

Argentina

Argentina covers an area of 2.77 million square kilometres bordering the South Atlantic Ocean between Chile and Uruguay. It is the second-largest country in South America (after Brazil) and occupies a strategic location to the sea lanes between the South Atlantic and the South Pacific Oceans: the Strait of Magellan, Beagle Channel and Drake Passage. Cerro Aconcagua is the tallest mountain in South America, whereas the Valdes Peninsula is the lowest point on the continent.

Among a population of 37.49 million, three-quarters of the people live in urban areas. The density of the

population varies significantly. More than a third of Argentina's population live in the capital city of Buenos Aires whereas few people live in Patagonia.



According to the United Nations Development Report, 2003, Argentina is ranked 34/175 countries, with a Human Development Index 0.849.¹ This places Argentina 34/175 countries worldwide.

PALLIATIVE CARE SERVICE PROVISION

Current services

Hospice activist Gustavo de Simone, consultant in palliative care and senior lecturer at the University of “del Salvador”, says:

‘From three or four teams at the beginning of 90s, we have more than 80 teams now throughout the country; 11 of them working in paediatric palliative care.’²

Most of these services are hospital based although a small number of the more developed services also provide home care (table 1). Marta Junin, sister in palliative care, gives an account of current palliative care developments in Buenos Aires public hospitals:

‘...amongst our 33 hospitals, we have got 9 hospitals that have “developing” or “mature” teams... that is, teams that have been working in palliative care for more or less ten years... “Developing” teams are mature teams that have been re-structured...and that they are in continuous development’³

As yet, there are no free-standing hospices. Only a few of these services are multiprofessional beyond a palliative care physician and nurse.

Table 1: Palliative Care services currently available in Argentina

City	Palliative care service	Hospital palliative care team	Home palliative care programme	Palliative care unit
Buenos Aires	‘Bonorino Udaondo’ Hospital (public service)	yes	no	no
	‘Clinicas’ University Hospital (public service)	yes	no	no
	‘Garrahan’ Hospital (paediatric, public service)	yes	no	no
	‘Gutierrez’ Hospital (paediatric, public service)	yes	no	no
	‘Hostal de Malta’ home palliative care programme and day care centre (non-governmental, non-profit organization)	no	yes	no
	‘Posadas’ Hospital (paediatric, public service)	yes	no	no
	‘Roffo’ University Cancer Institute (public service)	yes	no	no
	‘Tornu’ Hospital (public service)	no	no	yes
	‘Valdomero Sommer’ Hospital (it also offers ‘distance care’) (public service)	no	no	yes
Cordoba	‘San Roque’ Hospital (public service)	yes	no	no
Neuquen	‘General’ Hospital (public service)	yes	yes	no
Mar del Plata	Community Private Hospital (private service)	yes	yes	no
Rosario	Private palliative care centre (private service)	no	yes	no
San Nicolas	Pain and palliative care centre (non-governmental, organization)	no	yes	no

Reimbursement and funding for services

Palliative care is not recognized as a medical specialty in Argentina. As a result, most financial resources come from non-governmental organizations and most health professionals work on a voluntary basis.

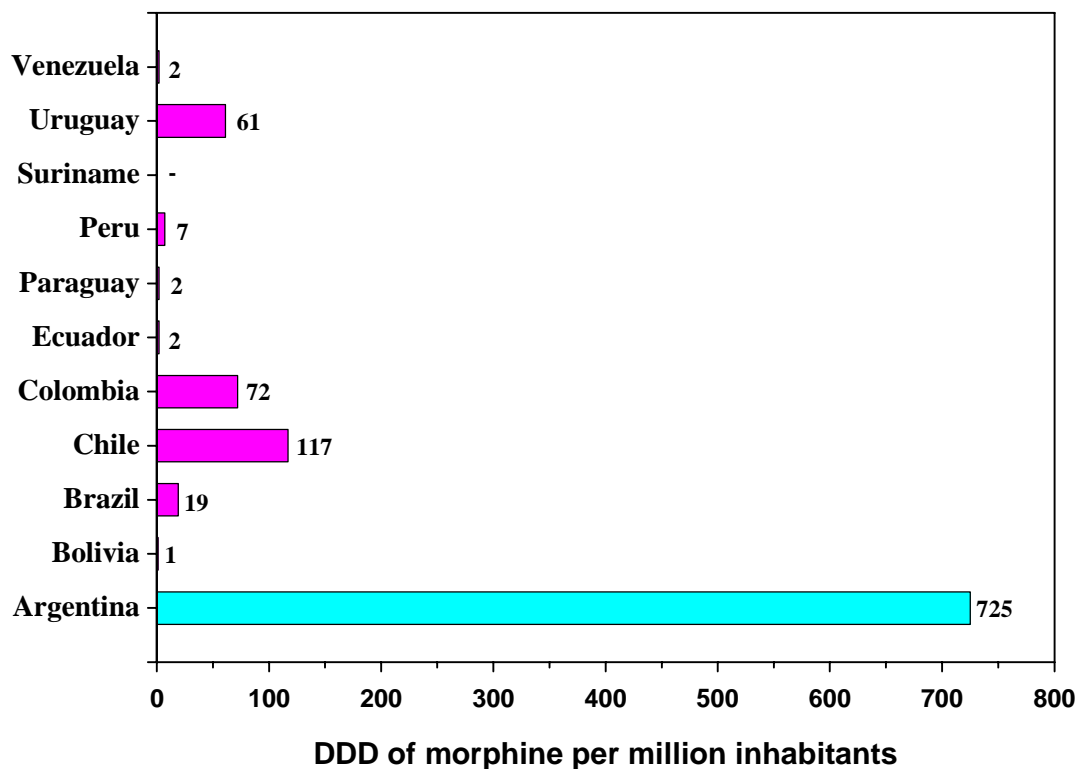
During the second half of 2004, efforts have been made in the context of the Argentinean Association for Medicine and Palliative Care (AAMyCP) towards obtaining official recognition and professional certification in palliative care for physicians and social workers⁴.

Opioid availability and consumption

Although opioid consumption increased in Argentina during the 1990s, opioids generally remain *available* but *inaccessible* within palliative care. From 1991-2 morphine prices doubled.⁵

Between 1994 and 1998 the consumption of codeine rose from 141 kilos to 373 kilos; pethidine consumption rose from 32 to 39 kilos (though only 4 kilos were consumed in 1997), and morphine consumption rose from 41 kilos to 504 kilos.

In the same period, the average number of defined daily doses⁶ of morphine consumed in Argentina was 725; this compares with 117 in Chile; 61 in Uruguay; and 3 in Ecuador (Graph 1).⁷



Graph 1. Average daily consumption of defined daily doses (DDD) of morphine per million inhabitants: countries of South America 1994-1998 - Source - International Narcotics Control Board (2000) Narcotic Drugs: Estimated World Requirements for 2000. Statistics for 1998. New York: United Nations.

National and professional organisations

In 1991, Pallium Latinoamerica emerged out of an earlier and similar initiative developed in La Plata to structure and organize palliative care education and training in the country.⁸ The Pallium website⁹ gives a history of palliative care in Argentina, together with details of education and research opportunities.

The Argentinean Association for Medicine and Palliative Care (AAMPC) was established in 1994. The AAMPC website¹⁰ includes:

~*Boletín Científico* (Scientific Bulletin) - a monthly release that covers clinical, ethical and educational topics directed towards a wide audience of palliative care professionals.

~*Normas - Legislación* (Rules - Legislation) outlining the legislative framework that regulates palliative care and the use of opioids

Links have been created with the International Association for Hospice and Palliative Care (IAHPC)¹¹

In October 2004, the AAMyPC announced the creation of a National Directory of Palliative Care aiming at systematically recording palliative care initiatives developed countrywide¹².

Palliative care coverage

Although around 80 teams provide palliative care in Argentina, only a few of them offer a wide range of services. Palliative care coverage across the country is mixed. In the metropolitan area of Buenos Aires the majority of services are available in hospitals and at home – most of them underpinned by good bereavement support and specialist training for health professionals. In some areas, palliative care is unavailable.

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

Table 2: Ratio palliative care services per million population

City	Ratio
Buenos Aires (including paediatric and adult services)	1:1.453m
Cordoba	1:1.486m
Mar del Plata	1:0.683m
Neuquen	1:0.392m
Rosario	1:1.277m

Palliative care workforce capacity

Most palliative care professionals work on a part-time basis; some are paid, others receive no salary. Dr Gustavo de Simone points out:

‘...there are yet not (governmental) funds allocated to the implementation of palliative care and this is a problem yet to be solved’¹³

Marta Junin describes the situation of staff nurses working in palliative care in public hospitals in Buenos Aires city:

‘situations we find in relation with nurses working in palliative care in our public hospitals in Buenos Aires are different...there some, very few...probably...five nurses...working full time in palliative care ...and I am including the University hospitals’¹⁴

Volunteers’ role appears very relevant for providing care support. For instance, Dr. Roberto Wenk, consultant in palliative care, describes his experience as follows:

‘I am a defender of voluntary work...we have been training our volunteers for some time now on assessing symptoms and on the semi-structured evaluation of symptoms...this speeds up the consultation time enormously’¹⁵

Education and training

Most palliative care teams provide specialist education; some ‘palliateurs’ teach in universities and medical organizations at the post-graduate level. Programmes currently operate in the cities of Rosario and Buenos Aires.

Full and part time training programmes emphasise the ‘hands on’ approach to palliative care. Specialist and multidisciplinary distance courses originate from Buenos Aires, some of them accredited by universities through the award of a diploma. Participants are required to have previous clinical experience. Physicians, nurses, social workers and psychologists are encouraged to join multi-professional teams, with small or newly-established teams receiving continuous support from the more developed education programmes.

As health professionals from Argentina and other South American countries participate in these programmes, such initiatives impact at both local and regional levels. Courses, symposia and workshops are held several times a year. Grants are scarce and students are usually self-funding - although some British organisations have recently supported students seeking training in Argentina. Undergraduate training in palliative medicine is unavailable.

The numbers of students undertaking basic and advanced courses at the Pallium Latinoamerica study centre are shown in Tables 3, 4 and 5 below.

Table 3: Number and origin of students attending the basic course at the Pallium Latinoamerica study centre, 1993-2001

	1993	1994	1995	1996	1997	1998	1999	2000	2001	Total
Buenos Aires	34	26	28	39	42	23	32	46	53	323
Cordoba						14				14
Patagonia							21		26	47
Curitiba (Brazil)							31			31
Londrina (Brazil)									24	24
Grand total (students)										439

Source: de Simone¹⁶

Table 4: Breakdown by profession of students attending the basic course at the Pallium Latinoamerican study centre, 1993-2001

	Doctors	Psychologists	Nurses	Social Workers	Others
Students	52%	22%	14%	8%	4%

Source: de Simone¹⁰

Table 5: Number and origin of students attending the advanced course (uniprofessional + multiprofessional) at the Pallium Latinoamerica study centre, 1993-2001

	1993/4	1994/5	1995/6	1996/7	1997/7	1998/9	1999/0	2000/1	2001/2	Total
Doctors	5	8	13	16	24	20	21	21	25	153
Nurses		1	2	3	4	5	4	5	7	31
Psycho-social staff	1	2	4	15	8	9	13	12	8	72
Grand total (students)										256

Source: de Simone¹⁰

The first library specialising in palliative care and psycho-oncology has been established by Pallium Latinoamerica. With over 170 books and palliative medicine

journals in English and Spanish, it represents a valuable source of information for community and other health professionals.

Marta Junin describes training courses available for nurses interested in palliative care:

‘In nursing, we have got training opportunities through the Department of Capacitation of the Government of the city of Buenos Aires. They are free courses...everybody interested can attend. Approximately, five courses are organized during the year ...for auxiliary and professional nurses. There is also post graduate training ...and advanced courses are available at palliative care study centres. For undergraduate nursing students, we have got 25 teaching hours allocated within the nurses’ syllabus...’¹⁷

During these courses, nurses are taught about the principles and philosophy of palliative care, the use of morphine and other strong opioids, pain assessment and documentation and how to break bad news to patients and families.

With the aim of raising health professionals’ awareness and knowledge of palliative care, trained nurses and doctors undertake teaching activities at several public hospitals in Buenos Aires. Each palliative care programme also provides opportunities to interested health professionals for palliative care education.^{4,12,14,21}

Since July 2004, the AAMyCP has encouraged the development of research initiatives countrywide through the creation of a Cooperative National Group on Palliative Care Research (Grupo Nacional Cooperativo de Investigacion en Cuidados Paliativos). It

aims at fostering the participation of palliative care professionals working in different regions of the country on different research projects¹⁸.

