

Palliative Care in Brazil: A Challenge to the Health-Care System

Ciro Augusto Floriani

Bioethics Council, Brazilian National Cancer Institute, Ministry of Health, Rio de Janeiro, Brazil.

Abstract: The global expansion of the modern hospice movement has been fast and impressive, and in developing countries this phenomenon has also been registered, despite the structural and operational difficulties of their health systems. This article will address the scenario of palliative and hospice care in Brazil, pointing to the challenges and difficulties for the implementation of this comprehensive programme within its health system.

Keywords: hospice care, patient care team, equity in the resource allocation, bioethics

Introduction

Since its birth some 40 years ago, the growth of the modern hospice movement and its global dissemination has occurred at a fast and impressive pace.¹ Recent records account for the presence of hospice care and/or palliative care in 115 countries, while in some 41 other countries, conditions exist for its development.² However, despite this welcome expansion, in developing countries several factors concur to render palliative care actions less effective. We make mention of the existence of policies for the tardy and restricted release of opioids, the lack of qualification of human resources, the allocation of resources primarily directed to other health areas, and the paucity of investments in palliative care teaching and research.^{3–5}

However, despite such a difficult scenario, important initiatives have been taken and are in progress in several developing countries.^{6–8} In Latin America, the World Health Organization and the International Association for Hospice and Palliative Care have been fostering changes in the strategies of incorporation of palliative care in health-care systems, with a strong emphasis on the field of palliative care education, and on the implementation of a more agile and less bureaucratic national narcotic control policy.⁹

Brazil, the largest country in Latin America, with a huge territorial extent and cultural diversity, shows a yet incipient, timid and unarticulated end-of-life policy, faced with the great challenge of having to incorporate palliative and hospice care in its health-care system.

In this article we will initially characterize the modern hospice movement in Brazil and, then, address the challenges inherent to the incorporation of palliative and hospice care into the established health-care model, signaling to some aspects relevant for a successful implementation of an end-of-life health-care model, duly adapted to the needs and possibilities of a health-care system such as Brazil has.

History of the Hospice Movement in Brazil

In Brazil, there are no reliable records related to what could have been the first hospice. However, the first hospice would most likely have been created 1944, in the city of Rio de Janeiro, located in the Penha District. Founded by the then director of the National Oncology Service, Mário Kröeff, the “Penha Asylum” was intended to assist poor patients with advanced cancer, who were unable to find a bed in general hospitals, or in the National Oncology Service.¹⁰ Of a private and philanthropic nature, the creation of that institution was, in fact, an attempt to respond to the problem created by patients with advanced cancer; as such patients would not draw the attention of traditional hospitals engaged in curative, teaching and research assistance activities. Later, the “Asylum” was expanded to become a reference oncology hospital, the Mário Kröeff Hospital.¹¹

Correspondence: **Ciro Augusto Floriani**, Rua Dr Nilo Peçanha, 01, bloco3, ap. 1506, Niterói, RJ, Brazil. Tel: +55 21 26131652; Email: ciroafloriani@terra.com.br



Copyright in this article, its metadata, and any supplementary data is held by its author or authors. It is published under the Creative Commons Attribution By licence. For further information go to: <http://creativecommons.org/licenses/by/3.0/>.

In 1968, the Tobias Clinic was created in São Paulo, a private anthroposophic clinic which, until the closing of its clinical inpatient unit in 1993, admitted terminally-ill patients, in particular patients with cancer, advanced hepatopathy and AIDS, with a philosophy very close to the modern hospice movement philosophy.

However, despite such isolated initiatives, it was only in the early 1980's when other palliative care units or centers emerged, with the majority of them delivering treatment to cancer patients and/or referred to as centers for treating chronic pain. These centers were found in the states of Rio Grande do Sul, Santa Catarina, Paraná, São Paulo and Rio de Janeiro. There are, currently, about 30 palliative care centers in Brazil,¹² the largest of them located at the National Cancer Institute, in the city of Rio de Janeiro (Cancer IV Hospital).

The Brazilian Association for Palliative Care (BAPC) was founded in 1997, a not-for-profit association aimed at the diffusion of palliative care across the whole national territory. The National Academy for Palliative Care was founded in 2005, with objectives similar to those of the BAPC in regards to the dissemination, teaching and research work on palliative care, and engaged in the recognition of palliative medicine as a medical specialization.

