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SOCIAL WORK AND PALLIATIVE CARE IN ROMANIA AND ITALY: A COMPARATIVE PERSPECTIVE

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Abstract: *THE PRESENT STUDY ATTEMPTS TO EXAMINE THE ROLE OF SOCIAL WORKER IN PALLIATIVE CARE (DOMAIN UNDER REPRESENTED IN ROMANIA). CLINICAL SOCIAL WORK WITH A FOCUS ON HEALTH ISSUES HAS BEEN THE MAIN DEVELOPMENT PATH FOR PALLIATIVE CARE SOCIAL WORK.*

THE ANALYSIS WAS BASED ON SOCIOLOGICAL METHODS- INTERVIEW AND CONTENT ANALYSIS. DATA WERE COLLECTED BY MEANS OF A SEMI-STRUCTURED INTERVIEW CONDUCTED WITH SOCIAL WORKERS FROM ITALY AND MEDIA ANALISYS FOR ROMANIAN PALLIATIVE SYSTEM. THE FINDINGS FROM THIS STUDY INDICATE THAT PALLIATIVE CARE PROVIDERS ARE INSUFFICIENT, THE PALLIATIVE CARE IS UNDERFUNDED AND WE NEED SPECIALIZED STAFF IN THIS FIELD, IN PARTICULAR SOCIAL WORKERS, MEMBERS OF THE MULTIDISCIPLINARY TEAM, WHO ESTABLISHES NETWORKS BETWEEN INSTITUTIONS AND AT COMMUNITY LEVEL TO FACILITATE ACCESS TO THE NECESSARY RESOURCES FOR THE BENEFICIARY AND HIS/HER FAMILY.

Keywords: PALLIATIVE CARE, SOCIAL WORKER, OCCUPATIONAL ROLE, PRACTICE

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1. INTRODUCTION

The World Health Organization states that palliative care is a way of dealing with the problems associated with incurable diseases in order to prevent and eliminate suffering, with the help of early identification of these problems through a thorough assessment, by treating pain and other physical, psychosocial and spiritual problems.

Palliative care aims to holistically address patients, whose illness is characterized by an unstoppable course and no longer responds to specific treatments (Purcaru, 2022). It seems strange that precisely in our days, when the results achieved through medicine have reached unimaginable heights, contemporary society is still facing a great health and cultural challenge, that of palliative care. This field is a rather new one among medical sciences and because of this, the discipline of palliative care, although regulated, at the institutional level, is still incomplete.

2. LITERATURE REVIEW

The European Association for Palliative Care states that this type of care is characterized by active and comprehensive care, provided to the patient when it is found that the patient's illness no longer responds to the treatment given to cure it. Palliative care is interdisciplinary in nature and involves the patient, the patient's family and the wider community. Palliative care respects life and regards death as a natural process. Its aim is not to hasten or slow down the moment of death, but to provide the best quality of life for the sick person until the moment of the earthly end (European Association for Palliative Care Revised Recommendations on Standards and Norms for Palliative Care in Europe (EAPC): A Delphi study, p. 695).

The difference between palliative care and terminal care is fundamental, the latter is addressed to patients who are in the period closely related to the event of death (weeks, days, hours). Palliative care is addressed to all age groups (including children), with chronic degenerative, oncologic, neurologic, respiratory, cardiologic, genetic diseases, etc., The news of a terminal illness produces a radical change in a person's life, not only in terms of the changes that occur in terms of physical appearance, but also in terms of the changes that occur at psychological, moral (isolation) (Iosif & Pop, 2023), social, family and in most cases even at economic level. The multidisciplinary approach of the patient and the involvement of different professional figures such as doctors, nurses, physiotherapists, psychologists, social workers, social workers, priests or spiritual assistants, volunteers, are fundamental, as they respond to all the patient's needs in order to improve the quality of life.

This approach stems from the observation that the needs of the terminally ill cannot be fully met by the bureaucratic model of hospital services, nor by the exclusive doctor-patient relationship. It is therefore considered necessary to have other professional figures to help the suffering person, enabling him or her to live the experience of illness with dignity (Coyle, 2016). However, in the given context, the family becomes an essential element in defining care as it is considered the main source of care provision. At the same time, the family itself needs support, since the fatigue and grief due to the loss of loved ones puts the stability of the family nucleus under strain.