HISTORY AND DEVELOPMENT OF PALLIATIVE CARE

Narrative history of palliative care

The development of palliative care in Argentina began with a small number of practitioners working with terminally ill patients during the 1980s¹⁹ which coincided with the beginnings of a democracy and the ending of years of violence. Progress, however, was slow, due largely to financial constraints. Eduardo Bruera:

‘Unfortunately, the evolution of palliative care in Latin America has been extremely slow because things change slower there because there's not enough money, because education costs money. And if there is no money, you don't have education, and so medical/ nursing education, and other disciplines, goes generally slower in those areas. What we have learned...is that the ladder or organisation, and command in the Third World in general, but specifically Latin America, unfortunately is not reliable. And so the changes need to be bottom-up.’²⁰

Two events were crucial. In San Nicolas - a city with 150,000 inhabitants – the anaesthetist Roberto Wenk established the Argentinean Programme in Palliative Medicine to provide palliative home care for seriously ill cancer patients. In Buenos Aires, a multidisciplinary team working at the Prager-Bild Foundation began a

palliative care programme that emphasised professional education and academic activity.

Both of these projects developed outside of the existing health system and prompted other initiatives. By the close of the 1980s, activists in major cities were exploring ways to provide and develop palliative care. Eventually, the first palliative care unit was established at the 'Hospital Privado de la Comunidad de Mar del Plata', located on the Atlantic coast around 400km south of Buenos Aires.

In 1988, a small number of practitioners founded Pallium, a palliative care program that provided hospital based-care to terminally ill patients and education to health professionals. Since its origin, this program has been based at the 'Bonorino Udaondo' National Hospital. Its distinctive characteristic has been a close and collaborative relationship built between the oncology department and palliative care services.³

During these early stages, support from the international community was invaluable. Advice on educational, philosophical and organizational issues was sought from experienced palliateurs in the United Kingdom and the United States. Once links were established, physicians and nurses gained opportunities to receive palliative care experience in more developed services/ programmes outside of Argentina.

In 1991, the first palliative care meeting in Latin American took place in San Nicolas. Encouraged by Eduardo Bruera, this meeting took the decision to found a national association. By 1993, twenty teams - made up of a physician, a nurse, a psychologist

and (occasionally) a social worker - were reported to provide palliative care in 14 Argentinean cities. In 1994, the Argentinean Association for Medicine and Palliative Care (AAMPC) was created to bring these initiatives together and give them formal representation.

As the 1990s drew to a close, two multidisciplinary palliative care programmes began in Buenos Aires: PALLIUM Latinoamerica and the Tornú Hospital-FEMEBA Foundation palliative care unit. These were charitable, non-government organisations, designed to provide clinical care to hospital inpatients and outpatients. Pallium Latinoamerica also established strong university links and developed post-graduate training courses at local and regional levels.

In 1999, the Argentinean Ministry of Health invited a number of health-related institutions to form an advisory committee to draft national standards for palliative care. In keeping with these standards, palliative care services would be organised on three levels and patients would be referred to an appropriate service according to their needs. The standards were approved in August 2000, whereupon palliative care was recognised as a medical discipline which should be available at all levels of the health care system. Accompanying legislation emphasised the importance of adequate analgesic provision. Currently, however, the legal and political frameworks designed to support palliative care remain poorly defined; operational standards have failed to be implemented; and national palliative care provision has yet to be achieved.

Hospice success stories /case studies

Among the 80 palliative care teams working in Argentina, the following are particularly significant²¹:

- a) In Buenos Aires city
 - The Tornú Hospital-FEMEBA Foundation Palliative Care Unit provides inpatient beds, an outpatient clinic and limited home care; approximately 350 patients are seen each year
 - PALLIUM Latinoamerica and the ‘Hostal de Malta’ palliative care program provides home care, inpatient and outpatient care (in public and university hospitals), bereavement support and day care (having previously established the first day care centre in Argentina)

- b) In Buenos Aires county
 - Well developed services exist in San Nicolas, General Rodriguez and in Mar del Plata

- c) Other cities:
 - Rosario, Tierra del Fuego, Cordoba, Mendoza and Neuquen – major cities within other counties.

In the following extract, Jorge Eisenclas, consultant in palliative care and lecturer at the University of “del Salvador” in Buenos Aires gives an insight into the operation of a palliative care service in Buenos Aires:

‘We are a team, a multidisciplinary team. We are doctors, nurses and social workers, psychologists, and voluntaries - volunteers, you say? So we have a centre for operations which a day centre works there too...people come to us by phone; they get in touch, or people come from the hospital too...those which are quite frail, we go to their house, to their homes, mainly we have permanent telephone contact and the doctor and nurses visit the patients at home. We see the patient once a week, twice a week, well it depends on the necessity, yes? And families will into the day centre too; and we go out of the day centre with a bereavement support programme. So we have been working in this project from last April - so it’s quite new, but really it’s working and all of us are very happy with what is happening there.’²²

Dr Roberto Wenk, consultant in palliative care, speaks about the organization of a palliative care unit in Buenos Aires:

‘ it is a unit that has six palliative care beds, with activity twenty-four hours seven days a week and personnel trained in palliative care ...it has a small teaching area and a small area where we conduct some research...It has three outpatient clinics, a room for families...From a clinical care perspective, it has a limited impact because we have got a small capacity to look after patients at home...17-20% of deaths occur at home, most deaths happen in the unit...the only patients we see at home are those living in the neighbourhood...This unit has been approved by the health authorities as a place for teaching and training in palliative care for junior doctors. This represents a very important achievement in palliative care ...95% of our patients are cancer patients...The

number of patients we cared for is around twenty patients...the other fourteen-fifteen patients are in beds allocated to palliative care in the main hospital...One of the problems we have got is that most of our patients...stay very long in hospital because of social and financial factors, not because of medical problems...[beds turn-over is very slow]...This problem has been contemplated at the other unit, the unit at the “Somer” hospital where we have got sixteen beds...we have got eight beds for acute patients and eight beds for chronic patients...patients with no financial resources or social support...”²³

Dr Manzini, consultant in palliative care and interested in the ethics of end of life care describes a palliative home care programme in Mar del Plata:

‘...the palliative care team, PADES, comprises physicians, nurses, social workers and secretarial support. This is the basic nucleus of the team. It has also support from other hospital services such as physiotherapists and other specialized services...I am the assessor of the team...currently there must be around 30-40 patients cared for at home...these patients are visited at home twice a day by a nurse...At the hospital we shared the internal medicine inpatients ward. There is not a specialist ward [allocated to palliative care in the main hospital]’²⁴

Elena D’Urbano describes her job as a social worker in a palliative home care plan and at the “Hostal de Malta” day care centre in Buenos Aires city:

‘In the home care plan my job comprises the admission interviews, conducted with family members...I assess families’ situations to look after the patient at home ... I establish a pact with them on what we are going to offer them and what is their compromise...It represents like the gate way for the team...I am also the person who follows up families ...and I provide bereavement support to them when they requested it or when we identify relatives in need of this help...I am also the coordinator of the activities at the day care centre ...The day care centre is in fact a strongly social orientated activity in which patients can spent several hours three times a week and where we carry out social activities with therapeutic aims. Patients take part on different activities...we trained volunteers...some of them with special abilities...and we use body techniques such as massage, reflexology, Rei Ki, yoga as well as artistic activities such as painting, music; we try to use techniques useful to the more fragile patients. It is a very interesting job... patients are encouraged to work with the disease, without denying the process of illness, to prepare for the future and to accept their present situation ...’²⁵

Life/oral histories

The following Argentinean ‘palliateurs’ have been interviewed in accordance with the IOELC’s Hospice History Programme protocol:

- a) Eduardo Bruera – interviewed by David Clark, 9 November 1995. Length of interview: 45 minutes

Summary of interview

Eduardo Bruera was born in Argentina in 1955, and in this interview, tells how his family tree reaches to Ireland through his mother and to Italy via his father. The son of a cardiologist, he went to medical school in Rosario, and gained his MD in 1979. Eduardo Bruera then moved to Buenos Aires for further training, and qualified in internal medicine and medical oncology in 1984. It was during this residency training that Eduardo Bruera noted the need of terminal cancer patients for symptom control and supportive care. However, despite finding other sympathetic medical students and publishing material himself in the US medical press, there were no posts in palliative care in Argentina, and he moved to Canada to pursue his interest. In 1984 Eduardo Bruera began a Fellowship in supportive care at the National Cancer Institute of Canada at the University of Alberta, and by 1988 had become the Director of the Palliative Care Programme in Edmonton, Alberta. This was a clinical and academic post, and Eduardo Bruera goes on to talk about education and research, as well as the reactions of local clinicians, the handover from pioneers of hospice to a second generation, and developments in Canada compared to those in Britain. Turning to Argentina, Eduardo Bruera draws attention to the difficulties caused by financial constraints and weak organisational systems and tells how the necessary changes must be 'bottom up'. For this reason, he considers that volunteers play a crucial role which eventually makes change irresistible. In 1993 Eduardo Bruera became Canada's second Professor of Palliative Medicine.

- b) Jorge Eisenclas, interviewed by Michelle Winslow on 2 October 2001 at Trent Palliative Care Centre, Sheffield, UK

Summary of interview

Jorge Eisenclas speaks first of his family tree: of his mother from Argentina and his father from Chile; of his paternal grandparents from Poland and his maternal grandparents from Austria. Such ancestry is emblematic of the Argentinean population, most of whom can trace their forebears to the countries of Europe – frequently Italy or Spain. In keeping with most Argentinean boys, Jorge Eisenclas dreamed of becoming a footballer but eventually pursued a career in medicine and focused on oncology. Eventually, he began to question the exclusively medical and curative attitude towards illness, and sought a broader approach by studying philosophy and psychoanalysis. When he heard of the work of Gustavo de Simone, he undertook the palliative medicine course being pioneered in Argentina - and subsequently became a member of Gustavo de Simone's palliative care team. Jorge Eisenclas speaks of the barriers faced by palliative care and tells how the Roman Catholic Church has offered unflinching support and challenged the taboos around death and dying. Although free-standing hospices are not found in Argentina, hospital services are increasing and home care is beginning to gain ground. These developments are supported by multidisciplinary teams which include doctors, nurses, social workers, psychologists and volunteers. Jorge Eisenclas closes the interview by reflecting upon the important contributions of Rubin Bild, Gustavo de Simone and Eduardo Bruera to the palliative care movement in Argentina.

- c) Gustavo de Simone – interviewed by Michael Wright, 2 April 2003 during the 7th Congress of the European Association of Palliative Care at The Hague, Netherlands. Length of interview: 36 minutes

Summary of interview

In this interview, Gustavo de Simone speaks of his training as a medical oncologist and recalls how he subsequently met a patient with advanced cancer while on national service in Patagonia. Coincidentally, a travelling bookseller sold him a copy of *Care of Advanced Malignant Disease* by Cicely Saunders which made an immediate impact upon his attitudes and practice. On his return to Buenos Aires, he joined the Bild Foundation, where he broadened his interests and became influenced by the Argentinean doctor, Eduardo Bruera and by the UK-based doctors Robert Twycross, Geoffrey Hanks and Andrew Hoy. In 1989, his work was extended to include a 'comprehensive cancer centre' in La Plata which allowed him to further develop his palliative care interests. In 1990, he became a founder member of the first palliative care association in Argentina. During the following decade, he honed his palliative care skills in London, Oxford and Leicester and undertook the Cardiff diploma course led by Ilora Finlay. On completion, he collaborated with Professor Mainetti and the Faculty of Medicine at La Plata University to establish Pallium Latinoamerica; a non governmental organisation which focuses on palliative care education. Alongside these innovations, Gustavo de Simone identifies three distinct phases in palliative care development 1) the mid-1980s to mid-1990s - a period of the isolated pioneers 2) the mid-1990s to 2000 - a time of palliative care growth and spread 3) 2000 onwards - a period of political and medical recognition. As the interview draws to a close, Gustavo de Simone acknowledges the palliative care advances in Argentina: the improvements in pain relief, the development of teamwork and the growth in public awareness. Despite these developments, however, there is a pressing need for the

implementation of government policy, for accessibility to morphine; and for improved levels of funding.

