



REVISTA BRASILEIRA DE ANESTESIOLOGIA

Official Publication of the Brazilian Society of Anesthesiology
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MISCELLANEOUS

Structuring a palliative care service in Brazil: experience report[☆]

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Received 28 April 2013; accepted 10 June 2013

Available online 29 April 2014

KEYWORDS

Palliative care;
Cancer;
Report

Abstract

Background and objectives: in Brazil, palliative care (PC) is not properly structured and that reality transforms this theme in a public health problem; therefore, initiatives become relevant in this context. This paper aims to share the experience that occurred in an oncology referral hospital in the State of Maranhão and present initiatives that helped in the development of PC Service.

Experience report: the hospital had an outpatient Pain and PC Service, but without specialized beds. The terminally ill patients stayed in common wards, which caused much unrest. A sensitization process was initiated in the hospital through initiatives, such as a photo contest called Flashes of Life and a ward called Room of Dreams, designed in partnership with the architecture course at the Universidade Estadual do Maranhão. The process culminated in the granting of wards to the PC and in the commitment of the Foundation, sponsor of the hospital, to run the project.

Conclusion: this experience was a reproducible local initiative for the establishment of PC in a cancer hospital. Local initiatives are valuable in Brazil because they favor a significant number of patients and show its effectiveness in practice to governments and society. To structure a PC service, it is essential to establish priorities that include the assignment of drugs for management of symptoms, humanization, multidisciplinary, sensitization and education of professionals.

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[☆] Study conducted at the Instituto Maranhense de Oncologia Aldenora Bello, São Luís, MA, Brazil.

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PALAVRAS-CHAVE

Cuidados paliativos;
Câncer;
Relato

A estruturação de um serviço de cuidados paliativos no Brasil: relato de experiência**Resumo**

Justificativa e objetivos: no Brasil, os cuidados paliativos (CP) ainda não estão estruturados adequadamente e essa realidade transforma essa temática em um problema de saúde pública e faz com que iniciativas nesse contexto tornem-se relevantes. Este trabalho objetiva compartilhar a experiência ocorrida em um hospital de referência em oncologia do Estado do Maranhão e apresentar iniciativas que auxiliaram no desenvolvimento do Serviço de CP.

Relato da experiência: no hospital, havia um Serviço de Dor e CP ambulatoriais, porém sem leitos especializados. Os pacientes em fase final de vida ficavam em enfermarias comuns, o que gerava muita inquietação. Foi iniciado um processo de sensibilização no hospital, por meio de iniciativas como um concurso de fotografias intitulado Flashes da Vida, e uma enfermaria, intitulada Quarto dos Sonhos, foi projetada em parceria com o curso de arquitetura da Universidade Estadual do Maranhão. O processo culminou com a concessão de enfermarias aos CP e com o compromisso da fundação mantenedora do hospital de executar o projeto.

Conclusão: essa experiência constituiu uma iniciativa local reprodutível de desenvolvimento dos CP em um hospital oncológico. As iniciativas locais encontram grande valor no Brasil, por favorecer um expressivo número de pacientes e demonstrar, na prática, sua eficácia aos governos e à sociedade. Para estruturação de um serviço de CP é imprescindível o estabelecimento de prioridades, que incluem a cessão de fármacos para o controle dos sintomas, a humanização, a multidisciplinaridade e a sensibilização e educação dos profissionais.

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Introduction

Modern techniques for improving the patient's health are important, but they become incomplete if different paradigms are not considered, especially when the chances of cure are limited. Technological advances in medicine should be proportionate to the human need of compassion for the terminally ill patients and their loved ones.¹

Within this context, palliative care (PC) emerged with the purpose of caring for patients until their last moments of life, seeking as much as possible, through a multidisciplinary approach, to minimize their discomfort and giving emotional and spiritual support to their relatives and friends.²

PC is a new science, defined by the World Health Organization (WHO) in 2002, currently defined as "an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".³