However, this is not an easy task, because of the lack of penetration of palliative care across the Brazilian academic milieu, particularly in medical schools. In such environments, isolated initiatives show the difficulties to develop sensitiveness to the need for teaching palliative care to medical school undergraduates, as opposed to the great interest of students for end of life issues.¹³ We should add to this the scarcity of post-graduate courses on palliative care. In a country with continental dimensions such as Brazil has, we ought to have a much larger offer of specialization courses on palliative medicine to meet the great demand for this type of care, however, at the time of writing this article only one such course was registered, with an one-year duration, and offered by National Cancer Institute. The course subject matter related to oncologic palliative care.

The Brazilian Health-Care System and the Incorporation of Palliative Care

The health-care system in Brazil is constituted of a public sector—called Unified Health System

(Sistema Único de Saúde—SUS), created in 1989 and providing health care to about 2/3 of the 180 million inhabitants—who use both the public health care services and privately-contracted services, and a freely selected private sector, maintained by private health-care plans and by health insurance institutions, serving some 40 million persons.¹⁴

The SUS has a decentralizing character, with social participation in the three government levels, with the Ministry of Health—at federal level—being in charge of the formulation, implementation, assessment and control of health-care policies. It comprises a complex network of health services, ranging from the Basic Care Network to tertiary hospitals and specialized care centers.¹⁴

Basic Care comprises a set of actions for health promotion and protection, for the diagnosis, treatment, rehabilitation and recovery from illnesses. Acting both in the individual and collective levels, Basic Care plays a leading role in the regulation of the health-care system, and according to recent directives from the Ministry of Health. It is comprised of; the Basic Health Units, the Family Health Program (FHP) and the Program of Communitarian Health Agents (PCHA). These programs aim to provide an intense family health care system in large part of the national territory. However it should be stressed that the structuring of Basic Care is currently under implementation.¹⁵

In the last 10 years, several initiatives by the Ministry of Health have incorporated palliative care as an important strategy for the health policy, some of which are briefly described below. The year 1998 saw the start of High-Complexity Centers on Oncology, foreseeing the need for a qualified team on palliative care, both for hospital inpatient treatment and for home treatment. This initiative is aimed at including palliative care in SUS oncologic care.¹⁶ The National Program for Humanizing Hospital Care was instituted in 2001, being engaged, among its other assignments, in the promotion of humanization in the health care of users of the public hospital network.¹⁷ Such a measure becomes relevant in face of the following reports on abandoned patients with advanced diseases using public health care.¹⁸ The National Program for Pain Care and Palliative Care was instituted in 2002, an important step towards the nationwide diffusion of palliative care, and this was when Reference Centers for Pain Treatment were instituted.^{19,20}

In the private sector, there are few records involving palliative and/or hospice care, but home care is a sector which has been experiencing strong expansion, since the 1990's. However, founded on the model known as "*hospital without wall*",²¹ and having as a consequence the "*hypermedicalization of home*",²² this is a problematic sector, from the ethical point of view, for end-of-life care.²³ There is, in this aspect, a long path to be walked towards the organization and qualification of home care services in the private palliative care level in Brazil.

Therefore, the implementation of a consistent and organized network for palliative care constitutes a challenging task both to public and private administrators and, despite all governmental initiatives, the implementation of palliative care in the Brazilian health care system is sluggish and unarticulated. There are important operational, ethical and cultural barriers to be overcome and corrected, some of which are described below. Confronting such issues is crucial for countries such as Brazil, so they may be capable of implementing a palliative care and hospice care model that would be assimilated in a non-critical manner, and being socially rooted and compatible with the needs and peculiarities of the country.

Human resource qualification

One of the most critical aspects of fundamental importance relates to human resource qualification on palliative care, leading to the need for creating continuing educational programs. As there are very few palliative care centers in Brazil, a major challenge is that of forming qualified teams to deal with end-of-life care in places located far from such centers. Formation of such teams should be carried out all over the national territory, based on a national palliative care policy, taking into account the various socio-cultural realities and the access to the existing health care system in the various regions of the country. There also ought to be, as part of this qualification strategy, a change in academic vision, with the urgent need for implementing a palliative care discipline in the curriculum of health professionals and, in particular, of medical students. Otherwise, the distortions regarding the decision-making process in the face of advanced and terminal diseases will not be corrected, rather perpetuating futile therapeutic solutions and situations of abandonment to the detriment of a

treatment procedure that would be more compatible with the advanced stage of illness.