Gustavo De Simone interviewed by Silvia Paz, 23 December 2003 in Buenos Aires. Length of interview: 65 minutes 21 seconds

Summary of interview

Dr De Simone's personal history was outlined during his previous interview with Dr. Michael Wright. In this interview, more specific issues, such as the 'Hostal de Malta' palliative care programme, ethical aspects of the end of life care in Argentina and opioids availability are explored.

Dr De Simone starts this interview describing the circumstances in which the 'Hostal de Malta' palliative care programme was developed as an initiative of two non-governmental organizations that brought their efforts together: the 'Asociación Argentina de Caballeros de la Orden de Malta' and the 'Asociación Pallium Latinoamerica' towards the end of 2000. They are both civil associations based in the city of Buenos Aires. The 'Asociación Argentina de Caballeros de la Orden de Malta' offered financial support and 'Pallium Latinoamerica' add the palliative care expertise, knowledge and skills to implement the programme. The 'Hostal de Malta' palliative care programme operates at a big house in the neighbourhood of Palermo Viejo in Buenos Aires. This house is a private property of Dr. De Simone's family. His family agreed for the house to be used as the space in which to run the programme. The programme offered home palliative care, bereavement support to

patients and families, a day care centre and it also serve to run different educative and training activities for health professionals and voluntaries. Around twenty patients are care for at home by the palliative care programme in the city of Buenos Aires with three million inhabitants. Dr De Simone remarks that although the programme represent a very interesting and innovative initiative, it remains highly insufficient. He went on to describe how the programme operates and to mention some figures that summarize the first two years of experience. For instance, 250 patients have been cared for since the beginning of the programme; 85% of them died at home; 16% required terminal sedation and the majority of the patients could stay at home with their symptoms controlled until death. Dr De Simone also gives details of the day care centre activities and of its organization. He emphasizes that the aim of this initiative is to generate an enjoyable space for patients giving prominence to creative activities. These activities are coordinated by the social worker Ms. Elena D'Urbano together with a group of volunteers and a psychologist who aid running it.

Dr De Simone mentions that there is still an significant proportion of oncologists who do not seem to accept this initiative easily; not only the 'Hostal de Malta' programme and the day care centre activities, but palliative care as a discipline in general. He describes several reasons that may explain this resistive attitude. Dr De Simone recalls that, on the hand, the neighbourhood has positively received the creation of the centre in the community and he thinks that it has also helped to bring themes on dying, death and suffering into the community in a more unprejudiced way; it is if as it has opened the dialog on these issues emphasising the importance of quality at the end of life. He says that, nevertheless, it remains difficult to bring discussions on end of life issues into the Argentinean society as a whole.

Dr. De Simone outlines what he thinks have been the main opportunities for the development of palliative care in Argentina, such as the increasing number of health professionals interested in the discipline; increasing opportunities for training; increasing interest to discuss end of life issues in the media that brings these topics into public awareness; slow and progressive recognition and acceptance of palliative care as a specialized discipline in the medical community, especially amongst geriatricians and neurologists; excellent links with well established groups in developed nations that represent opportunities for updated training and education. He thinks that, in the Argentinean culture, there is always a tendency to perceive that initiatives coming from abroad to be better than own experiences. He points out that there are still huge dissimilarities between what is said and what is done in practical terms by the national health ministry. Although palliative care has been legally recognized within the national health service and principles for its implementation have been agreed, no governmental funding is devoted to palliative care yet. He recalls that there is a need for rationalizing the country's expenditures in all social sectors and palliative care may be seen as a way for providing adequate care to seriously ill patients at a comparatively lower cost and this may represent an opportunity for obtaining truly effective palliative care support. He thinks that the country's recent financial crisis has brought to many people consciousness a sense of limitation and has made them think about suffering and constraints in a country usually characterized for unlimited expenditures. In this circumstance, palliative care is a better accepted option and end of life topics have become talkative themes and not "taboo" as they were twenty years ago.

Dr De Simone describes the situation of palliative care services in public hospitals in the city of Buenos Aires. There are thirty three public hospitals in Buenos Aires, only four of them – and three paediatric hospitals- have consolidated palliative care teams. There is no home palliative care and the figure of a General Practitioner (GP) is unusual except for those people who can pay a private medical service. He also briefly describes the availability of palliative care for HIV/AIDS patients. He says that most HIV/AIDS specialists form teams that help on communication and psycho-social aspects, but failed to build up a proper palliative care team profile that should include symptoms control. Most AIDS patients remain care for the specialist and the support team.

Dr. De Simone went on to describe educative opportunities in palliative care in Argentina. He remembers that earliest educative initiatives in the country emerged in the 1980s with the Prager-Bild foundation followed by other programmes, such as the LALCEC programme in San Nicolas. They were small, but pioneering endeavours. During the early 1990s, a more solid training programme, called PALLIUM, emerged to train health professionals in palliative care at a post graduate level. This programme was initially strong linked to the ‘Mainetti’ Foundation, the Academy of Medicine and the National University of La Plata with academic support from the Oxford International Centre of Palliative Care chaired by Professor Robert Twycross. As a result of financial and institutional crisis, the ‘Mainetti’ Foundation’s and the National University of La Plata’s left the programme towards the end of the 90s. The programme established links with the ‘del Salvador’ private University in the city of Buenos Aires. Since its commencement, more than 500 health professionals including physicians, nurses, social workers and psychologists have been trained in the

programme. In 2003, a system was created in which a physician with expertise in palliative care is awarded a grant to work as a palliative care advisor in five different hospitals with no palliative care teams in the city of Buenos Aires. The physician undertakes educative and clinical duties. In this way, it is expected that each of these five hospitals would implement its own palliative care team in two years. Audit of this activity has shown improvements in communication and symptoms control with the intervention of the palliative care team.

Dr De Simone describes barriers to adequate cancer pain control, such as the considerable number of health professionals unable to adequately apply the basic principles of the WHO pain ladder to control pain; communication skills remain poor among junior doctors as well as their abilities to identify the psycho-social components of pain and suffering; accessibility of opioids to patients is highly inadequate in the way that although all strong opioids are available in Argentina in different formulations and presentations, patients are unable to buy them because of their costs. Only inpatients admitted in public hospitals can get their analgesics with no costs and sometimes, it is necessary to admit the patient in order to give him or her appropriate analgesia. In this way, bureaucracy increases health expenditures enormously. Neither the national social security system nor the mutual systems cover the total cost of analgesics for outpatients and commercial presentations are much more expensive compared with home made preparations. Although home made preparations may lack the rigorous control of commercial products and be defective in their preparation, it is a risk to be weighed when prescribing opioids to patients. The prescription of strong opioids requires the use of especial prescription forms. Their cost is paid by the physician who prescribes the opioids (15 Argentinean pesos (£ 3)

per 20 forms). Although it has been improved, there is only one office where these forms can be obtained in the city of Buenos Aires. In other provinces, providing offices are even scarcer. Dr De Simone also describes that, although less significant than twenty years ago, myths in the use of morphine still exist both amongst health professionals and within society. Education remains a major scope of palliative care.

Dr De Simone speaks about the importance of religion and spiritual issues towards the end of patients' lives and describes what he considers are the main ethical dilemmas at end of life in Argentina. He says that justice and equity in the accessibility to palliative care for all patients who need it; respect for the individual and the individual's needs (autonomy) and inequity on resources allocation remain the major ethical controversies. He also speaks about the use of complementary and alternative medicines by palliative care patients and describes what he thinks is the position of palliative care with respect to euthanasia, palliative or terminal sedation and futile medical treatments.

Finally, Dr. De Simone concludes with a very positive view on the future of palliative care in the country and in Latin America and remarks on the importance of encouraging multidisciplinary work in end of life care in order to explore and add to the social and cultural dimensions of the issue

- d) José Mainetti – interviewed by Silvia Paz, 18 December 2003, La Plata, Buenos Aires, Argentina

Summary of interview

Dr. Mainetti starts his interview by describing four stages in his professional development: *training* - the earliest years spent at the primary and secondary school, and at the university; *peregrination*: - around the world spending time as a fellow at different centres and universities; *teaching* - back home with the knowledge and experience gained during the previous years; *retirement* - a time to reflect on the past and on experiences gathered over the years and to re-think the present and the future.

Dr Mainetti is 65 years-old and considers he has reached the last stage of his career - the retirement stage. As a young boy he went to primary and secondary schools in La Plata; both were religious schools. In 1955, he started his medical degree at the Medical School at the Universidad de La Plata together with a degree in Humanidades y Ciencias de la Educación at the same University. In 1961, he became a medical doctor and obtained his degree in Philosophy. Ten years later, he finished his PhD in Philosophy, entitled “Reality and mystery of the human body”. In this work, he aimed to build a bridge between Philosophy and Medical Practice.

He explains that, during the early 1960s, a relationship between medical practice and philosophical concepts was almost unacceptable. A positivist, biomedical, hegemonic and reductionist model prevailed in the practice of medicine at the time. Thirty years later, the discipline of Bioethics emerged to build a connection between the more practical and the more human aspects of medical practice. In his interview, Dr. Mainetti very frequently refers to figures of Greek mythology to illustrate his thoughts. In this case, he mentions “Minerva” and “Esculapio” to exemplify the relationship between “knowledge” and “the art of cure”. Two events were crucial for

the emergence of Bioethics. First, the practice of medicine needed philosophical concepts to deal with ethical dilemmas recently emerged as a result of its development and of the application of new technologies and scientific concepts to medical practice. Second, Philosophy developed around “public affairs” and left behind the more intellectual environments and monasteries. Since the 1960s, the practice of medicine changed radically because of the introduction of technology and innovations. Philosophy provided the ethical context for this development. Bioethics emerged as a result of a reflective exercise between the two disciplines.

Dr. Mainetti spent time studying in Paris, Germany and Spain alongside recognised figures in the subject such as Paul Ricoeur and Pedro Laín Entralgo. In 1969, together with his father, Dr. Mainetti created the Fundación Mainetti. They aimed to generate an appropriate space in which to be able to bring together and discuss two main dimensions of medical practice: the techno-scientific and the human aspects: his father was 65 and wanted to retire as a cancer surgeon. The foundation appeared to him an opportunity to further develop ethical and philosophical concepts. He is today 94 and is still chair the foundation- “Quirón” was adopted as the emblem that illustrates the foundation’s philosophy.

During the 1970s, similar initiatives developed in the US and strengthened the growth of bioethics worldwide. Dr Mainetti thinks that a change in the paradigm of medical practice was taking place at the time – for example, the foundation of St Christopher in London constitutes an example of this changing paradigm. The Fundación Mainetti started in a very simple and modest place outside the hospital. In 1985 it moved to the oncological centre in La Plata, which is its current location. Many barriers and

difficulties then appeared. Conflicts and divisions amongst its members emerged when it began to put into practice the philosophical and ethical concepts promoted by the foundation. Dr Mainetti's relationship with his father was not easy. It was difficult for him to put in practice the more philosophical and humanistic concepts in a surgical environment that was strongly orientated towards radical procedures and extensive surgery. In this environment, ethical dilemmas were described in terms of "cure" or "not cure" and of "recovery" or "non-recovery" from the operating table.

Palliative care appeared to him as a discipline in which philosophical and ethical concepts could be considered alongside the practice of medicine. However, the "palliative care idea" was strongly resisted by colleagues who were mostly trained in cancer surgery. Dr Mainetti's son, Jose Luis, trained in oncology, has devoted himself to palliative care and this has represented an opportunity for Dr. Mainetti to become closer to current palliative care issues.

In 1984-5, Dr. Mainetti was visited by Prager Bild who had the idea of building a hospice in Argentina. Democracy had been recently restored in the country and Prager Bild managed to obtain political support. The idea of building a hospice also appeared very attractive to a group of volunteers who enthusiastically supported the project. However, a joint effort did not prosper and the relationship with Bild ended as a series of teaching sessions and conferences in the subject of palliative medicine. During the 1990s, Dr Mainetti became the president of the Fundación Mainetti. He contacted Dr Gustavo De Simone who was working as an oncologist at the Hospital Udaondo in the city of Buenos Aires. Dr De Simone moved to La Plata and they worked together to create a palliative care programme named "San Luis Gonzaga". This program

strongly emphasized education and training in palliative care. Out of this early initiative, PALLIUM emerged as a training program in palliative care that exists today in the city of Buenos Aires and is directed by Dr De Simone. National and local financial crisis and worsening relationships with his father and colleagues made the palliative care programme “San Luis Gonzaga” unsustainable in La Plata. From Dr. Mainetti’s viewpoint, this programme might well represent a very good initiative if it would develop further. For instance, it comprised different religion representatives, anthropologists, volunteers and lay people as well as health professionals devoted to palliative care. The team worked at a well-known cancer centre in the city and in the region. Palliative care and Bioethics could then develop as linked disciplines in this environment. However, the subsequent institutional and financial crisis led to its disintegration.