According to the WHO, PC provides relief from pain and other distressing symptoms; affirms life and regards death as a natural process; intends neither hasten nor delay death; integrates the psychological and spiritual aspects of patient care; gives support to help patients live as actively as possible until death; gives support to help the family during patients' illness and in their own loss; uses a team approach to address the needs of patients and their families, including counseling on loss, if necessary; provides quality of life and may positively influence the course of disease; is applicable early in course of illness in conjunction with other therapies

intending to prolong life; understand and manage clinical distressing complications.³

The WHO considers PC as an urgent humanitarian need worldwide for people with cancer and other fatal diseases. In less developed countries, PC is of particular importance, as a high proportion of patients are diagnosed in advanced stages of disease, when treatments are no longer effective.³

In Brazil, the aging population, the increasing incidence of cancer and the emergence of acquired immunodeficiency syndrome (AIDS) increase the need for this type of care in the country.⁴

Regarding cancer, data from Datasus show that in 2010 neoplasm was responsible for 15.74% of deaths in Brazil and for 11.22% in Maranhão. In absolute numbers, this amounted to 178,990 deaths in Brazil and 2822 in Maranhão.⁵ In contrast, there is no PC structure in the country that meets the existing demand. There is a minimum supply of specialized beds, which is restricted to the big cities. Thus, the condition in which the deaths due to cancer occurred and continue to occur should be considered.

In this paper, we discuss the existing needs for structuring a PC service within the Brazilian reality and report the experience of a group that helped them to be met in an oncology unit.

Experience report**Study design**

A descriptive, experience report study conducted at the Instituto Maranhense de Oncologia Aldenora Bello (IMOAB) in São Luís, Maranhão, from May 2010 to August 2011.

Study center

IMOAB is a high complexity oncology center, a referral hospital for cancer in the State of Maranhão since its founding in 1966. It is among the 65 pain and palliative care services in Brazil indicated by the Brazilian Association of Palliative Care (BAPC).

The center has ward beds for adults and oncopediatrics, a surgical center, intensive care units, an oncologic emergency care service of chemotherapy and radiotherapy, and outpatient services. Approximately 80% of visits are provided by the Unified Health System (SUS) and the remainder by health insurance or private.

In 2003, the IMOAB's Pain and Palliative Care Service was structured, with outpatient and ward visits, however, without beds dedicated to PC. This service is a practice field for the Academic League of Pain of Maranhão (LAD-MA), Universidade Federal do Maranhão (UFMA), which played a key role in the experience reported below.

World strategies

Photograph contest - flashes of life

Despite having a PC service in the institution, it was done in common, non-specific clinics and wards in which patients received treatment alongside other terminally ill patients. This situation generated much unrest, which sparked the interest of giving prominence to palliative care in the institution and draw attention to the problem. So the idea of the photo contest Flashes Life emerged—a way of encouraging hospital staff to observe their patients and see them in different situations, needs, sufferings, and joys and recording and disseminating these “looks” both inside and out of the IMOAB.

Initially, a regulation has been prepared with all the contest information, as well as its primary objectives. This regulation, together with the application forms, was left in the Department of Humanization of the hospital, in the hands of the professionals involved with the project who could give the necessary information and incentives.

For promotion, posters were displayed in flannelgraphs at the hospital and leaflets distributed. LAD-MA, together with representatives of the Department of Humanization, also made visits to various hospital departments to advertise the contest.

The contest was open to all employees of the IMOAB. Entries and receipt of the photographs were made in the Department of Humanization. The photos were received in CD and should be of patients treated at the institution and photographed by employees. Each patient had to sign an informed consent, allowing the use of images by the organization.

In order to encourage participation, the top three finishers win cash prizes and the following seven honorable mentions. The contest was supported by the pharmaceutical industry, which provided the financial support for prizes.

Photographs were judged by professionals from various fields, who had no employment relationship with the IMOAB. The judging panel was composed by a photographer, an artist, a journalist, a nurse, a psychologist, and a physician.

The contest was launched in late May 2011 and lasted until the beginning of August, date of the awards ceremony, which took place in the auditorium of the Regional Council of Medicine, with the presence of guests and hospital employees and members of the LAD-MA. It was later published in the local newspaper, which occupied an entire page with the winning photos and messages of humanization.