Reference and counter-reference

Another important issue relates to the interruption of the curative treatment and to the follow-up and progress of palliative treatment, considering that in Brazil, the few places where palliative care teams are available, the offer of parallel curative and palliative treatment would not be usual. An initial strategy could be that of using the Basic Care Network as an important link to treatment continuity. To that effect, the institution of continuing education in palliative care would be fundamental to professionals of the PCHA and FHP as part of a strategy of national diffusion of palliative care, with the Ministry of Health being responsible for providing the technical support to municipalities for the organization of qualified teams capable of monitoring and treating patients with advanced and terminal diseases, and their environments.

In this sense, the reorganization of reference hospitals would be required, with sufficient offer of beds available to inpatients, in addition to palliative care qualifications of the medical staff, to prevent care treatment from being interrupted. Additionally, the arrangement of a permanent kind of contact network among such teams, of Basic Care and medical staff, with palliative care centers could be of great help to the decision-making process.

Besides the lack of integration among the different care levels, we also observed that the operation of the local palliative care centers is not mutually articulated, with the absence of an effective national policy.²

Narcotic control policy

A crucial issue for an adequate structuring of end-of-life care, in developing countries, refers to the continued and quick availability of opioids. This is a recurring concern, preventing palliative care from being implemented in health systems and may not be addressed without strongly confronting such issues.^{24,25} The restricted access to opioids in Latin America has been denounced in the Declaration of Florianópolis,²⁶ constituting an important hindrance to a successful implementation of good palliative care programs, in addition to configuring a practice of legitimated abandonment

imposed upon patients suffering from advanced and terminal diseases.

Attention to informal caregiver

The recognition, on the part of professionals providing assistance to patients, of the burden and needs of informal caregivers is another aspect of utmost importance.²⁷ Such burdens tend to be aggravated by the patient's approaching death and the mourning phase, and can be manifested in several dimensions.²⁸ Therefore, strategies to welcome all caregivers are highly important. These strategies should address, among other things, all information aspects and allow for the possibility of temporary replacement/respite, should the caregiver so desire this, for their own "recovery", if at all possible. It is also necessary that professionals of the palliative care team be fully aware of the most varied situations likely to be faced by the patient's family, from expressions of recognition of the benefits and the importance of such a work, to situations of repudiation and hostility.²⁹

Quite often, the caregiver prefers hospitals to care for patients with advanced diseases, rather than accepting private home care, moreover in the face of short life expectations. There are, obviously, several motivations for that, but one should consider as an important argument the fact of the caregiver "not coping" with performing certain tasks, being under intense stress, or not feeling capable of dealing with symptoms. Actually, the lack of control over symptoms is one of the key reasons for hospital admission of terminally ill patients.^{30–32} The important issue here is that the team providing private home palliative care should be able to rely on back-hospitals at any time and have the flexibility to review its "routine of procedures".

It should also be considered that not all caregivers have elected to be a caregiver,³³ and not all caregivers are prepared to be closer to a dying patient, a fact that has to be understood and respected by the team, in which case specific support should be available and offered to both caregiver and patient. In view of this and with consideration of the significant importance of the role of the caregiver, the Ministry of Health and the Ministry of Social Development and Hunger Fighting implemented a caregiver qualification project in five regions of the country, inside

the National Program for Elderly Caregivers, implemented in 1999.³⁴

Physician-patient relation

Amongst all the issues, maybe the most challenging and difficult one is related to the disclosure of the diagnosis and prognosis to the patient. The model of physician-patient relationship prevailing in Brazil is culturally sanctioned by a paternalistic vision, and in most cases excludes the patient from his diagnosis and from participating in the clinical decision-making process, thus making it easier for the physician to share such issues with the patient's family. Such a practice opposes the philosophy of the modern hospice movement, strongly centered on the patient's desires and preferences. This leads us to question what kind of palliative and hospice care is being built in Brazil. Not having the patient's autonomy as a core value, how should the fundamental issue of the patient's right to know the truth be accounted for, an aspect which is deemed crucial for a proper approach and one of the foundations of the palliative care philosophy?³⁵ How could palliative care be possibly provided, and what would be the quality of this offering, in an environment of omissions and lies?

One of the consequences of such a model of relationship is the erosion of the patient's autonomy, leading to increasing isolation, and no longer realizing what happens around him by medical practices that often perpetuate or add more suffering, and with the need for "controlling" everything occurring with the patient. With this in mind, a field of paternalistic practices will be wide open, with the construction of a "*silence conspiracy*"³⁶ between the physician and the caregiver/family, in which the patient—theoretically, the most interested party in decisions concerning his own life—is expropriated from his dying process. Such a pact crystallizes a relationship of symmetry between the physician and the patient's caregiver/family, deepening an asymmetric relationship between both and the increasingly isolated patient, now incapable of finding and expressing his anxieties and desires.