Although Dr Mainetti describes himself as being at the retirement stage of his professional career, he feels nowadays he is “starting again”. He considers however that earlier ideas have now spread throughout the country and several palliative care initiatives developed simultaneously during the 1990s. Although this was in a poorly defined way, local and national governments always supported the provision of palliative care in La Plata. But, unfortunately, palliative care has not been yet been formally implemented in public hospitals in the country. Dr Mainetti has recently been involved in a few national projects aiming to protect and promote the rights of terminally ill patients and their “living wills” in law and there is a motion to integrate Bioethics and Medicine at a more regional level that would include the MERCOSUR. Dr. Mainetti hopes that bioethics will have a place in the practice of medicine in

Argentina in the near future as ethical discussions appear more often among health professionals.

Currently, the provision of palliative care in La Plata is very thin. Only two doctors and a nurse provide palliative care to cancer patients in the hospital. There was a program dedicated to HIV patients linked to physicians working on infectious diseases. The initiative was developed by a psychiatrist who had a son that died from HIV disease. Teaching activities on HIV/AIDS prevention were carried out at schools and prisons, but these did not include clinical care of HIV/AIDS patients.

Talking about ethical dilemmas at the end of life, he remarks that palliative care is the best modality in which to care for dying patients, considering that the palliative care approach at the end of life has been accepted internationally. Differences exist however among groups in the provision of palliative care worldwide. A major ethical dilemma appears when discussing euthanasia and assisted suicide in the context of palliative care internationally. Dr. Mainetti thinks that the level that the discussion on these topics has reached in Holland, Australia, Belgium, Oregon and probably in England marks an evolution in the way societies think about end of life issues. He says that the euthanasia movement will probably find its way into society because it represents what could be described as the last stage in the medicalization of death.

In relation to the medicalization of death, Dr. Mainetti identifies several interpretations such as

- a) brain death
- b) personal death - or death as a personal act

- c) the individual's participation in matters relating to dying and death
- d) the appropriation of death by technology and life support machines
- e) the postponing of death through the manipulation of chronogenes by biotechnology
- f) the transposition of death – through 'near death' experiences
- g) palliation
- h) the administration of death
- i) killing

Although it is very much debated today, Dr Mainetti feels that euthanasia might eventually be accepted in the more developed societies. However, in Argentina it will take a long time and much effort to openly discuss the topic. In Argentina, a very conservative and traditional way of thinking on dying and death still prevails. The Catholic Church, for instance, treats themes such as euthanasia and abortion as taboo. There is not an appropriate political context in the country to discuss issues such as euthanasia. He finds no moral impediment to accept euthanasia as an option at the end of life in a spiritually mature and developed society and feels that, in the future, the principle and practice of individual autonomy will prevail in medical practice. Palliative care and euthanasia may eventually exist together as possible options at the end of life. Dr Mainetti thinks that there are strong traditions, arguments and conservative ideologies among medical professionals' discussion on end of life matters. Dying and death have acquired over time a social dimension that the medical profession cannot ignore. A natural or private death almost does not exist any more. 70% of deaths nowadays are

technologically and medically assisted. Palliative care, as a medical discipline dealing with end of life care, has the difficult task of having to differentiate itself from the euthanasia movement but whilst at the same time promoting its own discussion.

Dr Mainetti says that terminal sedation is justified based on the principle of double effect. In Argentina, doctors are still trained in an environment very much influenced by religious and catholic precepts. Special emphasis is given to the “sanctity of life” and Hippocrates’s oath prevails very strongly in medical practice. He recognises that implementing end of life options such as euthanasia is politically and socially very risky in any society and remarks that palliative care should always be the first option at the end of life, and that only in some exceptional cases should euthanasia should be contemplated. Palliative care should always be encouraged and supported.

Much has been done to protect patients’ autonomy and confidentiality. During the 1960s, it was unthinkable to disclose a fatal prognosis to patients: omnipotent families and doctors held the truth from the patient when an incurable condition was diagnosed. Families and doctors understood this silence as a heroic act to prevent suffering in the patient. According to the patients’ spirituality and personal orientation to death and dying, Dr. Mainetti speaks about three types - or models - of dying and death:

- a) heroic
- b) Christian
- c) rational or knowledgeable

Palliative care recognises suffering as an acceptable event in life, but works to ameliorate and avoid unnecessary suffering. In the past, suffering was usually accepted as a sign of stoicism and courage and the administration of morphine was a taboo never acknowledged. Argentinean medical professionals do not express their true opinions and do not openly talk about end of life matters and about their difficulties on dealing with them. There is, however, a sort of “clandestine discussion” going on, a conspiracy of silence in the profession. Nowadays, intensive care doctors have got comparatively more actively involved in bioethical and in palliative care discussions.

Regarding complementary therapies, Dr Mainetti thinks that they should also be analysed from a bioethical perspective to define their social role and value.

The use of morphine or other strong opioids to relieve pain at the end of life remains very poorly defined in the mind of many health professionals’ - there is a grey zone, still undefined when considering the use of morphine for pain relief when somebody is dying . This confusion appears as a result of misunderstandings on the true role of opioids and fears of inducing the patient’s death. Promoting respect for individual autonomy and adequately introducing the practice of living wills may eventually help health professionals to make better decisions at end of life.

Finally, Dr Mainetti outlined some thoughts for the future:

- a) to consolidate the development of Bioethics in the country and in the region (Brazil has developed in a very steady way so far)

- b) to rebuild the Latin American School of Bioethics (In 1990, the Latin-American School of Bioethics started with a strong educative mission and was internationally recognized. In 1994, the second world congress in Bioethics was organised in Buenos Aires)
- c) to encourage discussion on research protocols involving human subjects in the country and in the region
- d) to promote the development of ethics committees throughout the country. They are organized as a national network. Through ethics committees, bioethics is introduced into the hospital environment to promote the discussion of medical ethical issues. However, there have been major economic barriers that have made it almost impossible to fully implement these committees.

He concludes by saying that in Argentina current financial constraints have led to the unethical and careless management of end of life matters. Palliative care should acknowledge this problem and bring forward strategies to solve the ethical dilemma of discrimination based on financial resources availability at the end of life. He thinks that there is a general tendency to ignore the real problem and that there is a lack of professional consensus and commitment in the current situation.

- e) Roberto Wenk – interviewed by Silvia Paz, 29 December 2003, Buenos Aires, Argentina.

Summary of interview

Dr. Wenk starts this interview describing where he was born, his early years as a young student and what may have probably influenced his decision of becoming an anaesthetist physician. He was born in Rosario in 1946. He moved to San Nicolas (in Buenos Aires) where he received High School education and went back to Rosario to study medicine at the University of Rosario. At the age of 16, he had an accident and had to be admitted into hospital and spent quite a long time as a hospital inpatient. As part of his treatment, he received lots of anaesthesia and became interested in the role of anaesthetics in medical practice. He decided to become an anaesthetist. He worked as an anaesthetist until 1995 when he decided to become a full time palliative care physician.

Dr. Wenk mentions that, during the 1980s, he wanted to know more about pain management and became interested in publications written by Bonica, Foley and Twycross. Based on his readings, he developed skills on controlling pain with no previous specialist training or experience. Dr. Wenk recalls a 14 year old boy with a central nervous system cancer who suffered from severe facial pain and who was one of his patients. He performed an invasive anaesthetic procedure to relieve the pain in his patient and the poor results he obtained made him realized that invasive procedures were probably not the best options to treat cancer pain. In 1984, Dr. Vittorio Ventafridda was one of the speakers at a congress on anaesthesiology in Buenos Aires and briefly referred to the management of cancer pain in his talk. Dr. Wenk felt that this was the area he wanted to develop and made contacts with Dr.

Ventafridda. He remembers that, at that time, people knew little about palliative care and the subject was better known as cancer pain control. Later, he was approached by a group of volunteers from the 'Liga Argentina de Lucha contra el Cancer' (LALCEC) and they decided to form a group of three or four volunteers that constituted the 'Centro de Control del Dolor' (Pain Control Centre) in San Nicolas (Buenos Aires). Dr Wenk remembers that they initially worked in a church and that they moved some time later to a hospital unit. In 1986 or 1987, Dr.Ventafridda offered him to act as the focal point in Argentina for the WHO cancer pain control programme. At the beginning of the 1990s, a patient donated to the Pain Control Centre in San Nicolas a property where the centre functions today. In 1992, he was invited to form a palliative care team as part of a mutual named FEMEBA in Buenos Aires. In 1993, formed an association called 'Programa Argentino - Fundacion FEMEBA' of palliative care. Dr. Bertolino was later invited to join the team because a physician with more clinical expertise was needed in the team. She had been in France gaining experience in palliative care at the 'Unidad de Cuidados Paliativos del Hospital de Dios de Notre Damme' (palliative care unit at the Notre Damme hospital) in Paris. Dr Wenk describes the many challenges faced in finding out support and the appropriate location for the palliative care unit. Finally, they placed the palliative care unit at the 'Tornu' Hospital in the city of Buenos Aires to provide outpatients and inpatients care and a day care centre, and support in palliative care for the hospital's inpatients. Dr. Wenk went on describing how the unit is organized, the clinical, academic, research and educative activities undertaken at the unit. He feels that its impact is still limited due to a very small home palliative care provision. Only 17-20% of deaths occur at home while most of them happen at the palliative care unit. The second palliative care unit of the 'Programa Argentino - Fundacion FEMEBA'

palliative care programme is located at the ‘Valdomero Somer’ hospital in the surrounding area of the metropolitan city of Buenos Aires. This was a hospital designated to care for patients affected of leprosy in Argentina. Most patients cared for in the programme are cancer patients. Socio-financial factors made the turnover of beds very slow as many patients need to remain in hospital because they have got neither the financial nor the social resources to be cared for at home or in another institution. Several post-graduate courses are organized for physicians, nurses, psychologists and volunteers and several teaching activities are carried out closely linked to the University of Buenos Aires and the Argentinean Catholic University.

Dr. Wenk mentions that aiming at developing a network of palliative care units in other hospitals in the region, a physician and a nurse trained in palliative care spent seven or ten days teaching palliative care at another hospital with no palliative care service. He describes several barriers to the implementation and further development of palliative care in the country, such as:

- a) lack of education, governmental interest and adequate policies
- b) deficient availability of opioids
- c) a working culture in which team work is rather hard
- d) a general attitude towards rejecting the implementation of changes and innovations amongst health professionals and administrators
- e) a general resistance to collect and register data
- f) limited availability of trained personnel in palliative care

He thinks that palliative care remains very much underpaid-or not paid at all.

Dr. Wenk also values the work done by volunteers very much. For instance, volunteers are trained on using assessment tools, such as the Edmonton Symptoms Assessment Scale (ESAS) and the mini mental test; they then see the patient and complete the forms before the medical consultation and play a crucial role in speeding up everyday work in clinics. He also remembers that, in San Nicolas, volunteers were also trained on preparing solutions of morphine that was bought in packs of 6 grams of morphine powder. Solutions were prepared using mineral water and a covered bottle to protect the solution from the light. He describes the use of the Edmonton –or Econo- injector to give subcutaneous morphine as a simple technology used in a few palliative care practices. He went on to speak about another model for providing palliative care to patients living far away from the hospital in rural or distant areas and unable to attend a medical centre. It is called ‘distance care’ and it consists of a symptom evaluation form that is completed by the principal carer. The most important symptoms are reported and described using two Likert scales: one for frequency and the other for intensity. Also the most significant physical signs are reported in the form. The carer brings this information to the consultation and it is used by a palliative care physician to make a possible diagnosis together with other test results. Based on this diagnosis, basic advice is given to the carer and medicines are prescribed to be given at home. The evaluation of carers’ satisfaction and the level of control of symptoms achieved have allowed for more patients to die at their homes rather than in a public hospital with no palliative care intervention. Dr Wenk remarks on the crucial role of the family in this model. He also considers that palliative care provision to HIV/AIDS patients is very limited because there is not a significant demand for this service.