The photos were used to decorate the stand of the laboratory that supported the project in the 9th Brazilian Congress on Pain, held in Fortaleza (CE) in October of the same year. It was also used in calendars, which were distributed to hospitals and educational institutions of the city.

Due to what was observed, the IMOAB's board of directors announced that it would grant three wards (two with two beds and one with one bed) to the Pain and Palliative Care Service of the hospital, aimed at terminally ill patients.

However, the wards' condition raised questions and reflections about the ideal conditions of a place intended to house a person in his/her last days of life. It was noted that to achieve the principles of PC in the hospital, and actually provide welfare to patients, it would be necessary to adjust the wards for this purpose. And with this intent, another project came on the scene.

Project extension: the room of dreams

The Room of Dreams was a partnership between the IMOAB's Pain Service and PC and the architecture course at the Universidade Federal do Maranhão (UEMA). It consisted of an extension project in which 11 students of architecture (UEMA) were inserted at the IMOAB. They had contact with the reality of the hospital, with the PC, and were challenged to design the ideal room for a patient with no prospect of healing and in the terminal phase of life.

After its approval as an official extension project of the UEMA, the Room of Dreams took three months to reach its initial objectives, namely: (1) create an environment of acceptance and humanization for individuals whose prospects of cure no longer exist, but aim to have physical, mental, social and spiritual wellbeing in their hospital stay, in many cases the last days before death; (2) entering students in project situations in which they can experience the daily life of a hospital as the IMOAB and link it with project practice.

The students got to know the architecture of the PC facilities, other wards, Pain Service and PC of the LAD-MA. Then, they measured and photographed the three wards that would be reformed. Through periodic meetings with their advisor to review the works, the students developed the project, which included layout from floor to ceiling plans and at least four views and details, in addition to specifications of materials and quantitative services.

The design of the rooms was presented to an audience that included teachers of architecture, LAD-MA members, including the coordinator teacher, staff and board of directors of IMOAB and the foundation that supports the hospital.

The projects had comfortable beds, with panels on headboards, chairs for companions, reading tables, storage for belongings, photo murals, wallpapers, refrigerator, television and air conditioning. Bathrooms had the doors enlarged and seats in the showers so the patient could take a shower,

even though he could not stay long standing, and grab bars to prevent falls. It is worth mentioning that the students received instruction to design everything they thought was best for the rooms—from floor and room lighting to beds.

The project presentation left everyone dazzled. The project coordinator presented the budget, which was approved by the president of the foundation, who has made a public commitment to make the Rooms of Dreams a new reality of the institution for patients in the terminal phase of life.

Discussion

Palliative care is still a young science. In 2012, only 45 years had elapsed since the founding of St. Christopher's Hospice by Cicely Saunders, a fact considered the hallmark of the PC. It has been 25 years since PC was first recognized as a medical specialty in the UK and 10 years since the WHO published a more current definition and new recommendations.^{3,6}

Since its birth, PC has developed and disseminated worldwide at a rapid and impressive pace.⁶ Some reasons are given for its rapid growth, such as the emergence of PC advocates, pain relief been considered as a human right, the aging population needs, and the desire to provide better care to patients in the final stages of life.⁶

Despite its impressive growth, especially in developing countries, several factors contribute to make the palliative care actions less effective. Among these are the existence of policies for restricted to delayed release of opioids, lack of skilled human resources, and shortage of investment in the area.⁴

The WHO highlights three key measures for the development of PC with a public health approach: (1) a government policy that integrates the services of PC in the structure and financing of the national health care system; (2) an education policy that consolidates training of health professionals and volunteers; and (3) a drug policy to ensure the supply of drugs for treatment of pain and other symptoms.⁷

We will now discuss these and other elements reported in the literature as necessary for the establishment of a palliative care service in Brazil and its relation to our results.

