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A Comparative Study on the Palliative Care in Romania and France

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Abstract

The palliative care has old tradition, as the single support and relief of suffering in terminally ill patients form, until the release of antibiotics and the development of modern medical technologies, investigation, diagnosis and treatment. In the 1960s the palliative care was officially recognized as a medical field, focused on the psycho-emotional and spiritual aspects without neglecting, however, the physical aspects of care. Further evolution differed on a country basis.

The health insurance systems in Romania and France are based on the same principle of solidarity. The history of the two palliative care systems has close start. In this context, we propose a comparative study to identify the differences and similarities between the systems of palliative care in the two countries. Certain evaluation criteria were selected for this purpose, in order to ensure a complex approach for this type of service. We have used the methods of study documentation and direct observation

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through an internship performed in a clinic in France, Groupe Hospitalier Saint Augustine-Malestroit.

In spite of the chronic low funding of the health system, non-challenging and lean health legislation, the system of palliative care has developed slowly, but progressively, in Romania. Though, the level of services is far below the needs. This is imposing a rigorous analysis of the factors affecting the quality of life of patients and the development of services strongly dependent on these.

The French health care system is an example of good practice regarding availability of health care, health care related services, accessibility to the patient, and the legal frame: national policies, legislation, financial planning models and quality control, training and human resources, including the emotional and spiritual support like patient special needs, family support, support for pediatric patients and their families, religious and psychological assistance, staff issues.

Keywords: *palliative care, hospice, needs, dignity, Romania, France*

Introduction

In ancient times, doctors and even the God of medicine, Asclepius, refused to handle hopeless cases. Treating such patients would have diminished the reputation of the doctor, even though this would have brought material advantages.

Palliative care has an old tradition, representing actually the only form of support and relief of suffering, for terminally ill patients, until the discovery of antibiotics and the development of modern medical technologies, investigation, diagnosis and treatment. In the 1960s it was officially recognized as a medical field oriented on the psycho-emotional and spiritual aspects. However, the physical aspects of care were still important. The psycho-emotional and spiritual aspects have become an integrant and indispensable part of the treatment. (Chochinov and Holland, 1998). The World Health Organization defines palliative care as the active and total care of patients whose illness no longer responds to curative treatment, focusing on the control pain and other symptoms, but also on the social, psychological and spiritual assistance, considered as well as essential for the patients welfare. The palliative care goal is to ensure the quality of life of the patient and his family, as the same sources mention. (International End-of-Life Care Observatory. Country

Reports, 2006). Health Insurance Systems in Romania and France work based on the same principle, namely that of solidarity, over 95% of the costs being covered by mutuality funds, palliative care being provided even completely out of insurance funds, regardless of the patient's status.

Methodology

Given this context, we proposed a comparative study between Romania and France in order to identify the differences and similarities between systems of palliative care in both countries. We selected 7 evaluation criteria for this purpose, to provide broader picture on this type of service. We have used the methods of study documentation and direct observation in an internship performed in a clinic in France, Groupe Hospitalier Saint Augustine-Malestroit by the first author.

The seven criteria comparing the palliative care in Romania and France were:

1. Availability of health care and health care related services to the patient;
2. The legal constraints: national policies, legislation, including the ethical dilemma of euthanasia
3. Financial planning models
4. Standards and protocols
5. Human resources including training
6. Emotional and spiritual support: patient special needs family support, support for pediatric patients and their families, religious and psychological assistance.
7. Epidemiological, demographic, cultural and historical aspects

Results and discussions

Development of palliative care in Europe-France-Romania has many differences and similarities whose analysis allows the identification of strengths and weaknesses and shaping a successful model.