But paternalism is not always morally problematic, even in terminal situations.³⁷ However, this should not be a rule, but rather an exception such as, for instance, in the presence of a cognitively incompetent patient not assisted by a legitimate proxy, or by a document declaring his treatment

desires and preferences, or by having verbally expressed what type of treatment is wished for oneself.

Conclusions

The difficulties in implementing palliative care in developing countries have many points in common, such as the precarious qualification of human resources, the non visibility by administrators of the importance of palliative care, and the difficult access to medications, in particular to opioids.

The challenges to the implementation of palliative and hospice care in Brazil are significant, and mention could be made as to the need for increasing the offer of specialized centers and for strong investments in the qualification of human resources, both from the technical point of view and of training to deal with issues related to terminality. In addition, a change in curriculum is imperative, with the introduction of palliative care teaching for health-care students, especially medical students. Other relevant aspects are related to the structuring of the hospital network, especially the parts located far from the large centers, to the need for support to caregivers and to the implementation of a national policy on palliative care that is, in fact, effective.

In face of this reality, the Brazilian health system has the difficult task of balancing, inside a scenario of restriction of resources, and in a pragmatic way, as is convenient to the administrator, the sense of what is real, with the “sense of possibility”,³⁸ in search for a sustainable model for end-of-life care, from an operational point of view, and ethically committed to protecting its vulneraries actors, i.e. the patient and his environment.

Disclosure

The author reports no conflicts of interest.

References

- [1] Clark, D. 2007. End-of life care around the world: achievements and challenges remaining. *Omega*, 56(1):101–10.
- [2] Wright, M., Wood, J., Lynch, T. and Clark, D. 2008. Mapping Levels of Palliative Care Development: A Global View. *J. Pain Symptom. Manage.*, 35(5):469–85.
- [3] Clemens, K.E., Kumar, S., Bruera, E., Klaschik, E., Jaspers, B. and De Lima, L. 2007. Palliative care in developing countries: what are the important issues? *Palliat. Med.*, 21:173–5.
- [4] Webster, R., Lacey, J. and Quine, S. 2007. Palliative Care: A Public Health Priority in Developing Countries. *J. Public Health Policy*, 28(1):28–39.
- [5] Rajagopal, M.R., Mazza, D. and Lipman, A.G. 2003. Pain and Palliative Care in the Developing World and Marginalized Population: A Global Challenge. Binghamton: The Haworth Medical Press.
- [6] Harding, R. and Higginson, I.J. 2005. Palliative care in sub-Saharan Africa. *The Lancet*, 365:1971–77.
- [7] Sepúlveda, C., Marlin, A., Yoshida, T. and Ullrich, A. 2002. Palliative Care: The World Health Organization's Global Perspective. *J. Pain Symptom. Manage.*, 24(2):91–6.
- [8] Stjernswärd, J. 2007. Palliative Care: The Public Health Strategy. *J. Public Health Policy*, 28(1):42–55.
- [9] De Lima, L. 2003. Pain Relief and Palliative Care Programs: The WHO and IAHPC Approach in Developing Countries. *Pain Pract.*, 3(1):92–6.
- [10] Brasil. 2007. Ministério da Saúde. Resenha da luta contra o câncer no Brasil: documentário do serviço nacional de câncer. Ministério da Saúde. Brasília. Ministério da Saúde 2 ed.
- [11] Teixeira, L.A. and Fonseca, C.O. 2007. De doença desconhecida a problema de saúde pública: o INCA e o controle do câncer no Brasil. Rio de Janeiro: Ministério da Saúde.
- [12] Melo, A.G.C. 2003. Os cuidados paliativos no Brasil. *Mundo Saúde*, 27(1):58–63.
- [13] Figueiredo, M.T.A. 2003. Educação em cuidados paliativos. *Mundo Saúde*, 27(1):165–70.
- [14] Almeida, C., Travassos, C., Porto, S. and Labra, M.E. 2000. Health sector reform in Brazil: a case study of inequity. *Int. J. Health Serv.*, 30(1):129–62.
- [15] Secretaria de Atenção à Saúde. 2007. Ministério da Saúde. Política Nacional de Atenção Básica. Brasília: Ministério da Saúde.
- [16] Brasil. Portaria no. 3.535/GM. Estabelece critérios para cadastramento de centros de atendimento em oncologia. *Diário Oficial da União*, 14 out.
- [17] Brasil. 2001. Portaria no. 881/GM. Institui, no âmbito do Sistema Único de Saúde, o Programa Nacional de Humanização da Assistência Hospitalar. *Diário Oficial da União*, 119-E, de 21 jun.
- [18] Schisler, E.L. 2003. Besieged by death—immersed in grief: death and bereavement in Brazil. In: Morgan JD, Laungani P, editors. Death and bereavement around the world, volume 2: death and bereavement in the Americas. Amityville. Baywood Publishing Company, 121–36.
- [19] Brasil. Portaria no. 19/GM de 03 de janeiro de 2002. Institui, no âmbito do Sistema Único de Saúde, o Programa Nacional de Assistência à Dor e Cuidados Paliativos. <http://portal.saude.gov.br/sas> (acesado em 26/Ago/2005).
- [20] Brasil. Portaria no. 1319 GM/MS. Cria, no âmbito do Sistema Único de Saúde, os Centros de Referência em Tratamento da Dor Crônica, 2002; 23 jul. www.saude.mg.gov.br/legislacao-sanitaria/estabelecimentos-de-saude/dor-cronica/portaria_1319.pdf. (acesado em 02/ Jun/2008).
- [21] Pousada, L. 1995. High-Tech home care for elderly persons: what, why and how much? In: Arras J., editor. Bringing the hospital home: ethical and social implications of high-tech home care. Baltimore: The Johns Hopkins University Press, 107–28.
- [22] Arras, J. and Dubler, N.N. 1994. Bringing the hospital home: ethical and social implications of high-tech home care. *Hastings Cent. Rep.*, 24:S19–28.
- [23] Floriani, C.A. and Schramm, F.R. Atendimento domiciliar ao idoso: problema ou solução? *Cad Saúde Pública*, 2004, 20:986–94.
- [24] De Lima, L. 2002. Advances in Palliative Care in Latin America and the Caribbean: Ongoing Projects of the Pan American Health Organization (PAHO). *J. Palliat. Med.*, 5(4):228–31.
- [25] Barnard, D. 2002. World Health Organization Guidelines for National Control Policies. *J. Palliat. Med.*, 5(4):575–7.
- [26] Stjernswärd, J., Bruera, E., Joranson, D., Allende, S., Montejó, G., Tristan, L.Q. et al. 1995. Opioid Availability in Latin America: The Declaration of Florianópolis. *J. Pain Symptom. Manage.*, 10(3):233–6.
- [27] Hileman, J.W., Lackey, N.R. and Hassanein, R.S. 1992. Identifying the needs of home caregivers of patients with cancer. *Oncol. Nurs. Forum*, 19(5):771–7.