Humanization

A hospital suitable for a PC service needs to have the patient as the focus of attention, not the disease. The purpose of humanization is to effectuate the care for the sick human being and promote his/her health, understood as the complete wellness. Therefore, humanization is considered indispensable to a place that wants to offer palliative care.²

Through the photo contest, we found a way to strengthen the humanization at the IMOAB, causing the staff to stop their daily activities, take pictures of patients and show them inside and outside the hospital; Flashes of Life put the patients, their situation, and their feelings into focus.

The contest also highlighted the commitment of IMOAB's Pain Service and PC to improve patients' treatment and sensitized the hospital board, which allocated ward beds exclusively to patients in PC.

Multidisciplinary

Providing quality of life to a patient with no chance of healing is a complex task that requires interdisciplinary planning, with multidisciplinary. Other science hardly has a strong multidisciplinary approach such as PC.² The work team includes professionals, patients, relatives, and the general public, dedicated to provide continuing care within mental (psychologist, psychotherapist, psychoanalyst, psychiatrist), social (social worker, volunteer), spiritual (priest, pastor, rabbi, guru), biological (doctor, nurse, physiotherapist, occupational therapist), and emotional scope, both for patients and their loved ones.⁸ Besides these professionals, depending on the clinical evolution of the case, other professionals and specialists may be called upon to cooperate with the team.

This paper shows another category of professionals who contribute to the pursuit of quality of life for patients beyond cure—the architects. Through the extension project, Room of Dreams, we add the architecture in the development of PC. The results of this partnership were projects of welcoming and warm environments, with minimization of hospital elements, and as close as possible to the ideal place for someone to spend his/her last days of life.

The Pain Service and PC partnership with the architecture built a reproducible process that has much to add to the PC services in its ceaseless struggle to provide quality of life for patients.

The contest Flashes Life also helped to strengthen the multidisciplinary, bringing together hospital staff toward a common goal—to see the cancer patient. The contest attracted interest and promoted contact between professionals from different fields with the growth of PC service in the hospital.

Education

Specialized training and basic knowledge and skills in PC are essential for all health professionals who deal with patients in the final stages of life, which makes education a crucial aspect for the establishment of such care.² One way to achieve progress in disseminating the practice of PC in healthcare is to prepare and educate future professionals to deal with the needs of patients and relatives facing life-threatening illnesses.⁹

In 2011, palliative medicine was accepted as a practice area by the Federal Council of Medicine (FCM), with training time of one year and the requirement of having the title, by the medical association, of specialist in anesthesiology, oncology, internal medicine, geriatrics, and family, community or pediatric medicine.¹⁰

This was a breakthrough in PC service in the country. However, the teaching of PC is still poor in Brazil. There are few colleges that provide some information about the area, usually in elective courses.¹¹ There is an urgent need to include education on the principles of PC in undergraduate, as well as graduate health care courses, also with few specialized courses in various regions.⁴

The formation of academic leagues in the area is something that helps to overcome the lack of information on PC

in health care courses. It is important to foster the creation of academic leagues at institutions of higher education in Brazil, particularly in health care courses, and offer theoretical and didactic support.⁹

The Academic League of Pain of Maranhão (LAD-MA) is multidisciplinary and includes nursing and medical teachers who work at the Pain Service and PC of the IMOAB. Since its foundation, the league promotes courses open to the general public on pain and PC. A Universidade Federal do Maranhão, to which the league is bound, has PC teaching in the curriculum of medical course.

The LAD-MA played a key role in all the steps of the PC implementation in the hospital, from ideation to the promotion of the work strategies reported here.

One of the challenges for PC training in the country is that there are few specialized centers.⁴ The implementation of a PC service in our hospital, in addition to all the benefits inherent to its creation, will be a field practice for the LAD-MA and, thus, contribute to the education of future professionals in the care of patients in final stages of life, and enable its expansion to a League of Pain and Palliative Care.

It is also worth mentioning the learning of the architecture students of UEMA with the Room of Dreams project, which shows the clear relationship between PC and sciences that go beyond health care.

