

Palliative care in Argentina: barriers, opportunities and recommendations for future developments

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Between September 2003 and September 2004, a research project was conducted to explore the development of palliative care in three Latin American countries – Argentina, Colombia and Mexico – as part of a MMedSci in Palliative Care at the University of Sheffield, supervised by Professor David Clark and under the auspices of the International Observatory on End of Life Care (IOELC). The research methods used included: a systematic review of the literature as well as face-to-face and telephone interviews conducted amongst palliative care pioneers, palliative care practitioners and ethicists involved in end-of-life care in the three countries. This paper describes the development of palliative care in Argentina in the context of some economic and epidemiological aspects. Dimensions of health care system organisation relevant to the provision of palliative care are presented along with an examination of opportunities for, and barriers to, palliative care development. The paper concludes with some recommendations for the future.

Palliative care in Argentina: opportunities for, and barriers to, its development

Palliative care started in Argentina during the 1980s. Several factors contributed to its emergence.

First, in the international context, the World Health Organization (WHO) committed itself to promoting the

recognition of pain in cancer patients as a health problem world-wide, and of special relevance in non-industrialised countries.¹ As part of its strategy, the WHO invited interested individuals working in pain control and cancer care to be ‘focal points’ of its Cancer Pain and Palliative Care Programme in their own countries. Dr Roberto Wenk, who was at the time leading one of the earliest initiatives directed towards promoting and improving cancer pain control in Argentina, agreed to be put forward for this role.²

Second, in the national context, democracy was restored to the Argentinean political system, which allowed health professionals to attempt more innovative approaches in health care practice and prompted a greater sense of freedom to communicate more openly with patients, carers and colleagues. Palliative care represented a new medical subject that emphasised the need for applying a novel philosophy on dying and death. New approaches in any practice were usually seen as subversive and they were discouraged under dictatorship.³ The return of democracy set the appropriate political context to pioneer initiatives in medical practice in the country.

Third, groups of physicians and nurses working in the main hospitals in major cities became aware of the need for new knowledge and skills in order to care more effectively for incurable patients dying of cancer, who at the time constituted a group frequently forgotten by the medical community.⁴

The earliest palliative care initiatives started almost simultaneously in the metropolitan capital of Buenos Aires, and in smaller cities, such as San Nicolas, La Plata and Mar del Plata. They provided pain relief and emotional support to terminally ill patients and their carers either in hospitals or at the patients’ home, mainly free of charge and with little or no institutional support. The creation of the Argentinean Association for Medicine and Palliative Care (AAMyPC) in 1994 gave formal recognition to subsequent palliative care undertakings. By that year, physicians, nurses, psychologists, social workers and professionals from other disciplines related to end-of-life care were grouped into 20 teams that operated mostly in the main cities.⁵

Over the decades, the development of palliative care in Argentina has been strengthened by:

- the importance that leading *palliateurs* have given to promoting palliative care education amongst health professionals
- the increasing support for palliative care services from non-governmental and private organisations

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- a growing recognition of the need to integrate the discipline within public and private health institutions
- the dissemination of information on end-of-life care matters and approaches directed to professionals and to the community
- an expanding professional and public interest in end-of-life issues and palliative care
- relatively flexible legislation on opioids
- the availability of diverse opioid formulations
- the emerging notion of the importance of promoting palliative care research and audit, within and amongst teams, to document local data and experiences.

Nonetheless, access to palliative care in Argentina remains difficult or impossible in smaller urban areas, towns and rural locations. Despite a relatively steady expansion, palliative care services are still quite insufficient to reach the vast majority of patients who might benefit from them.