Dr. Wenk thinks that, instated of being an initiative encouraged and supported by health authorities, palliative care has developed because of personal and individuals' motivations lacking hierarchic order within the health system. He considers that this has been a major barrier for its proper development. Dr Wenk went on describing barriers to adequate opioids availability, myths towards the use of morphine and costs of analgesics. He believes that home made medicines are the only way to provide strong analgesics to patients with no financial or poor resources because commercial preparations are inaccessible to them. He considers that these as well as the many futile, ever-endless oncological and expensive treatments prescribed to terminally ill patients are major ethical concerns. He thinks that euthanasia is not a topic to be discussed in Argentina as it is not an option at end of life while there is not adequate palliative care available to everybody in the country. Information on euthanasia is, on the other hand, usually very complex and this aids to misunderstand the topic. He feels that terminal sedation can be a therapeutically valid option in palliative care patients with intolerable and uncontrollable suffering. Consent should be given by the patient if possible or the family and he estimates that no more than 5% of cases of palliative sedation have been registered in his team.

Dr Wenk went on to describe the role of religion, spirituality and the family at the end of patients' lives as well as to speak about barriers to adequate communicating terminally ill patients about their diagnosis and prognosis and the use of complementary and alternative medicines by this group of patients.

Finally, he concludes that the future of palliative care is promising locally and regionally because society is tending to make a more humane approach to life events

and is becoming more aware of suffering because of disease as different from the daily suffering of Latin American life. He thinks that the time it takes for changes to take place is much longer in Latin America than in other places because of its culture. Although palliative care is not a priority for health authorities, there is a growing interest in the subject in all regions and positive results should be seen in the future

- f) Elena D'Urbano – interviewed by Silvia Paz, 29 December 2003, Buenos Aires, Argentina

Summary of interview

Elena D'Urbano starts this interview describing her experience as a University student. She was studying at the School of Law when discovered that a career in Law did not really motivate her and decided to change and become a social worker. Elena moved to a private university where a more flexible time schedule allowed her to have a job in the morning, go to university in the evening and attend her practices during weekends.

She took her first job as a social worker at the district hospital in Tigre –Tigre is a very attractive area of the Buenos Aires county made of a river delta and many small interconnected islands- Elena remembers going out with a physician, a nurse and a nutritionist in a boat to visit peoples' homes to show them how to use purified water and some basic principles of hygiene. She describes that some people, for instance, did not have a watch or a clock and if they had to take an

antibiotic, she showed them how to use the position of the sun as a guide of the time of the day. During the Argentinean military dictatorship, it became unsafe to hold a job as a social worker and opportunities in her carrier became very limited. She decided to stop working actively as a social worker and to undertake other jobs. She used this time to gain further training and education on this and other areas related to social work.

As soon as military governments lost power in Argentina, Elena got a job as a social worker dealing with released prisoners and their families. It was her duty to guarantee an appropriate social support for the prisoner to be inserted back into society. Later, she worked at the University of Buenos Aires where she dealt with the awarding of financial aids to students of poor backgrounds. Elena also taught at the University of Buenos Aires for several years. In 1992, she got a job as supervisor of the social service department at the Hospital Udaondo in the city of Buenos Aires. This job represented for her an opportunity for better remuneration and carrier development. At this point, Elena describes the overall duties of a social worker in a public hospital in the city of Buenos Aires dealing with patients and families' financial and social issues.

In doing this job at the hospital, Elena developed a particular interest for those more lonely, dying or terminally ill patients with no families or resources. She met Dr. Gustavo de Simone and Ms Marta Junin who were, at that time, creating a palliative care team at the hospital. Elena joined them on a part-time basis to acquire skills in dealing with terminally ill patients. Following this experience, she became a member of the Udaondo hospital palliative care team and this is a

position she holds since 1995. Her principal role is to offer bereavement support to patients and families.

Elena thinks that working in the city of Buenos Aires demands a great deal of professional creativity due to the highly diverse culture of its population. Buenos Aires inhabitants behold European, American and native influences as well as very different social backgrounds. These very diverse characteristics are truly mixed in every aspect of Buenos Aires daily life and she finds this to be a quite unique characteristic, different from other multicultural cities she knows. Elena describes that the more recent Argentinean financial and social crisis has affected an important sector of society leading to a general decrease in the social status of the population. She says that a new social sector, the “new poor”, has emerged. This sector is made of middle class people who could previously access to certain commodities that following the crisis, they have to live with very limited resources and in almost poverty. She describes that this sector is highly vulnerable and finds more difficult to cope with bad news because it has suffered many subsequent losses such as private properties, stable jobs and good education for their children. The idea of a terminal disease represents for these people another highly devastated burden. Elena says that traditional poor sectors are used to live in poverty and in general they have better mechanisms for adjusting to adversity and losses. Governmental resources have not been allocated to support these more vulnerable sectors and strategies have not yet been proposed. Public hospitals have to respond to an increased demand from people who lost their social security and look now for free medical attention.

Elena mentions that patients' access to strong opioids is very limited and this constitutes a serious matter in their care. While in hospital, patients have their analgesic medicines covered by the government and analgesia is freely provided but when they are discharged home, it becomes very difficult to guarantee the adequate provision of opioids to them as they have to pay for their medicines.

Elena describes her role at the Hostal de Malta palliative care programme. Here, she develops an active role interviewing families before patients are admitted to the programme. In this interview, Elena assesses the family supportive structure and network. After the patient has been admitted to the programme, she follows the family up and coordinates its bereavement support. Bereavement support is offered to anybody who may need it and especially to vulnerable family members considered to be at risk of a conflictive grieving. She also coordinates the activities of the day care centre and organizes training courses for volunteers. These courses emphasise the basic principles of palliative care. Some of these volunteers may later form part of the day care centre staff according to their interests and abilities. She describes that the day care centre activities are strongly oriented to patients' social needs and preferences. The aim is to encourage activities socially meaningful and with a positive impact on patients' functioning while improving their quality of life and encouraging their search for gratification. At an initial interview, patients are assessed and arranged into groups according to their preferences, abilities and level of functioning and activities such as dancing, tango, music playing, cooking and painting are organized. The day care centre offers a relaxing environment in which to discuss the process of illness as well as present and future plans from a more constructive perspective for the patient. On

Elena's view, the day care centre represents an opportunity for patients to be protagonists of their care and for carers to have some free and resting time during the week. Elena also describes that many patients who attend the day care centre are quite lonely either because their carers work long hours during the day or because they leave alone. She thinks that organizing the activities of the day care centre represents a big challenge as patients' interests are very variable and individual and this approach to health care is quite innovative within the health care system in Argentina.

Elena finds that working as a social worker may be very frustrating at times because the ultimate goal of the job is to achieve an acceptable good quality of life for disadvantaged people but knowing that this goal, if achieved, will not last very long. She mentions that lots of her job relies on political and governmental measures beyond her personal control. This factor was even more relevant when she was working, for instance, with children living in the street. She finds that working in palliative care is somehow different. In palliative care, quality of life can be certainly improved for patients and families and good quality of life can be achieved until the death of the patient. The remaining life span of the patient is a period of time known to be limited in which aims and scopes can be perceived and this seems to represent a complete circle for her. She also finds that in palliative care it is possible to work very close to people with their spiritual and other very intimate issues that make the job very gratifying for her.

Elena mentions that the major ethical dilemma in caring for terminally ill patients in Argentina derives from the country's lack of clear and consistent social

measures, and of consequent political strategies. In this context, she thinks, it is very difficult to ensure equity and justice in patients' health care.

Finally, Elena feels that a lot has been achieved since 1995 and she hopes that a similar pattern of developments will continue during the forthcoming years. She concludes by pointing out that to have had the opportunity for working in palliative care has been a privilege for her; it has been a very rewarding job that has offered her an opportunity for personal enrichment.

g) Jorge Manzini – interviewed by Silvia Paz, 30 December 2003, Mar del Plata, Buenos Aires, Argentina

Summary of interview

Before going to University, Dr. Manzini had two main professional interests: biochemistry and medicine. Finally, he decided to study medicine, though neither of his relatives had a medical career. It may have been that books on medical topics inspired his inclination towards medicine. As a medical student, Jorge Manzini went to Catamarca to study the prevention, transmission and diagnosis of the disease caused by vinchucas. He enjoyed caring for sick patients in their homes – in Catamarca people lived in very simple and precarious conditions - and researching the disease vector. After completing his internship in internal medicine, he became interested in oncology and worked as a medical oncologist during 1970 and 1971, but became found this job upsetting. He decided to leave

his job as an oncologist. For some time afterwards, Dr Manzini worked as a clinician and as a teacher assistant at the Medical School for free in the city of Buenos Aires. He lost his job in Buenos Aires and was unable to find a paid job there, so moved to Mar del Plata to work as a clinician in an outpatient clinic for tourists during the summer holidays. A few months later he was appointed as an internist at the “Hospital Interzonal” in Mar del Plata. Having now had a house built, Dr Manzini needed to increase his monthly income and looked for a second job at the “Hospital Privado de la Comunidad” in the same city. He was appointed as the clinician at the outpatient clinic for retired people there. A year later, he was offered a job doing domiciliary visits from the same hospital. In this new job, he looked after chronically and terminally ill patients on a regular basis – mainly old patients suffering from respiratory and heart diseases, arthritis and cancer. Dr. Manzini and a colleague had the idea of developing a systematic approach to the care of this group of patients, in an initiative never undertaken in that hospital service before.

In 1984, a colleague in onco-haematology suggested the creation of a committee of deontotatology which aimed to create a space in which to analyse and discuss ethical dilemmas when caring for terminally and seriously ill patients. People with special interest in the subject were brought together. This was an opportunity for Dr. Manzini and the newly created team to contact other people with similar interests and to spend some time reviewing the literature and discussing ethical dilemmas at the end of life.

Through the newspaper, Dr. Manzini and the team got to know about the arrival of Ruben Bild in Argentina. Dr Bild was locally recognised as a palliative care figure trained in London and Spain. In March 1986, Ruben Bild agreed to visit the Hospital Privado de la Comunidad in Mar del Plata. Dr. Manzini remembers that after discussing their ideas, Dr. Bild suggested to the home care team that they create a palliative care section in the hospital. The palliative care section was established soon afterwards in 1986 and although very encouraging results were achieved, it lacked sufficient institutional support and it was discontinued after three years.

Dr Manzini maintained contacts with a group of people working in bioethics at the University of Mar del Plata. He found a close relation between the development of bioethics and palliative care and for several years he worked towards implementing both disciplines in the Hospital Privado de la Comunidad. Finally, in 1995, a committee on bioethics was established within the main ethics committee of the hospital. Simultaneously, the Department of Family Medicine supported the development of a palliative care service to provide home palliative care – Programa de Atención Domiciliaria y Equipo de Soporte (PADES). Both initiatives, the committee on bioethics and the home palliative care service, were still functioning at the time of the interview in 2003, and undertaking extensive clinical and academic commitments.

Dr Manzini has been the assessor of the palliative care programme since the late 1990s. He considers that for the development of innovative disciplines such as palliative care and bioethics in Argentina it was crucially important to recover

democracy in the country. He recalls the first meeting on caring for terminally ill patients in the country that took place in 1986 and how Mr. Alfonsín, the first Argentinean democratic president, launched the meeting. Dr Manzini also recognizes that Dr Robert Twycross has been a key figure, a mentor, in the development of the discipline in Argentina - in a philosophical and educative way and because of his constant support by being a regular visitor and participant at the main conferences that take place in the country.

Although the home care service at the Hospital Privado de la Comunidad started in the 1970s, according to Dr Manzini, palliative care and bioethics have only been recognized and accepted by peers during late 1990s.

PADES involves physicians, nurses, a social worker and secretarial support and it has strong links with other services in the hospital such as the physiotherapy unit. Dr Manzini strongly supports the idea of establishing a hospice as a specialized palliative care centre in which to concentrate education, research and clinical care in palliative medicine. He feels that best quality of care and education can be achieved with these conditions. In 2000, a project was initiated to establish a hospice attached to the Hospital Privado de la Comunidad, but the initiative failed to develop because of the country's 2001 financial collapse. In 2003, the project was being re-considered by the hospital authorities.

Dr Manzini describes how PADES - the home palliative care programme - looks after around 30 to 40 chronically and terminally ill patients suffering from malignant and non-malignant conditions and living at home. The program does

not care for HIV patients, as the number of cases in the hospital is small and because HIV patients now live longer with good quality of life if they receive appropriate drugs regimen.

