an indigenous mother, or vice versa
 - Mulato*: the child born from a white father and a black mother, or vice versa
 - Zambo*: the child born from a black father and an indigenous mother, or vice versa
- ⁴³ See information available at <http://www.nadir.org/nadir/initiativ/agp/free/colombia/colombia.htm> and <http://www.infoplease.com/ipa/A0107419.html> visited in June 2004
- ⁴⁴ *Situación de Salud en Colombia. Indicadores Básicos, 2001* available at <http://www.gerenciasalud.com/art42.htm> visited in June 2004
- ⁴⁵ United Nations Development Programme 2003. Launched by the United Nations in 1990, the Human Development Index 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. Current values range from 0.944 (Norway, 1/175 countries) to 0.275 (Sierra Leone, 175/175 countries). Available via <http://www.undp.org/hdr2003> visited in June 2004
- ⁴⁶ Marina CD *Sistemas de salud en Israel y Colombia* available at <http://www.gerenciasalud.com/art157.htm> visited in June 2004

⁴⁷ *Situación de Salud en Colombia. Indicadores Básicos, 2001* available at <http://www.gerenciasalud.com/art42.htm> visited in June 2004

⁴⁸ Munar Cardozo ML *Acreditación de las EPS y el sistema de calidad de salud en Colombia y su relación beneficio-costos desde el punto de vista de los usuarios* available at <http://www.monografias.com/trabajos11/acreddeps/acreddeps.shtml> visited in June 2004

⁴⁹ IOELC interviews:

Issa Fonnegra de Jaramillo – 29 March 2004 - Length of interview 67 minutes 40 seconds

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Jairo Moyano–7 April 2004- Length of interview minutes: 41 minutes 21 seconds

Liliana De Lima- 6 February 2004- Length of interview 53minutes 40 seconds

Rene Rodriguez–26 April 2004- Length of interview minutes: 37 minutes 18 seconds

⁵⁰ Marina CD *Sistemas de salud en Israel y Colombia* available at <http://www.gerenciasalud.com/art157.htm> visited in June 2004

⁵¹ For a full description of this law, see <http://www.gerenciasalud.com/ley100colombia.htm> available only in Spanish

⁵² Marina CD *Sistemas de salud en Israel y Colombia* available at <http://www.gerenciasalud.com/art157.htm> visited in June 2004

⁵³ Munar Cardozo ML *Acreditación de las EPS y el sistema de calidad de salud en Colombia y su relación beneficio-costos desde el punto de vista de los usuarios* available at <http://www.monografias.com/trabajos11/acreddeps/acreddeps.shtml> visited in June 2004

⁵⁴ available at <http://www.who.int/country/col/en/> visited in June 2004

⁵⁵ WHO *Estimates of Health Personnel Physicians, Nurses, Midwives, Dentists and Pharmacists (around 1998)* available at http://www3.who.int/whosis/health_personnel/health_personnel.cfm visited in June 2004

⁵⁶ <http://www.infoplease.com/ipa/A0107419.html> visited in June 2004

Major sources (as referred to in the web site):

The World Factbook 2001; Center for International Research, U.S. Bureau of the Census; *The Columbia Encyclopedia*; *The World Book Encyclopedia*; *Encyclopædia Britannica*; U.S. State Department and various newspapers. Inflation is based on consumer prices

Some definitions:

Gross domestic product (GDP): the value of all goods and services produced domestically.

Purchasing power parity (PPP): the PPP method involves the use of standardized international dollar price weights, which are applied to the GDP produced in a given economy. The data derived from the PPP method provide a better comparison of economic well-being between countries than conversions at official currency exchange rates.

For a comparative table on health expenditure rates amongst South American countries, see the country report for Argentina in this web site

⁵⁷ IOELC interview: Helena Restrepo–3 April 2004- Length of interview minutes: 64 minutes 22 seconds

“...han sido muchas cosas que hay que ir cambiando en paralelo: de un lado la formación de los médicos, el preparar las instituciones para que logística, estructural, de unidad, de equipo, tengan la infraestructura física. Y también ha sido un tema muy arduo a nivel de las políticas del país para que esté realmente reglamentado como especialización, pero también con la posibilidad de que los pacientes puedan adquirir estos servicios”

⁵⁸ Moyano J, Ruiz F, Vainio A (2002) Cancer pain management in Colombia. *European Journal of Palliative Care* 9(3): 98-101