A series of factors has contributed to the wavering progress of the discipline in the country:

- subsequent financial crisis, which has negatively affected all social welfare provision, including health care and health education
- bureaucracy, passiveness and inequality in the distribution and allocation of health resources nation-wide
- national health care plans directed largely towards childhood diseases, malnutrition and acute medical events
- poor strategies to recognise and support effectively the development of palliative care services within the public sector at the governmental level
- a national health system that only provides medicines free of charge to hospital in-patients, combined with the low salaries and pensions of most patients in the community who struggle to pay for their medicines despite many palliative care medications being readily available in the market

- shortage of funds to run and to guarantee the continuity of already established palliative care services
- difficulties in sustaining continuous volunteer work and charitable funding
- scarcity of grants to encourage palliative care education and training
- a concentration in Buenos Aires of the most structured and formally recognised educational programmes and training opportunities
- lack of expert support and formal supervision for most palliative care professionals working in areas distant from the main cities
- low or non-existent salaries for palliative care professionals
- absence of recognised palliative care standards for practice and for the organisation of services
- lack of operational networks among palliative care providers
- weak links between palliative care providers and other vested interests
- absence of professional accreditation
- long-standing professional and public misconceptions on the use of morphine and end-of-life care approaches
- prevailing professional and public reluctance towards addressing matters of dying and death.

Palliative care and the Argentinean national health system

The inequality in the allocation of health resources countrywide and the very limited support given to palliative care by governmental authorities are widely perceived as key obstacles amongst palliative care practitioners in the country.⁶ In 2001, health care costs in Argentina were amongst the highest in South America.⁷ In that year, the

Table 1. Expenditures on health for Argentina, for neighbouring countries and in Europe

Indicator	Non-industrialised countries				Industrialised countries		
	Argentina	Brazil	Chile	Uruguay	France	Spain	UK
Total expenditure on health as percentage of GDP (2001)	9.5	7.6	7.0	10.9	9.6	7.5	7.6
Total health expenditure per capita (Intl \$, 2001)	1130	573	792	971	2560	1630	1989
General government expenditure on public health as percentage of total expenditure on health (2001)	53.4	41.6	44.0	46.3	76.0	71.4	82.2
Private expenditure on health as percentage of total expenditure on health (2001)	46.6	58.4	56.0	53.7	24	28.6	17.8

Table 2. Efficiency performance of the Argentinean health system in the regional context

Country	Index	Position	
France	0.994	1/191	
Colombia	0.910	22/191	
Chile	0.870	33/191	
Venezuela	0.775	44/191	
Paraguay	0.761	47/191	
Uruguay	0.745	55/191	
Argentina	0.722	75/191	
Ecuador	0.619	111/191	
Brazil	0.573	125/191	
Bolivia	0.571	126/191	
Guyana	0.554	128/191	
Peru	0.547	129/191	
Sierra Leone	0.000	191/191	

government spent 1130 Intl \$ per inhabitant on health care, which represented 9.5% of the country's GDP.⁸ These figures represented the first and the second highest, respectively, in South America and they were close to those for industrialised countries such as France, Spain and the UK (Table 1). Half (53.4%) of this investment covered the costs generated by the public health sector which looked after 70% of the general population. The other half (46.6%) was directed at the private health sector, including 'mutuals', which represented the remaining 30% of the country's inhabitants.⁹ These percentages differed considerably from those described in industrialised countries where 70% or more of expenditures on health are devoted to the public sector. In Argentina, on the other hand, a substantial proportion of the government's spending on health was directed towards covering the costs of the relatively small and less vulnerable private sector (Table 1).

In 2000, the WHO set up a new way of measuring performance based on the results obtained over three main areas: (i) improvement in the health of the population; (ii) enhanced responsiveness of the health system to the legitimate expectations of the population; and (iii) fairness in financing and financial risk protection.¹⁰ This overall health system performance score places Argentina 75/191 countries world-wide. According to this, the health system in Argentina is of average efficiency. The Colombian, Chilean, Venezuelan, Paraguayan and Uruguayan health systems are more able to achieve their potentials given their inputs than the Argentinean one, while the health systems in Ecuador, Brazil, Bolivia, Guyana and Peru are less effective (Table 2).