The palliative care is the last step of medical care before the unavoidable end. When such services are proposed and provided, the death is imminent at any moment of time, more or less, in a matter of months. The acceptance of death put a big challenge on both the patients and family on one side and on the care givers on the other side. Initially seen as defect body, the patient concept evolved to the patient as

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body and mind, and in 1967, Cicely Saunders founded St. Christopher's Hospice in South London based on this one. (Centeno, 2007)

Palliative care initiate in France in 1987 is simplistic. In 1973, after a study trip to St Christopher's Hospice, publication of father Patrick Verspieren had a significant impact. The Ministry of Health became aware of the need to consider the management of these patients at end of life and of a group of experts on assisting terminally ill patients. (Wary, 2002)

In the late 70s, the Anglo-Saxon research on therapeutic suffering end is published in French journals. On French territory, the hospice movement grows. The first specifically dedicated services or consultations will create a service terminal cancer in Cognac-Jay (Paris), palliative care consultation in the hospital of Saint-Simon Cross (Paris). Geriatric services also include comprehensive care in their practices, and doctors working for the development of palliative care at home. Thus, in 1984, Ministry of Health formalizes palliative care by the "Circular of 26 August 1986 on the organization of care and support for terminally ill", often called "Circular Laroque." This work continues with the first palliative care unit (PSU). Other facilities will follow quickly on different ways: hospital beds, clinics with day beds, mobile teams, homecare. (Monitoring End of Life Care, 2009).

During the same period non-governmental organizations began activating. JALMALV (until death accompany life) was created in 1983 in Grenoble before becoming a federation. The UNASP (National Union of Associations for the development of palliative care), derived from the ASP founder, was born in Paris in 1984. (Wary, 2002)

In 1989, attention has directed in terms of training specialists. Many of these associations, like-minded objectives, approached of health professionals (doctors, nurses, psychologists, social workers) to found the French Society of Palliative Care and Support (RFS). Its mission is to represent, promote and facilitate the action of natural or legal persons involved in the hospice movement and support for people in later life, in order to develop and improve the management care of people and the quality of care received. The RFS is including their spokesperson governments. (Institute National de Prévention et d'Education pour la Santé, 2012)

France has placed special emphasis on the creation of a specific legislation to support the medical system and the beneficiaries. We had to mention some very important data on the legal frame:

- 1991: law of 31 July introduced Hospital palliative care in missions any health facility;
- 1993: the report of Dr. Delbecque, at the request of the Ministry of Health, reported on developments since 1986 and the circular issued proposals;
- 1994: improvement of the management of pain and workings on texts in this direction;
- 1998: Bernard Kouchner, Minister of State for Health, said that "palliative care and pain is a public health priority." The 1999-2001 triennial plan involves several training (medical school and nursing institutes) and the creation of new health care facilities;
- 1999: The legal Circular Laroque, the Act of June 9 passed unanimously by parliament guarantees a right of access to palliative care for everyone in later life. The law also establishes a support that can leave people wishing to accompany the near end of life.
(Wary, 2002);
- 2000: The circular of 22 March the National Health Insurance Fund (CNAM), defined contribution fund health and social action of the body to maintain the homes of people in later life. It provides in particular financial assistance (under certain conditions) for the payment of nurses and purchase of specific equipment. An endowment was created to support the training of volunteer support, and the management is entrusted to the RFS. In addition, the government publishes the circular of 30 May, which encourages the development of hospital at home by the Regional Hospital Agencies (ARH), indicating that these structures are involved in the management of pain and palliative care;
- 2002 of 19 February circular specifies organization of palliative care, and accompaniment. It defines the tasks and operating procedures regarding networks palliative care and homecare, the concept of affirmative action in all services and the concept of palliative care beds identified. This circular is accompanied by a

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second national development program in palliative care 2002-2005 focuses on three areas:

- The development of palliative care at home;
- Further strengthening and creation of specialized structures;
- Public awareness and information of the entire social body to the palliative approach.

The cancer plan presented to the President of the Republic stressed the need to develop supportive care, enabling comprehensive palliative care and support management to the patient. (Comité national de suivi du développement des soins palliatifs et de l'accompagnement, 2012)

Between late 2004 and the spring of 2005, in an emotional context particularly dramatic, a parliamentary commission was set up, chaired by Jean Leonetti. Numerous hearings of physicians, philosophers, sociologists, representatives of religions, actors palliative care (including PACS), representatives of the social body, shed light on his work. All recommendations from the report of this mission has resulted in a bill that was unanimously adopted by 548 votes in the National Assembly on 1 December 2004 and passed in terms consistent with the Senate on April, 2005. Promulgated on 22 April 2005, the law was published in the Official Journal. (Comité national de suivi du développement des soins palliatifs et de l'accompagnement, 2011).