Dr Manzini describes how it was very hard to gain recognition and acceptance at the earliest stages, but relates that the relationship with other medical disciplines in the hospital has increasingly got better over the years. There are still colleagues however who do not easily recognize any important role for palliative medicine in caring for seriously ill patients.

Dr Manzini considers that, in his experience, there are three main ethical dilemmas in caring for seriously ill patients in Argentina: 1) handling of information and communication with patients and families and communication among and within professional care teams; 2) decision-making for discontinuing vital support measures 3) the allocation of resources – although patients at the Hospital Privado de la Comunidad can afford their treatment costs, poverty is a serious problem in other hospitals and health services in the city.

Dr. Manzini remembers that, with the creation of the first palliative care section at the Hospital Privado de la Comunidad in 1986, the use of oral morphine was introduced into clinical practice in the hospital. The palliative care team at the time negotiated with local pharmacies for the preparation of home made formulations of oral morphine. These preparations were cheaper than commercially available morphine preparations– especially the slow release formulations that had just appeared at that time. Today, solutions of oral morphine

remain the most frequently prescribed and used formulations. Other available strong opioids are used as alternatives to morphine when needed. Dr Manzini describes how patients looked after by the palliative home care team can usually afford the costs of opioids and other medicines prescribed for the palliation of symptoms.

Dr Manzini also reflects on the significant delays that exist in telling the truth regarding diagnosis and prognosis to cancer patients. He feels that oncologists frequently tend to nourish a false hope in patients by prescribing one treatment after another and expecting a positive outcome. This attitude makes it very difficult for the palliative care team to tell patients the truth about their fatal prognosis when active treatments are no longer indicated. Families also usually prefer patients to ignore a life threatening prognosis. Dr Manzini says that in PADES there exists a policy to which the patient and the family agree – by signing an informed consent document - on keeping patients well informed, to the extent that they would like to know about their diagnosis and prognosis. He agrees that the conspiracy of silence compromises patients' autonomy and decision-making in medical treatments and end of life choices. He describes how families and patients usually welcome a more open and trustful attitude when the dialogue is managed by skilled professionals. Although religious leaders are not currently part of PADES, they are called in when patients request spiritual or religious support. Dr Manzini estimates that at least 50% of cancer patients receiving active oncological treatment also receive a complementary or alternative therapy although only a very small proportion of patients talk openly about it. When the subject is brought up with the palliative care team by patients or families, ethical

dilemmas usually emerge such as questions about respect for autonomy, patient's beneficence and allocation of resources. Dr Manzini describes how there are big commercial interests supporting these types of oncological treatments and some of them might be enormously expensive - families may even consider selling their properties to pay for these therapies- As the palliative care team assessor, Dr Manzini advises and encourages discussions on these and other bioethical issues.

Although financial and social crises have severely compromised the development of palliative care, Dr. Manzini holds a very positive attitude towards its future in Argentina. Several factors may contribute to its further development. For instance, he considers that palliative care represents a comparatively cheap option for good and rationale provision of care; that there are many experienced professionals working and teaching the discipline in the country and that several initiatives have developed to formally introduce palliative care for undergraduate health students and as a medical specialization at the post graduate level.

In conclusion, Dr Manzini describes some figures for the first year (1986-1987) of functioning of the palliative care section at the Hospital Privado de la Comunidad: among 100 patients cared for, 88% died at home; 31% died fully informed about their diagnosis and prognosis and 67% died accepting the illness process. Dr Manzini thinks these are very relevant results when considering the social and medical context of the time: during the mid-1980s, a cancer diagnosis and a fatal prognosis were rarely made known to patients in Argentina.

- h) Marta Junin – interviewed by Silvia Paz, 23 January 2004, Buenos Aires, Argentina

Summary of interview

Marta Junin starts this interview talking about her early years as a nurse student and how she developed her interest in caring for dying patients. After finishing her secondary school, she worked as secretary to an architect for ten years and in her own time she studied to become a nurse. After obtaining her nursing degree, Marta left her job as a secretary and became a full-time nurse. She was 28 years old. She continued her nursing training until obtaining the highest level in the nursing profession in Argentina.

In the course of her work, Marta discovered that she needed to improve her skills in dealing with dying and chronically ill patients and their families. Looking for training opportunities in this area, she knew from the newspapers of the arrival back in the country of an Argentinean psychotherapist, Dr. Ruben Bild. Dr Bild had spent many years at St Christopher's Hospice in London and he wanted to introduce the idea of hospice care into Argentina. Marta attended his courses on how to approach and communicate with dying patients and became a member of Dr Bild's foundation first palliative care team after completing the courses. Dr. Bild had created that foundation with private funds that aimed to look after dying patients and their families at home and to promote training and education in this area for health professionals in Argentina.

Marta describes the early palliative care team formed at the Prager-Bild foundation and her experience of being one of its members. The team was formed in 1986 and she worked for it until 1989. It was a home palliative care team that included two physicians and a nurse. They worked for free in their spare time. Everybody had a paid job. Marta describes how, initially, patients and families were sceptical about the idea of being cared for at the end of life, partly because it was a type of care freely provided and also because patients did not know that to be medically cared for when incurable was a right they had.

Nevertheless, patients and families were always very grateful. Marta remembers this experience as a very enriching and gratifying one. She mentions that members of that incipient palliative care team later became head of departments at their working places. For instance, Dr Germ became chair of the paediatric palliative care team at the Hospital Garrahan and Dr Sauri took the chair of the palliative care team at the Instituto Universitario de Oncologia Roffo - both located in the city of Buenos Aires.

During the mid-1980s, Marta remembers that several palliative care meetings took place in the city of Buenos Aires with the presence of international visitors, such as Dr Robert Twycross, Dr Geoffrey Hanks and Dr Vittorio Ventafridda. In 1989, Marta decided to spend some time at the Istituto Nazionale dei Tumori in Milan, Italy. In Argentina, the Bild foundation was closed due to financial and other resource constraints. The Bild initiative lasted from 1985 to 1989. At the time, a lack of resources made working in palliative care in the country very hard. Marta describes how the palliative care idea was seen by the Argentinean

medical community as a discipline that lacked scientific grounds and, in a culture in which what is more expensive is better, ‘palliateurs’ working for free were not seen as serious professionals.

Later as palliative care strengthened, a sense of competition between palliative care and other disciplines caring for cancer patients emerged. Marta thinks that palliative care had no recognition because it proposed a model of care that was the very opposite to the prevailing idea of maintaining active treatments with chemo- or radiotherapy until the patient’s death. The idea that patients might benefit from stopping these therapies at some stage was not considered. As time went on, health professionals looking after cancer patients became more knowledgeable and interested in palliative care, and a few of them either got trained or incorporated palliative care experienced professionals into their services.

In Italy, Marta met Professor Ventafridda and obtained a position as a staff nurse at the Istituto Nazionale dei Tumori in Milan. She recalls this was a brilliant experience, full of opportunities for doing work in the home, hospital and day centre care and for obtaining grants for further palliative care training and education. However, after a year and a half in Italy, she decided to return to Argentina. At her arrival in the country, Marta remembers that the palliative care situation remained very much the same and she realized that in many aspects it was necessary to start from scratch.

She formed part of the group of people who created the Asociación Argentina de Medicina y Cuidados Paliativos with the aim of strengthening palliative care initiatives in Argentina. Back in the country, she spent two years without having a job because she wanted to get a position in palliative care nursing. In 1993, a first job for a palliative care nurse was created at the Hospital Udaondo, which is a public hospital in the city of Buenos Aires. The chair of the oncology service at this hospital, Dr. Enrique Roca and another staff oncologist, Dr. Gustavo de Simone who was working in palliative care, were looking for an experienced palliative care nurse to set a hospital palliative care team.

Marta got the job and remarks on Dr. Roca's invaluable support for the development of palliative care in the oncology service. She feels it represented a very unusual attitude for an oncologist at that time. This approach of incorporating palliative care into the oncology service has now been adopted by a few other sections in public and private hospitals. Since 1993, Marta has worked as a full time staff nurse in palliative care at the Hospital Udaondo. Her job was initially quite resisted by colleagues because it is unusual for an Argentinean nurse to attend consultations from different services, to spend time talking to patients and families and to have certain flexibility on time schedules. A nurse in Argentina usually works attached to one particular service and their time schedules are tightly controlled.

Alongside her clinical duties, Marta has developed an extensive educative activity with the aim of introducing palliative care into the nursing curriculum. She coordinates training courses on palliative care and pain management for

nurses at the Departamento de Capacitación in the health section of the government of the city of Buenos Aires. These courses provide training for interested nurses in the 33 public hospitals existing in the city of Buenos Aires. These training courses are organized in two levels: 1) for auxiliary nurses, and 2) for professional nurses. Marta describes how much of her current professional attention and effort are devoted to teaching palliative care, with the aim of eventually introducing the discipline in the 33 Buenos Aires public hospitals.

Marta describes how, at their working places, most nurses trained in palliative care frequently face the problem of not having equally trained physicians. This makes the practice of palliative care extremely hard for them. Many nurses facing this problem refer palliative care patients to hospitals where this modality of care is provided, although Marta recognizes that this should not be an acceptable measure. She says that progressively many more nurses come to the courses knowing what palliative care is and looking to gain knowledge and skills in the subject while others still attend the course because of curiosity about knowing what palliative care is about. Palliative care courses are free of charge and accessible to any nurse interested in palliative care. There are also postgraduate courses.

Twenty five academic hours in palliative care have been introduced into the undergraduate curriculum for student nurses at the University of Buenos Aires. It is the aim to introduce palliative care education into all levels of training to all health professionals. Teaching sections comprise practical exercises and theoretical information. They are very much focused on communication skills and on pain management, mostly on the use of strong opioids and non-

pharmacological as well as complementary therapies in cancer pain control. In this interview, Marta gives some figures on the provision of palliative care in public hospitals in the city of Buenos Aires: Nine out of 33 public hospitals have developing or mature palliative care teams. Three other university hospitals and a national paediatric hospital also have well developed palliative care teams. Marta defines 'mature teams' as those with ten or more years of palliative care experience and 'developing teams' as those mature teams that are experiencing deep changes in their structure or organization. In the remaining 24 public hospitals, the picture is rather mixed. Some of them have only interested professionals who have not yet constituted a palliative care team; others have very incipient teams and some have no palliative care provision at all.

Marta describes how there are many health professionals who still believe that cancer patients have to suffer pain as part of their disease and that pain relief is not achievable in this circumstance. She says that there are many myths surrounding the use of morphine among patients, carers and physicians - such as fears of addiction and of inducing or accelerating the patient's death. Morphine is seen as a last resort and many concerns arise among medical practitioners when having to inform their patients and carers about the use of morphine. Much of these fears are rooted in misunderstandings and a lack of knowledge and skills about the use of strong opioids. Marta says that members of the palliative care team have the role of encouraging reading and skills in using morphine among junior doctors. They also show junior doctors how to properly assess pain and in the handling of information to patients. These tasks are much harder to accomplish among the more senior hospital staff. Marta describes how

methadone has now become easily available and that many doctors find it easier to prescribe methadone to patients just because they do not have to talk about morphine with them. Marta mentions several barriers to the adequate use of strong opioids such as the lack of governmental support at local, regional and national levels. For instance, while expensive cytostatic drugs used in cancer chemotherapy are available free of charge to patients, opioid analgesics are not.

From her nursing perspective, Marta also speaks in her interview about a series of ethical dilemmas in caring for dying patients in Argentina:

- a) lack of communication skills among physicians dealing with seriously ill patients and their lack of interest in getting these skills
- b) lack of respect for patients' autonomy in medical decision making. Marta describes how very often medical decisions are made in hospital multidisciplinary meetings by physicians who do not consider patients' wishes or wills. The nurse, who is usually closer to the patient, should have a more defined role in this process and express the patient's wishes
- c) the use of the 'lethal cocktail' in terminally ill patients is frequently decided by the physician and the patient's family. In the lethal cocktail, different psychotropic drugs that act in the central nervous system are mixed together and given to patients to sedate them and blur their consciousness, but without properly relieving their symptoms and suffering. These mixtures may accelerate the death of the patient. Argentinean nurses usually believe that they have to

follow any prescription made by a physician even if they do not agree with it. Marta describes this circumstance as a serious ethical dilemma among nurses trained in palliative care and knowledgeable of alternative measures for symptom control and end of life care. Nurses' rights to refuse to give treatment to patients on justifiable grounds are now protected by law, but most people do not know about it

- d) futility and the use of unnecessary treatments in terminally ill patients - such as hydration and nutrition, and a lack of ability to recognize and accept what may be the patient's real needs at the end of life are other serious ethical concerns

Marta describes that only five nurses probably have a full time position as a staff palliative care nurse in the city of Buenos Aires. Most palliative care nurses work part time and most of them with a very limited schedule devoted to palliative care. Finally, Marta reflects that palliative care was introduced into Argentina in 1985 and 19 years later results of the palliative care initiative are emerging. Her aim is to carry on teaching and promoting palliative care among health professionals. And, hopefully, there will be a palliative care team in each of the 33 public hospitals in the city of Buenos Aires in the near future.