Health policy in Argentina has not given systematic and formal attention to the care of the incurably ill, and palliative care has not been recognised as a medical specialty within the national health system. As a consequence, most teams secure budgets for services through the contribution of private and non-governmental organisations and most palliative care professionals are paid under the auspices of other specialties. There are, however, no

standardised approaches to charitable funding and to organising volunteer work amongst teams, which adds to the financial vulnerability of services.

The Argentinean national health system favours the existence of many more medical specialists than general practitioners or family doctors, as well as of many more physicians than nurses. In 2004, for instance, it was estimated that there were 86,000 nurses and 108,800 physicians in the country.¹¹

Nurses trained and working full-time or most of their time in palliative care are extremely scarce. There are only about five nurses who devote most of their time to palliative care in public hospitals in Buenos Aires, a city of over 13 million inhabitants (2003 estimates).^{12,13}

This combination of a high proportion of specialist physicians, a very low nurse/physician ratio of 0.08 and only very few nurses dedicated to palliative care on a full-time basis makes it very difficult to organise and co-ordinate continuous follow-up, support and home care for palliative care patients.

The epidemiological transition in Argentina and the place of palliative care

Reasons for the poor attention given by Argentinean governments over the years to the care of the chronically ill and the dying may include:

- the age structure of the Argentinean population which comprises a high proportion of young people; in 2004, 89.5% of Argentinean inhabitants were below 65 years of age (Table 3)

Table 3. Age structure of the Argentinean population (2004 estimates)¹⁵

Population age sectors	Percentage of population
0–14 years	25.9%
15–64 years	63.6%
65 years and over	10.5%

Median age, 29.24 years

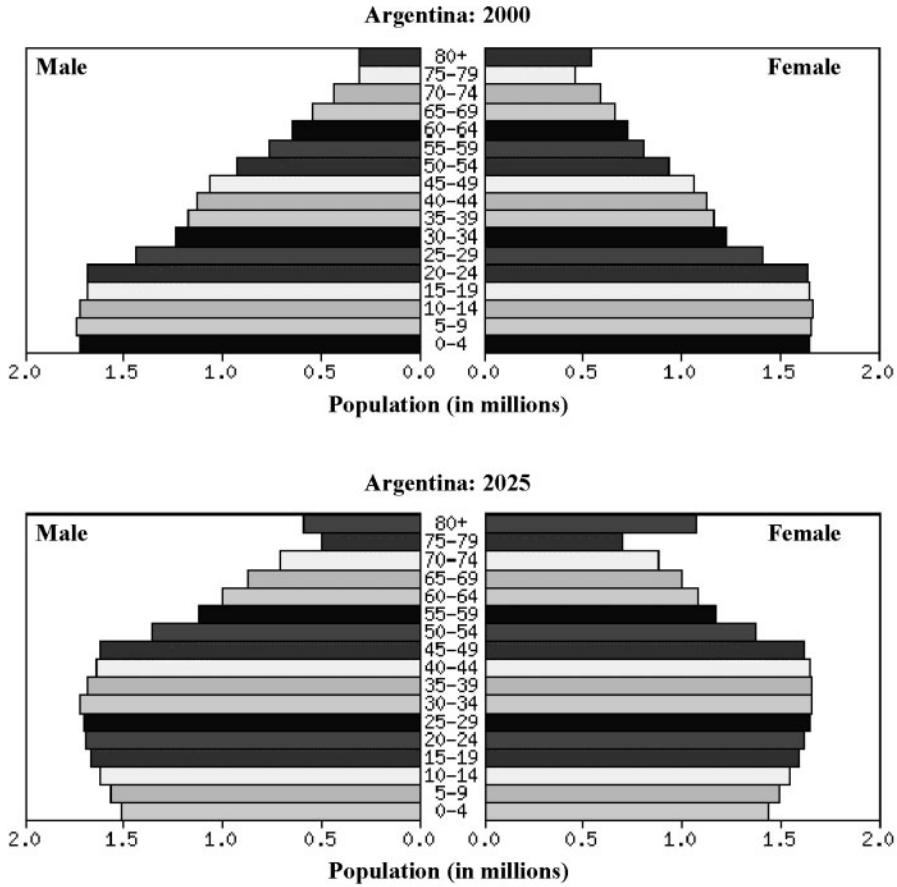


Fig. 1. Comparison of Argentina’s pyramids of population for 2000 and as estimated for 2025 (Source: US Bureau of Census).