Although there is not such a big gap in time between the two countries regarding the onset of palliative care, the difference consists in the further evolution.

Palliative care was introduced in Romania only six years difference of the French debut by promoters, charitable foundations, mainly supported by external partners, without any support from the authorities. Palliative care services have emerged in Romania at non-governmental association level involving foreign partners, 2 years after the political regime change in fall of 1989. Only in 1992 were founded: Romanian Association for the development of palliative care; the first hospice for children with AIDS, belonging to the Romanian Foundation for Children's Aid and English-Romanian Foundation Hospice "The House of Hope" (in Romanian "Casa Speranței"). Currently, 32 providers are working, 10 public and 22 private, delivering 46 services.

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Romania is ranked on the 22nd place in the European hierarchy as what means resources and on the 7th place as what means vitality. Service availability assessment reveals that only 5.9% of the potential beneficiaries have access to specialized services, i.e. 150 beds at 21 million inhabitants. 26 counties out of 41, have no palliative care service. (Vladu, 2008)

Current legislation contains only general references to palliative care. An EU report from 2008 reveals that the French system is noteworthy for the wide availability and variety of free palliative care services, the research structure which is solidifying thanks to the support of the Ministry of Health, and the continued backing by the parliament. Care is usually based delivered through the hospital, with the main of palliative care teams working in this setting, although recently home care has also seen rapid development. In the last ten years, the vitality of this field has grown dramatically, evidenced by the quantity of palliative care associations which have sprung up (110 organizations under the umbrella of the Société Française d'Accompagnement et des Soins Palliatifs (SFAP), representing 15,000 members) and consistent legislation (renewed approximately every three years) which defends palliative care as a right for all citizens. The formulation and implementation of a national plan on palliative care has also been named as one of the three health priorities of the President of the Republic. Prescription of painkillers still requires a special document. There is strong resistance to these drugs from both GPs and many palliative care practitioners. (European Parliament's Committee on the Environment, Public Health and Food Safety, 2007)

Regarding human resources, training, and research, the results confirm the attention that both the Government and professional organizations give to the performance of professionals. Statistics of the Ministry of health of France mentions the existence in 2011 of palliative care GPs, including home care, pain management, and family support, 450 physicians and almost 2,000 nurses working in palliative care in France. One sample hospital support team in Paris consisted of two doctors, five nurses, a psychologist and a secretary. While there is an optional postgraduate course in palliative care (required for those working in the field) and teaching hospitals incorporate palliative care education into their courses as well as carrying out research, many

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French doctors have complained that their pain management training is insufficient. (Institute National de Prévention et d'Education pour la Santé, 2012)

In Romania, the training of doctors and nurses working in palliative care program services is provided only by the Association "The House of Hope" (in Romanian "Casa Speranței"), the one that has brought in this kind of medical care. The courses are approved by the College of Physicians and takes 2 years. But the costs are quite high for the current income of doctors and nurses, so that the accessibility is reduced even from this point of view.

In 2005, there were an estimated 66 full-time palliative care workers, including 17 physicians and 38 nurses. In 2012, have been reported 700 palliative care workers. (Catalogul Serviciilor de Îngrijiri Paliative din România, 2010)

Regarding emotional and spiritual support, it should be noted that each team structure has a clinical psychologist, but can also request neuropsychology support. The majority of palliative care clinicians work in formal or non-formal associations with various religious establishments, convents of nuns or monks. Thus, all clinics receive spiritual support from priests and nuns, being also observed the confessional option. (Aubry and Dayde, 2010)