- [28] Floriani, C.A. and Schramm, F.R. 2006. Cuidador do idoso com câncer avançado: um ator vulnerado. *Cad Saúde Pública*, 22(3):527–34.
- [29] Levine, C. 1999. Home Sweet Hospital: The Nature and Limits of Private Responsibilities for Home Health Care. *J. Aging Health*, 11(3):341–59.
- [30] Brown, P., Davies, B. and Martens, N. 1990. Families in Supportive Care—Part II: Palliative Care at Home: A Viable Care Setting. *J. Palliat. Care*, 6(3):21–7.
- [31] Steinhauer, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L. and Tulsky, J.A. 2000. Factors Considered important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA*, 284(19):2476–82.
- [32] Maida, V. 2002. Factors that Promote Success in Home Palliative Care: a Study of a Large Suburban Palliative Care Practice. *J. Palliat. Care*, 18(4):282–6.
- [33] Montgomery, R.J.V. 1999. The family Role in the Context of Long-Term Care. *J. Aging Health*, 11(3):383–416.
- [34] Brasil. 1999. Portaria Interministerial no. 5.153 MS/MPAS. Institui o Programa Nacional de Cuidadores de Idosos. *Diário Oficial da União*, 8 abr.
- [35] Rousseau, P. 2002. Physicians and end-of-life care. *Am. J. Hosp. Palliat. Care*, 19(1):9–11.
- [36] Taboada, P., Ugarte, A.R. and Bertucci, M.V. 2000. Dimensión ética del morir. *ARS medica*, 2(2):31–44.
- [37] Kite, S. 2001. Can. medical paternalism ever be justified? *Eur. J. Palliat. Care*, 8(4):151–154.
- [38] Musil, R. 1978. *Der Mann Ohne Eigenschaften*. Reinbek bei Hamburg. Rowohlt. Verlag.