- the fact that acute and preventable conditions, such as cardiovascular diseases, malignant tumours and respiratory diseases have been the main causes of death.¹⁴

In the coming decades, however, Argentina as well as other Latin American countries will face the major challenge of an ageing population. By 2025, it is estimated that while the proportion at younger ages will remain largely unchanged, the number of inhabitants over the age of 65 years will increase by more than 2 million (Fig. 1).¹⁶

This epidemiological change is the consequence of rising life expectancy, and of the economic transition which implies the urbanisation and industrialisation that most developing countries are going through as part of globalisation. Predisposing factors to chronic illnesses due to changes in life-style, such as physical inactivity, increased use of tobacco and unhealthy diets, will add to other problems already in existence in low and middle income countries, such as low birth weight, folate deficiency and chronic infections. A growing incidence of heart disease, stroke, cancer and diabetes as well as dementia and other medical conditions associated with older age groups will constitute sources of chronic disability and long-term suffering if left unattended.

It has been demonstrated that palliative care represents an adequate approach to providing cost-effective professional care at the end of people’s lives.¹⁷ Most Latin families welcome the opportunity of caring for their relatives at home if appropriate support exists. Sustained and well-organised palliative care services may well empower family members to care more effectively for their loved ones at home thus ensuring continued care, as well as reducing overall medical costs and the burden on health care institutions.

The problem of the availability of opioids

The cost of medicines is one important limitation for providing palliative care to patients in the community.¹⁸

Argentinean patients have to pay for their medicines when outside hospitals and with low (or non-existent) pensions or salaries, medical treatment at home usually represents an unaffordable cost for many. For instance, in 2002, the average monthly cost of standard treatments with strong opioids largely exceeded the monthly income of most patients living in Argentina. It was estimated that while one month treatment with 180 mg equivalent dose of oral morphine cost about US\$ 350, the average monthly income was only about US\$ 140 ± 54.¹⁹ As a conse-

quence, despite being largely available in the market and the prescription process being relatively flexible if compared with other Latin American countries, strong opioids are inaccessible (or unaffordable) to many palliative care patients.

In 2003, several medications usually prescribed to elderly and chronically ill patients were included in the national formulary of essential drugs. By the end of 2004, only oral formulations of morphine had been included and many other medicines used in palliative care as well as in severe pain management, including alternative formulations of strong opioids, remained excluded.^{20,21} A discount in the final cost applies to medicines included in the national formulary, but terminally ill patients have to pay the full price for their palliative medications because most of them have been left out.

Two main consequences result from this. On the one hand, unable to afford the drugs, patients need to be admitted into hospitals to guarantee the adequate provision of basic medicines to control their symptoms, hugely increasing the costs of care and the burden on patients and families who may prefer to remain at home. On the other hand, palliative care practitioners have no option but to rely on cheaper 'home-made' formulations to facilitate the access of out-patients to basic drugs. Although it has been argued that, in a context of financial vulnerability, the continuous provision of palliative care would be in danger without this resource, the risks of prescribing 'home-made' medicines where quality and effectiveness have not been rigorously controlled and tested ought to be assessed.^{22,23}

The problem of accessing palliative care services

Most palliative care services in Argentina are located in the main urban areas, such as: the capital city of Buenos Aires and its periphery; Mar del Plata; Neuquén; Rosario and Córdoba (Fig. 2).