The example of Malestroit clinic is enlightening in this respect. It acts in a very old work relationship with the Order of Augustine Sisters from Jesus. Almost 150 patients receive a visit from a priest of catholic religion or any other confession upon request. The priest is not wearing official robes. They are dressed regular and religious assistance is offered only on request. In the remaining visits, the priest acts as a simple conversation partner. He never talks to the patient about his possible death or burial ritual. This issue is addressed only to the family or person of confidence of the patient. (Lamau, 1996)

In Romania, "the most spiritual support is provided by priests on staff at public hospitals and volunteer priests at private or non-governmental institutions, although there are a few psychologists in some centers, notably the "House of hope", that also provide this support", is mentioned in the report of the European Union, that being the only available official data. Spiritual care is offered by the priests of the hospital. The priests exist there before the creation of the palliative

care program and have no special training to work with such patients. In the same circumstances are also the psychologists. (European Parliament's Committee on the Environment, Public Health and Food Safety, 2007)

Considerable differences between the two countries are notable in terms of legal provisions: thus, if the Palliative care legislation in France dates back to 1986, with regular revisions and updates, in Romania there are no laws or regulations in this regard. Health Law 95/2006 does not include references to this type of care. Moreover, the settlement of palliative care services is not done as such. Practical, the services for patients are settled as for chronic ill patients or with cancer. The expression "palliative care" does not exist in the Romanian health law. Association for Development of the Palliative care program is still trying to impose a series of changes to this law.

These changes have been submitted to the Parliament since 2010 and aim a few items, namely introduction to title I, chapter III, of the law on health palliative care aside the curative and prophylactic one. There are also aimed: to cover all of the palliative costs by the insurance law and the right of every patient who meets the medical conditions to qualify for this type of care (a minimum of 10 beds per 100,000 inhabitants), recognition of palliative care program of the hospital, outpatient or home care and their reimbursement. Furthermore, the legislative proposal includes also a clear definition of the palliative care program and of the types of services they require.

Some legislative progress but must be mentioned. In 2002 was published the standards for services. In 2005 a law relaxed the rigid bureaucratic processes for opioid prescription. Currently, there is no national plan for palliative care program in effect, however, there is a strong lobby for this and in fact one is being formulated through the Ministry of Public Health under the auspices of a National Plan for Cancer Control. (Bogdan, 2008)

In France, the legislation systematically evolves so that it recognizes the right to palliative care for any patient that requires it. The law also makes provisions for education and training as well as compensation for family members who take a 3-month leave from work to care for a dying relative. Euthanasia and assisted suicide are not legal, despite a strong pro-euthanasia movement. However, advance directives

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are legal in France, a provision which was included in the 2005 law on patients' rights and end-of-life care. (International End-of-Life Care Observatory. Country Reports, 2006)

Financially speaking, the palliative care in France is fully integrated into the national health system, which is free to all residents. Palliative care provisions include specific mechanisms for home-care funding. (European Parliament's Committee on the Environment, Public Health and Food Safety, 2007)

The Romanian government funds entirely or in part the in-patient units through the national insurance funds. The insurance system does not practically finance palliative care but services for chronically ill patients or through the national program for oncology patients, as there is no chapter dedicated to this type of service. Home care is not included, and many hospice organizations depend on international support, private donations, and other sources of income to meet costs.

Conclusions

Although the two systems palliative grew in short distance of time, further development was very different. By involving of health authorities, in just 11 years, in France, the legislation, organizational structure and functioning of palliative care became the most competitive at international level, like the English system which has the oldest tradition in the field. In the same period of time, Romania has not even succeeded to introduce in current legislation the concept of palliative care, to formalize it.

In the context of chronic low funding of the health system, a non-challenging and lean health legislation, palliative care in Romania has developed slowly, but progressively, however the level of services is far below the needs. This is imposing a rigorous analysis of the factors affecting the quality of life of patients and the development of services in direct correlation with these.

The palliative care is a current reality even in Romania. The globalization with the technological insertion in medicine brought the specific end of life issues even in this side of the world. Proper attention is requested from the government in terms of law framing and regulations.

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