Drug supply

When a patient is in the final stages of an incurable disease, intensive treatment of pain and other symptoms is often required to preserve his/her quality of life.¹² A key issue for the proper implementation of PC in Latin America is the rapid and continuous supply of opioids.⁴

In our country, the supply of analgesics for pain control is limited, restricted to a few pharmacies and nonexistent in some municipalities.¹¹ The proper and recommended use of opioids by the WHO is still unknown and discriminated by health professionals.¹³ In parallel, we also emphasized the idea that people have regarding morphine: that it is aimed at patients in agony, may hasten death, and that its use is always associated with addiction.^{11,14}

Recently, the federal government launched an ordinance that expands the arsenal of analgesic and adjuvant drugs for chronic pain treatment and completes these parameters, despite some limitations, such as the number of opioid drugs, which remains restricted to codeine, morphine, and methadone.¹⁵

Our experience has shown the feasibility of implementing a hospital-based PC from an already established pain service and outpatient PC, where the difficulties regarding the supply of drugs were already being addressed. The IMOAB has for some years a structured pharmacy that provides medications to patients to control pain, nausea, vomiting, insomnia, constipation, among others. This preliminary plan is of great importance in the sedimentation of PC in a hospital.

Government support

One of the biggest obstacles mentioned in the literature^{2,6} for the viability of PC programs in developing countries is the lack of government commitment to the PC philosophy.

In these countries, and Brazil is included, many of the difficulties in implementing PC services derive from the absence of governmental strategies and consistent national policy for pain relief generated from listening and extensive discussions with the societies involved with pain.

The role of governments is so important that it determines the way PC is developed in a particular country. Globally, two scenarios of PC development are described: the bottom-up and top-down approaches.⁶

The bottom-up model is characterized by an energetic group of activists that identify a local need and initiate activities to improve the scenario. That is how palliative care started in countries like Zimbabwe and Myanmar, where Maureen Butterfield and U Hla Tun, respectively, founded the first PC services in these countries after contact with cancer patients, both because their daughters had the disease.⁶

The top down model occurs when the Ministry of Health is involved in the early stages, encouraging, legislating, creating a national policy and, finally, incorporating the PC to the national health system of the country. This was the model adopted by the Philippines, Mongolia, and Kazakhstan, and it is a central feature of the WHO project in Africa.⁶

The implementation of a consistent and organized PC network is a challenging task. Despite all the government initiatives, PC implementation in the Brazilian health system is slow and disarticulated.⁴

In our country, faced with obstacles, a common identity for PC professionals was built— militant of the humanization cause of dying. It is noted that the existence of services created and maintained thanks to the effort and dedication of individuals or groups who work hard as advocates of the cause and face government bureaucracy to create palliative care services. PC services in Brazil have their own peculiar characteristics and emerged mostly from pain services within hospitals.⁴

The reported experience follows the national trend of creating PC services from pain services. The Pain Service of IMOAB slowly gained ground and importance within the hospital. With a pharmacy that provides medications for adequate analgesia of cancer patients and with the support of the hospital board, a favorable environment for the development of PC was created.

This work has shown some local initiatives that can, similar to other services in our country, bypass the lack of national policies in the area and enable the implementation of a palliative care service. Reproducible tools that sedimented the implementation of PC from a pain service in a cancer hospital were reported.

The International Observatory on End of Life Care (IOELC) stated that it is when we add the top-down and bottom-up models, i.e., combine local energy with a national policy that the maximum range of coverage, education, resources, supply of drugs and growth is achieved.⁶

Many governments have yet to recognize and be persuaded that PC should be included in policies and health services. For this purpose, evidences of the PC effectiveness are required. It is known that local initiatives do not replace a national policy, but with them a growing number of patients are favored, which makes evident the effectiveness of PC—so palliative care gets stronger and finds once and for all the space it needs to achieve.

Conclusion

Local initiatives regarding PC have great value in our country, making this kind of attention accessible and demonstrating its effectiveness to society. However, it is necessary that the federal government set a national health policy directed to consolidate PC in Brazil.

Conflicts of interest

The authors declare no conflicts of interest.

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