As shown in Figure 2, most services are concentrated in the central part of the country, while the northern and southern regions have no palliative care facilities. Palliative care seems insufficient if the ratio of palliative care service/million inhabitants in each of the cities described is considered. For instance, there is one palliative care service available for every 392,000 inhabitants in Neuquén; for every 1,453,000 inhabitants in Buenos Aires and for every 1,486,000 inhabitants in Córdoba.

These figures are far behind international standards for adequate palliative care provision.²⁴ But, because these indicators ought to be interpreted according to the needs of the population in each community mainly based on the deaths from cancer and degree of social deprivation rates, a comparison with international standards for palliative care provision seems inappropriate.

Distance from main cities in a vast territory such as Argentina is an important issue that affects remote locations.



Fig. 2. Main urban areas where most palliative care services are located in Argentina (ratio palliative care service/million inhabitants for each city).

Being the second largest country (after Brazil) in South America, effective communications are crucial to guarantee access to palliative care programmes clustered in the main cities of the central part of the country. But communication systems in Argentina are poor (Table 4). Transportation is mostly based on local public services, and on inter-regional bus and aircraft services; cars are only accessible to the population who can afford them. As described in Table 4, only 3.17% of the national territory has paved highways (1998 estimates) while railway facilities are only available in 1.7% of the country's extent (2000 estimates).²⁵ Thus, long-distance travelling from southern or northern areas to the capital, for example, can be very expensive or enormously time consuming.

In these circumstances, the Internet represents an invaluable tool for people living outside the main cities who seek access to information and to advice from experienced professionals. However, only 10% of the Argentinean population (2001 estimates) uses this resource (Table 5).²⁶

Table 4. Transportation coverage

Transportation system	Coverage
Highways	Total – 215,434 km Paved – 63,553 km Unpaved – 151,881 km (1998 estimate)
Railways	Total – 33,744 km (2000 estimate)
Airports	1369 available (2001 estimate)

Transportation coverage seems meaningless if the extension of the Argentinean territory of 2.77 million km² is considered.

A reasonable assumption that flows from the scarcity in transportation and communication facilities is that many health authorities, policy makers, health-care practitioners, patients and families living in distant cities never get to know about the existence of palliative care in the country. Many patients, on the other hand, living in towns or more rural areas who could certainly benefit from palliative care cannot get it either because they cannot physically or financially afford the travel to attend regular medical consultations, or because it is unfeasible for health carers to visit them at home. In order to respond to these needs, a model for providing palliative care to people living in distant suburbs or in rural areas has been suggested.²⁷ It is based on a first consultation conducted to assess patients' and families' needs and on regular telephone follow-up for medical advice and support.²⁸

Barriers to formal palliative care training and continuous palliative care education

The current barriers to formal palliative care education and training in Argentina are those: (i) affecting health professionals living in areas distant from main cities; (ii) derived from currently available palliative care education modalities; and (iii) concerning the delivery of palliative care education in main health institutions

The more experienced and well-structured palliative care education and training programmes only exist in Buenos Aires with some other minor initiatives described in Rosario.²⁹ The programmes in Buenos Aires are the only ones in the country committed to providing continuous education and opportunities for clinical training and formal supervision to those professionals interested in becoming palliative care specialists. The lack of effective

Table 5. Internet services coverage

Communication system	Coverage*
Internet service providers	33 (2000 estimate)
Internet users	3.88 million (2001 estimates)

*Argentinean population – 38,740,807 inhabitants (2004 estimate).

transport and communication systems makes it difficult, or unaffordable, for health-care practitioners living far from the capital city to access palliative care training. Distance learning courses provide theoretical information, but chances for supervised 'hands-on' practice are scarce and most professionals usually acquire their clinical skills from personal experience.

Most education in palliative care is delivered in part-time courses; some of these require the student's attendance and others are by distance learning. With information and the few skills acquired over a year or two in this way, the vast majority of doctors and nurses come back to their work places where there usually is no end-of-life care expertise. They acquire their clinical skills by sharing their practice with equally inexperienced colleagues.