PUBLIC HEALTH CONTEXT

History

Following independence from Spain in 1816, Argentina experienced periods of internal political conflict between conservatives and liberals and between civilian and military factions. After World War II, Juan D. Perón, an army colonel, emerged as the leader of the post-war era, winning the presidential elections of 1946 and 1951. Perón's political strength was reinforced by his second wife, Eva Duarte de Perón known as "Evita", and her popularity with the working classes. A long period of Peronist authoritarian rule and interference in subsequent governments led the armed forces to take power and to send Peron into exile in 1955. Argentina entered a long period of military dictatorships with brief intervals of constitutional governments. By early 1970s, Argentina was a nation shaking on economic and political collapse. Left- and right-wing terrorist groups were killing hundreds of people countrywide. The military junta that took power in 1976 imposed the martial law and began the "dirty war" to restore order and eradicate its opponents. Years later, the Argentine Commission for Human Rights in Geneva charged the junta with 2,300 political murders, over 10,000 political arrests, and the disappearances of 20,000 to 30,000 people. An increasing pro-democratic public sentiment together with powerless military forces led the return of democracy in 1983. As the 1983 elections approached, inflation hit 900% and Argentina's crippling foreign debt reached unprecedented levels. Mr. Raúl Alfonsín, leader of the Radical Civic Union became the first democratic president to win elections after more than thirty years of authoritarian governments. Growing unemployment and quadruple-digit inflation, however, led to a Peronist victory in the elections of May 1989 and Mr. Carlos Menem came into power in 1990. Menem promoted economic austerity measures that deregulated businesses and privatized state-owned industries. But after eight years into Menem's two-term presidency, Argentina entered its worst recession in a decade.

Menem's economic policies, tolerance of corruption, and forgiveness of military leaders involved in the dirty war eventually lost him the support of the poor and the working class who had elected him. In 1999, Mr. Fernando de la Rúa became president. Despite the introduction of several tough economic austerity plans, by 2001 the recession slid into its third year and by the end of 2001, Argentina collapsed economically. After a period of deep social and political instability, the congress named Mr Eduardo Duhalde president who soon after announced an economic plan devaluating the Argentinean peso. The devaluation plunged the banking industry into crisis and wiped out much of the savings of the middle class. In the 2003 presidential elections, Peronist Néstor Kirchner became president. Argentina's economy has been slowly rebounding since its near collapse in 2001.

Population

From the 1850s to the 1950s, the population was swelled by the arrival of European immigrants, mainly from Italy and Spain. The official language is Spanish, and 92% of Argentineans are Roman Catholics. Protestants and Jewish represent 2% whilst other faiths represent 4% of the population. Due to the current economic constraints, younger people are leaving Argentina - many of them returning to the homelands of their ancestors.

According to 1995 estimates, ninety-six per cent of the population are literate and most people live in urban areas in 2003 (table 6)

Table 6: Population structure^{26, 27}(2003 estimates)

Total population	38,740,807
(a) urban population (%)	88
(b) rural population (%)	12

Epidemiology

In 1997, the population of Argentina was made up of around 17.50 million males and 18.17 million females. Live births totalled 363,105 males and 349,140 females.

In the same year, there were 267,136 registered deaths (147,704 males, 119,136 females). Among these deaths, the highest number was due to diseases of the circulatory system; 48,264 males, 43,838 females. Malignant neoplasms were the second major cause of death; 28,295 males, 23,260 females (a total of 144.5 per 100,000 population).

In 2001, cardiovascular diseases represented the first cause of death in the country amongst both the male and the female population and malignant tumours were in second place. Respiratory diseases were in third place²⁸.

In 2003, it was estimated that the Argentinean population grew 1.05% with a life expectancy rate of 74.4 years for the total population (table 7)

Table 7: Population demography (2003 estimates)

Annual growth rate (%)	1.05
Crude birth rate (000)	17.47 births
Life expectancy at birth (total population) (2002 estimates)	74.4
(a) for men	70.8
(b) for women	78.1
Crude death rate (000)	7.58 deaths

Health care system

De Simone draws attention to the lack of support for palliative care programmes in Argentina’s health care system and highlights the under-treatment of pain and other symptoms:

‘There is...a misdistribution of “acute and chronic beds”, with a high prevalence of ‘acute’ hospitals and a lack of palliative care programmes. A research study on terminally ill cancer patients performed 10 years ago showed that pain and other symptoms were mostly under-treated, and that there were adjustment disorders in nearly half of patients’ families.’²⁹

In 2001, the total health expenditure per capita in Argentina was 1,130 international dollars (Intl \$) representing the highest figure in the region.³⁰ This health expenditure compares with other South American countries as follows: Uruguay \$ 971; Colombia \$ 356; Peru \$231 and Ecuador and Bolivia \$ 177 (both countries shows the lowest figure in the region) (Table 8).³¹

Table 8: 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

Total health expenditure in Argentina represents 9.5 % of GDP. This compares with 10.9% in Uruguay (the highest percentage in the region); 7.0 % in Chile; 5.5% in Colombia; 4.7% in Peru and 4.5% in Ecuador (the lowest percentage in the region) (Table 9).

Table 9: 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: Source: WHO statistics 2000-2002

Although official data are currently unavailable, it is thought that the devaluation of Argentina's currency in 2001 has significantly altered these figures.

Table 10 shows the principal sources for public and private health expenditure in the country.

Table 10: Selected national health accounts indicators (2001 estimates)³²

Indicator	Value
Per capita GDP in international dollars	11,920
Total health expenditure	
Total expenditure on health as % of GDP	9.5
Public health expenditure	
General Government expenditure on health as % of total expenditure on health	53.4
Per capita government expenditure on health in international dollars	604
Sources of public health expenditure	
Social security expenditure on health as % of general government expenditure on health	58.6
Private health expenditure	
Private expenditure on health as % of total expenditure on health	46.6
Sources of private health expenditure	
Prepaid plans as % of private expenditure on health	31.1
Out-of-pocket expenditure on health as % of private expenditure on health	62.40

The WHO overall health system performance score places Argentina 75/191 countries. This composite measure of overall health system attainment³³ is based on a country's goals relating to health, responsiveness, and fairness in financing. The measure varies widely across countries and is highly correlated with general levels of human development as captured in the human development index.

The health system is organized around three main providers:

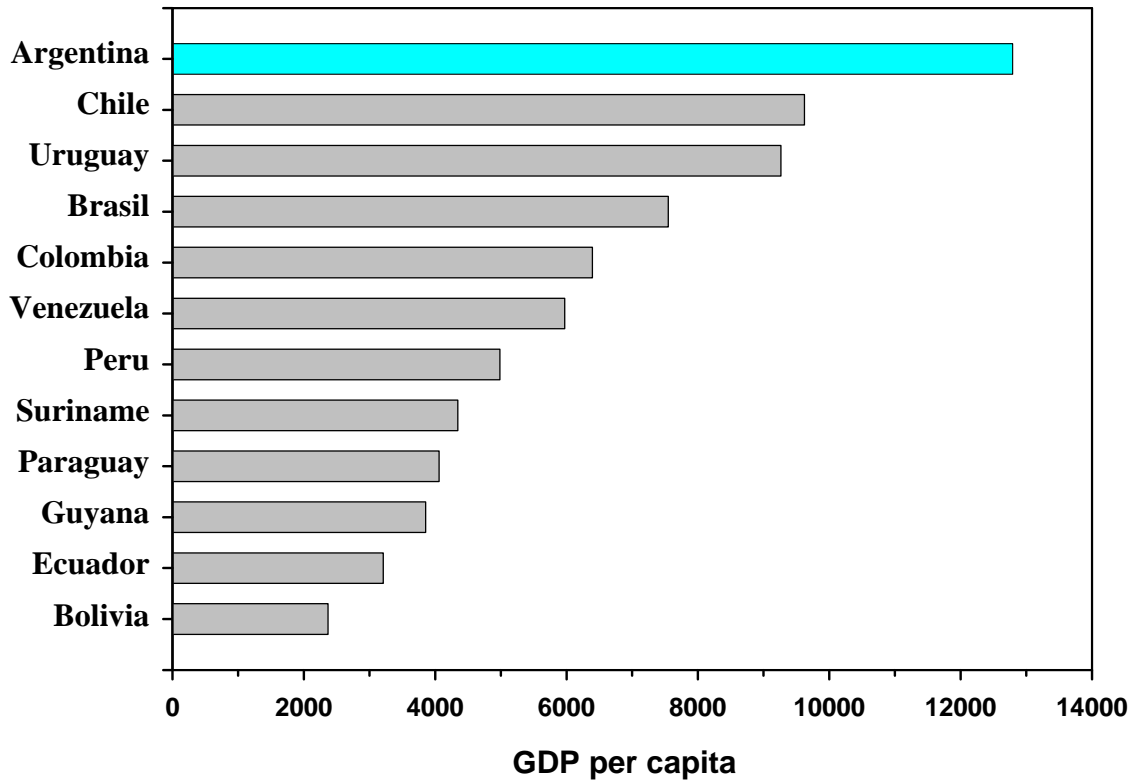
- the *public sector* - which supplies free clinical care for hospital inpatients and outpatients. A charge is made to outpatients for medicines. This sector covers about 50% of the population
- '*mutuals*' or *social plans* (around 300 in number) - administered by trade unions. Employers and employees each pay a fixed fee. The 'mutual' covers the cost of medical care and medicines in varying proportions; differences between the fixed fee and the actual cost of treatment is paid by the patient. In the past, these plans have usually covered around 45% of the population, although the percentage has fallen recently due to increasing unemployment - with more people resorting to provision within the public sector provision
- the *private sector* – where patients meet the total cost of their medical care; this sector covers around 5% of the population.

There are more physicians (150,000) than nurses (85,000) in Argentina; there are also more medical specialists than general practitioners or family doctors.

Political economy

The economic collapse of 2001 – a result of poor financial administration and political instability - brought about higher levels of unemployment and a sudden fall in GDP. As a result, poverty has increased and the country's external debt is estimated at more than US\$ 145 billion.

In 2000, GDP per capita in Argentina was Intl \$12,791 as compared with \$9623 in Chile; \$4985 in Peru; \$ 6,394 in Colombia and \$2368 in Bolivia (Graph 2)



Graph 2. Gross Domestic Product (GDP) per capita in international dollars (Intl \$) in countries of South America, 2001- Source: WHO statistics 2000-2002

Most Argentinean economy relies on the international selling of its natural resources (table 11) High inflation and unemployment rates are main economical and social burdens.

Table 11: Summary of Argentinean economic profile ^{34, 35}(2002 estimates)

GDP/PPP	\$458.3 billion
GDP per capita	\$10423.11
Inflation (1990-2000)	8.9%
Inflation rate (consumer prices) (2002, yearend)	41%
Unemployment (2003 estimates)	16.3%.
Labor force (1999 estimates)	15 million
Natural resources	fertile plains of the pampas, lead, zinc, tin, copper, iron ore, manganese, petroleum, uranium.
Agriculture	sunflower seeds, lemons, soybeans, grapes, corn, tobacco, peanuts, tea, wheat; livestock.
Industries	food processing, motor vehicles, consumer durables, textiles, chemicals and petrochemicals, printing, metallurgy, steel

ETHICS AND ETHNOGRAPHY

Ethical issues

The emergence of palliative care has fuelled the debate surrounding patient autonomy at the end of life. In recent years, the media has increasingly addressed issues relating to ethics, pain relief and quality of life, and these topics have attracted attention in palliative care scientific meetings and other professional forums.³⁶

Nevertheless, there is a growing consensus that end of life issues should be discussed more fully: a position strengthened by the growing debate surrounding euthanasia and physician assisted suicide. Eisenclas and De Simone write:

‘it is imperative that the medical profession ask itself what their members are doing in relation to end of life care, what teaching should be provided in medical schools and spread the debate across society. We believe it is necessary not only to increase knowledge and arguments for debate, but also to consider the emotional and cultural aspects of the subject and promote a multidisciplinary debate on the issues involved.’³⁷

Freedom of choice is compromised for patients in Argentina due to:

- a) a patriarchal/protective presence of family members in medical decision-making
- b) a paternalistic attitude towards patient care on the part of physicians
- c) the strong influence exerted by the Catholic Church on public debate
- d) a lack of communication skills among health care professionals.