Regular seminars, national and regional educational meetings and information available mainly through the websites of the Argentinean Association of Medicine and Palliative Care (AAMPC)³⁰ and the International Association for Hospice and Palliative Care (IAHPC)³¹ provide opportunities to interested professionals for regularly up-dating information on palliative care.

In the main city hospitals, on the other hand, the lack of knowledge and skills on pain management and end-of-life

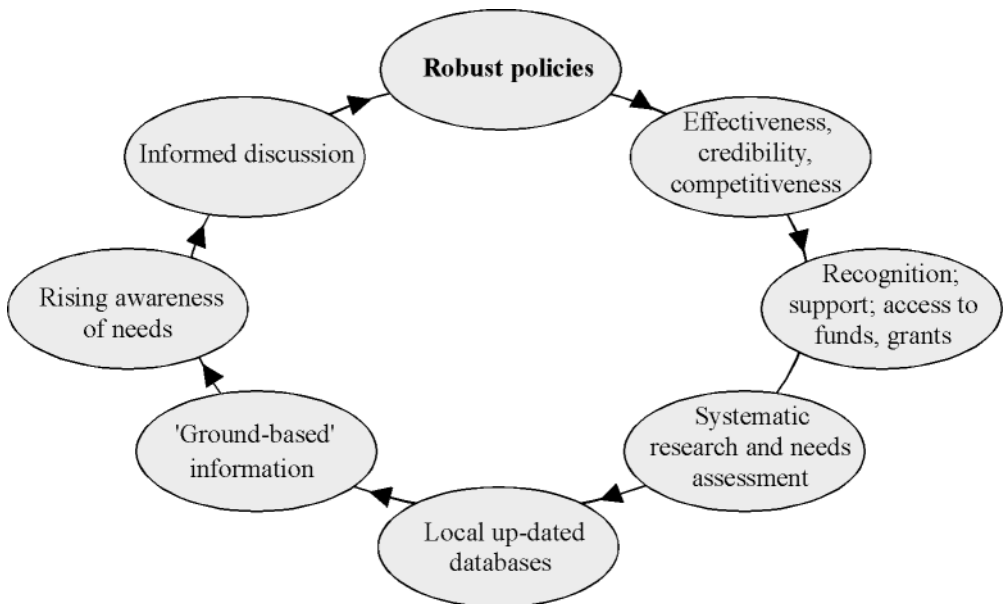


Fig. 3. Agreed and standardised palliative care policies are vital to consolidate the growth of the discipline countrywide.

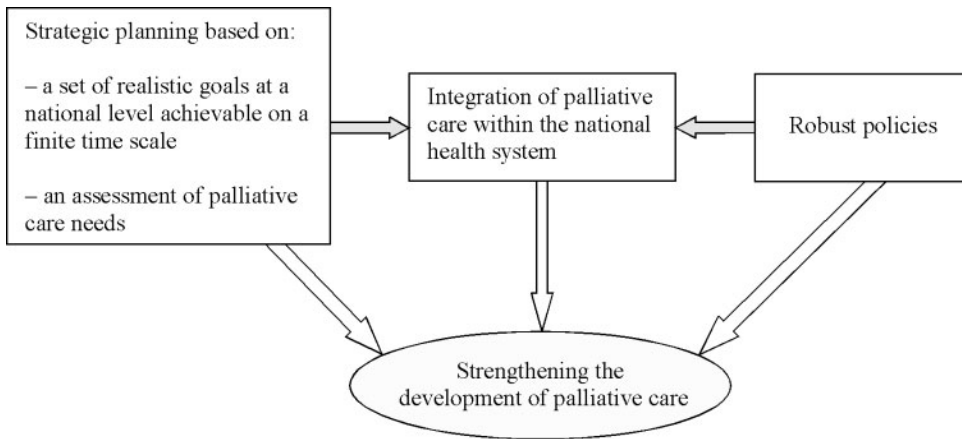


Fig. 4. The integration of palliative care into the national health system, strategic planning and robust policies strengthen the future of the discipline.