During consultations with terminally ill patients, a ‘conspiracy of silence’ frequently envelops any discussions relating to diagnosis, ‘fatal’ prognosis, dying and death. The family wishes to protect the patient from ‘unnecessary suffering’ whereas the patient wants ‘to mitigate the spiritual pain’ in the family. Although mentioned as a barrier to effective doctor-patient communication at the bedside, ‘traditional families’ have nevertheless been an invaluable resource for the development of home care programmes.

Issues and priorities

Several factors jeopardize palliative care developments in Argentina, including the following:

- a) lack of an operational network among palliative care providers
- b) weak links between palliative care providers and other vested interests
- c) the absence of palliative care standards and professional certification
- d) concerns about opioids addiction and the mythical view of morphine as the “last resort”
- e) difficulties in obtaining and paying for certain drugs eg alternatives to morphine
- f) low (sometimes no) salaries for palliative care professionals
- g) a shortage of funds to run services and extend professional qualifications
- h) difficulties guaranteeing volunteer work and charitable funding
- i) a lack of recognition of palliative care needs at the national level
- j) insufficient palliative care provision within the health system,
- k) bureaucracy, passivity and inequality regarding health resources; their distribution, availability and allocation,
- l) a failure to address issues surrounding death and dying

Despite these many barriers, palliative care developments in Argentina lead the way in South America. Activists continue to raise the awareness levels of both society and government. Opioid consumption has increased over the last ten years and in 2001, Argentina recorded the highest morphine consumption in the region. The challenge

now facing Argentina is to integrate palliative care into the national health systems, to continue to change the attitudes of both society and the medical profession, and to increase the coverage and availability of palliative care.

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² IOELC interview: Gustavo de Simone – 2 April 2003

³ IOELC interview: Marta Junin -23 January 2004- Length of interview 73 minutes

“..en nuestros 33 hospitales tenemos 9 hospitales que tienen equipos en desarrollo o equipos maduros...Nueve son los equipos en desarrollo y maduros, dentro de los hospitales públicos de Buenos Aires...equipos maduros o equipos en desarrollo, o sea que tienen equipos que hace por lo menos aproximadamente diez años que están trabajando en cuidados paliativos... equipos en desarrollo, son equipos maduros que a lo mejor se reestructuraron; por eso están como en un continuo desarrollo”

⁴ Argentinean Association for Medicine and Palliative Care (AAMyCP) Carta Paliativa # 3 “Mensaje del Presidente” available at http://www.aamycp.org.ar/docs_download/CARTA%20PALIATIVA%203.pdf visited on November 2004 (Spanish only)

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¹² Argentinean Association for Medicine and Palliative Care (AAMyCP) Boletín Científico Octubre 2004 Editorial available at http://www.aamycp.org.ar/docs_download/Bolet_Octubre_2004.pdf visited on November 2004 (Spanish only)

¹³ IOELC interview: Gustavo de Simone – 23 December 2003

“...no hay fondos destinados a la implementación de cuidados paliativos, y eso es una, un obstáculo que todavía no fue superado...”

¹⁴ IOELC interview: Marta Junin -23 January 2004- Length of interview 73 minutes

“Las situaciones que se viven en nuestros hospitales públicos de Buenos Aires...en relación con las enfermeras que trabajan en equipos de cuidados paliativos son diferentes. Hay algunas, muy pocas, yo diría que pueden llegar a ser ...uno, dos, tres, cuatro, con mucha suerte cinco, pueden llegar a trabajar full-time en cuidados paliativos - y estoy hablando aparte de hospitales municipales, los que se relacionan con la universidad de Buenos Aires”

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- ¹⁵ IOELC interview Roberto Wenk – 29 December 2003- Length of interview 70 minutes
“Yo soy un defensor del trabajo voluntario; yo en San Nicolás soy un voluntario. Yo creo que el voluntario, si uno lo capacita en determinadas técnicas es una..., agiliza el trabajo a un cuidado paliativo tremendo. Nosotros, a nuestros voluntarios los entrenamos, desde hace mucho tiempo, en lo que es monitoreo de síntomas y en evaluaciones semi-estructuradas de síntomas; entonces eso agiliza el tiempo asistencial tremendo”.
- ¹⁶ de Simone: Pallium Latinoamerica website: see <http://www.pallium.org>
- ¹⁷ IOELC interview: Marta Junin -23 January 2004- Length of interview 73 minutes
“En el área de enfermería, fundamentalmente tenemos la posibilidad a partir de nuestro departamento de capacitación del gobierno de la ciudad de Buenos Aires. Son cursos gratuitos a los cuales pueden tener acceso todo el que esté interesado. Se dictan aproximadamente cinco cursos por año...a nivel de auxiliares y a nivel de enfermeros profesionales y licenciados, hay formación en el postgrado también, en el área universitaria con cursos avanzados, a través de centros de estudios de cuidados paliativos. Después lo que también estamos trabajando muchísimo es en el pre-grado...tenemos el reconocimiento de 25 horas cátedra dentro de una materia...de enfermería...”
- ¹⁸ Argentinean Association for Medicine and Palliative Care (AAMyCP) Carta Paliativa # 3 “Mensaje del Presidente” available at http://www.aamycp.org.ar/docs_download/CARTA%20PALIATIVA%203.pdf visited on November 2004 (Spanish only)
- ¹⁹ Wenk R (1993) Argentina: status of cancer pain and palliative Care. *Journal of Pain and Symptom Management* 8(6):385-387
- ²⁰ IOELC interview: Eduardo Bruera – 9 November 1995. Length of interview: 45 minutes
- ²¹ see Argentinean Association for Medicine and Palliative Care (AAMyCP) Boletín Científico Octubre 2004 available at http://www.aamycp.org.ar/docs_download/Bolet_Octubre_2004.pdf for further details on current palliative care developments in the county as well as other similar documents available on the AAMyCP website: <http://www.aamycp.org.ar> (Spanish only)
- ²² IOELC interview: Jorge Eisenchlas – 2 October 2001
- ²³ IOELC interview: Roberto Wenk – 29 December 2003
“...es una unidad que tiene seis camas de cuidado paliativo, con actividad veinticuatro por siete, con personal específico para cuidado paliativo. Y eh..., tiene una pequeña área de docencia, una pequeña área de..., donde hacemos algo de investigación, tiene tres consultorios externos, tiene una sala de familia...Es una unidad que tiene, desde el punto de vista asistencial, tiene un impacto limitado, porque tenemos poca capacidad de asistencia a domicilio. O sea tiene una..., 17-20% de muertes en domicilio, la mayoría es muerte en internación...Entonces, los únicos pacientes que vemos en domicilio son los que viven en el barrio ¿no?... esta unidad fue aprobada como sitio de concurrencia en cuidados paliativos, lo cual marca una..., un punto muy importante, uno lo dice libremente, pero que se acepte, o sea, que acepten lo que es concurrencia, las autoridades de salud, las autoridades de docencia, es muy importante en cuidados paliativos ¿no?... diría que el 95% (de los pacientes) es de oncología... El número de pacientes que permanentemente está en tratamiento está alrededor de los veinte, los otros catorce - quince pacientes están en las camas asignadas que están dentro del hospital. Uno de los problemas que tenemos es que los pacientes tienen una muy baja rotación, en cuanto a la utilización de camas, y eso se debe a que son pacientes...nuestros pacientes, la mayoría de los pacientes que tienen una internación prolongada, la tienen por factores socio-económicos, no clínicos. Son pacientes que una vez que ingresan en un sistema de cuidado, no tienen quién los continúe...cosa que en la unidad del Somer, los separamos. En la unidad del Somer tenemos dieciséis camas...”

tenemos ocho camas de agudo y ocho camas de crónico. Y dejamos las ocho camas las ocho camas para estos pacientes con falta de recursos socio-económicos”.

²⁴ IOELC interview: Jorge Manzini – 30 December 2003- Length of interview 49 minutes
“...el equipo de PADES tiene médicos, enfermeros, asistente social, y secretarias, ese es el núcleo básico. Y después tiene todo el apoyo del servicio de fisioterapia y de todos los servicios del hospital con especialistas... Yo estoy trabajando como asesor... camas de cuidados paliativos pueden ser 30 o 40 fácil en domicilio.....Es decir, esos pacientes reciben dos visitas diarias de enfermería, por ejemplo...En el hospital se comparte la internación con los servicios de medicina interna, no hay un lugar especial de internación”

²⁵ IOELC interview Elena D' Urbano – 29 December 2003- Length of interview 33 minutes
“En el plan de asistencia domiciliario mi trabajo consiste en las entrevistas de admisión, a donde concurren los familiares, donde yo evalúo cual es la condición de esa familia para recibir a ese paciente en domicilio, y además, también establezco un pacto con ellos, que es lo que les vamos a ofrecer y hasta donde es el compromiso de ellos; es decir, como es la puerta, el punto de partida para el equipo. Por otra parte, soy la persona que me ocupo del seguimiento de las familias....Y después, bueno, hago actividad de duelo, que trabajamos a demanda, o sea, a partir de aquel que requiera una asistencia específica que lo demande, o aquel que nosotros identifiquemos como algún familiar de mayor riesgo. Y otra de las actividades que hago es la coordinación de centro de día...El centro de día, en realidad, es una actividad fuertemente social donde los pacientes puede pasar tres veces por semana bastantes horas, y donde fundamentalmente lo que se trata es de trabajar todo un proceso de socialización con fines terapéuticos. Los pacientes trabajan con distintas técnicas..., nosotros formamos voluntarios, que algunos tienen algunas habilidades especiales, y trabajamos tanto con técnicas corporales como masajes, reflexología, Rei Ki, yoga, como trabajamos también con actividades artísticas: pintura, música; digamos que tratamos de utilizar todas las técnicas que pueden ser útiles para personas más debilitadas. Es un trabajo muy interesante porque, en realidad, se genera un ambiente donde, sobre todas las cosas, se trabaja con la enfermedad, sin la negación del proceso de enfermedad y, bueno, ir preparando también la situación ¿no es cierto?, la situación futura y también la aceptación presente.”

²⁶ World Health Organisation statistics 2000-2002. See <http://www.who.int/country/arg/en/> visited in August 2004

²⁷ see http://www.nationmaster.com/country/ar/People&b_define=1 visited in August 2004

²⁸ see <http://www.indec.mecon.ar/> visited in August 2004

²⁹ De Simone (2000) Palliative care in Argentina. *Palliative Medicine* 14:323

³⁰ The WHO defines the international dollar as a common currency unit that takes into account differences in the relative purchasing power of various currencies. Figures expressed in international dollars are calculated using purchasing power parities, which are rates of currency conversion constructed to account for differences in price level between countries

³¹ World Health Organisation statistics 2000-2002. See <http://www.who.int/country/arg/en/>

³² See <http://www3.who.int/whosis/country/indicators.cfm?country=arg&language=en#economic> visited in August 2004

³³ Tandon A, Murray CLJ, Lauer JA, Evans DB. Measuring overall health system performance for 191 Countries. GPE Discussion Paper Series: No 30; WHO

³⁴ <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

³⁵ See [http://www.nationmaster.com/country/ar/Economy visited in August 2004](http://www.nationmaster.com/country/ar/Economy%20visited%20in%20August%202004)

³⁶ See <http://www.bioetica.org> – a web site dedicated to medical ethics. “*Cuadernos de Bioética*” (Bioethics Notebooks) is a regular release that includes notes and experts’ viewpoints on a wide range of topics with particular emphasis on the practice of medicine in Argentina and Latin America. Discussions on ethical dilemmas at the end of life are included

³⁷ Eisenchlas JH, De Simone G (2003) From Argentina. *Palliative Medicine*, 17(2):151