care on the part of more senior clinical staff has been described as an obstacle that has seriously hindered palliative care education amongst junior trainees.³² For similar reasons, it may also be difficult for nurses trained in palliative care to share their knowledge and apply their learning in their approach to terminally ill or dying patients.³³

In general terms, palliative care education in Argentina lacks standardisation and there are no clear pathways for specialisation. It has not been included in the undergraduate curriculum of medical students, although concepts on pain management and palliative care have been incorporated as part of core surgical subjects in the curriculum of nursing students.³⁴

Towards strengthening the development of palliative care in Argentina

The growth of palliative care in Argentina faces four main challenges:

- to integrate palliative care into the national health system
- to introduce countrywide agreed and standardised palliative care policies
- to secure funds for future developments
- to improve currently available modalities for palliative care education and training.

Over the next 20 years, the older sector of the Argentinean population will increase, steadily bringing about a higher incidence of chronic illnesses and cancer which will require proper care. Investments in preventive measures are important, but it is also crucial to secure long-term care and adequate support for people close to the end of their lives, and for their families. Palliative care has been referred to as the most cost-effective modality to offer professional care to this sector. The ultimate aims are to improve the quality of life of terminally ill patients and their families, to diminish the burden on health institutions and

to promote the social integration of the incurably ill. These are strong arguments for palliative care. The integration of the discipline into the national health system is essential if we are to see an increase in its availability countrywide.

Agreed and standardised policies for service organisation and function, clinical practice, education and training, and systematic quality control are needed to foster the effectiveness, credibility and competitiveness of palliative care as a medical specialty (Fig. 3), as well as to be in a position for claiming recognition and formal support and for competing for local, regional or national, private or public funds. Systematic research and assessments of the palliative care needs of the population are important to generate local data bases and to produce ‘ground-based’ information in order to inform health authorities, policy makers, palliative care services, the health profession and the public about these issues. The encouragement of continuous informed discussion and of network collaboration amongst palliative care teams, and with other health sectors, is central to the consolidation and growth of the discipline.

Palliative care providers and related sectors, including health authorities, policy makers, health professionals, health educators, and representatives of the pharmaceutical industry may well be brought together to discuss and agree upon priorities in the care of the terminally ill. There are several examples of initiatives of this kind in the literature, although they have usually been conducted at a regional rather than at a national level.³⁵

In the context of a medical culture very much orientated towards ignoring end-of-life care matters, it could be argued that the insufficient robustness of palliative care education may have contributed to the lack of support for palliative care from other medical specialties and from local health authorities. For health professionals willing to become palliative care specialists and to devote all or most of their professional time to palliative care, a standardised palliative care

core curriculum designed for doctors and nurses in training as well as a clear pathway for specialisation are decisive if the discipline is to claim formal recognition as a medical speciality in the country. For those health professionals with a more limited interest in the discipline, current educative modalities might be sufficient.

In undertaking these tasks, international organisations, such as the International Association for Hospice and Palliative Care (IAHPC), the International Observatory on End of Life Care (IOELC), Help the Hospices (HtH) or the National Council for Palliative Care (NCPC) represent valuable sources of expert advice, educational opportunities, up-dated and research-based information, and chances for international collaboration and exchange of information.

To reach agreement on a set of realistic goals at a national level, achievable on a finite time scale, amongst all sectors involved, and based on known end-of-life care needs is vital to the strategic planning of palliative care (Fig. 4).

Conclusions

Argentina has led the way in palliative care in Latin America. In the years ahead, it must plan and strengthen the future of the discipline and be ready to respond to forthcoming epidemiological challenges.

Acknowledgements

I am very grateful to Dr Gustavo De Simone, Dr José Mainetti, Dr Jorge Manzini, Dr Roberto Wenk, Ms Marta Junin and Ms Elena D'Urbano for their invaluable contributions to this project.

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