With regard to the multidisciplinary team, it must be organized and coordinated in such a way that the assessment of the patient is not done in a superficial way. Any kind of intervention must be discussed at team level, based on the information held by each team member, and all decisions will be made on the basis of common projects and objectives among team members. It is essential that the professionals in the team have specific characteristics and skills, such as the specialized training required in a field as sensitive as palliative care, as well as having professional technical and interpersonal skills. Moreover, multidisciplinary team members must have a reflective ethical capacity that helps them to cope with and deal with unexpected situations (Sever Cristian, 2004; Dubois, 2005). Another important characteristic is that each team member must recognize his/her own limits and tolerance level.

Social work and palliative care

In the field of palliative care, the social worker need to step in to meet a series of needs that fall within the social area of the patient, offering a personalized intervention plan, appropriate to the requirements of the patient and his family. Following an in-depth intervention, necessary to understand the real situation of the patient and the family, the social worker provides the whole family with the necessary information on how to address the existing needs (Small, 2001; Iosif and Pop, 2023; Iosif, 2024). At the same time, on the basis of the professional skills and experience acquired, the social worker provides the beneficiaries with information on their legal rights and on the most appropriate care setting. All the while, the social worker works both with the internal resources of the multidisciplinary team and with other territorial authorities.

The role of the social worker in palliative care intervention is to assist patients and their families in identifying problems that may interact with the ability to manage the transformations brought about by the illness. To this end, the social worker establishes networks between institutions and at community level to facilitate access to the necessary resources for the beneficiary and his/her family. Both patients and their families need the social worker's help and support at all stages of their illness. They provide guidance, counselling and support through each stage of accepting the diagnosis, accessing treatment and managing the emotional and mental management of the prognosis.

The social worker's intervention starts with the medical diagnosis. They will act at the request of the attending physician and will note the case in the medical observation sheet. Another of the social worker's tasks is to support the patient in making choices about how he or she wishes to live the last moments of his or her life and to ensure that the person under observation maintains a proper relationship with the specialists. From the point of view of professional practice, social workers are obliged to be aware of the medical situation of their patients, and to participate in programs aimed at continuing professional development (CFCECAS, 2000).

Hospice structures: comparative perspective Italy and Romania

In 1967, on the initiative of Cicely Saunders, the world's first hospice - St. Christopher's hospice - was established in London. Palliative care in Europe was modeled on hospices in Great Britain, which were adapted to cultural and social diversity.

The hospice is a residential structure, alternative or complementary to the patient's home, in which socio-medical services consisting of specialized palliative care are guaranteed for patients with incurable, advanced-stage illnesses (Hoff et al., 2024) In Italy, palliative care began to develop in the 1980s, at the initiative of Professor Vittorio Ventafridda, then director of the Pain Therapy Service of the National Institute for Tumor Research and Treatment in Milan, and Virgilio Floriani, engineer and founder of the eponymous association (Berno, 2023). At that time, the conclusion was reached that the problems of cancer patients went beyond physical pain control and that the hospital, as it was organized and structured, was not the most appropriate place for those in the final stages of life. The 'Floriani model' was thus born, with the hospital as its operational base and the ultimate aim of spreading palliative care to the home, all with the help of a multidisciplinary team.

As a result, an integrated model between the public and private sectors is being developed, which will spread throughout Italy through non-profit organizations, thus giving birth to the first palliative care units.

In Italy, the hospice network has become a point of reference for all health care. Legislative Decree 450/98, amended by Parliament into Law 39/99, was the first step towards the establishment of specific legislation on palliative care, which provided for the adoption of a national program to set up one or more structures dedicated to palliative care with the aim of giving priority to patients with terminal oncological diseases.

According to the D.P.C.M of 14 February 2001, published in Gazzeta Ufficiale no. 129, with reference to the coordination and organization of social and health services, it is specified that palliative services and treatments for terminally ill patients, provided in outpatient, home, semi-residential or residential structures, based on the law 28/2/1999, are fully funded by the National Health System (Balducci, 2016, pp.150-158).

In terms of how to realize hospice networks, the regions use different methods, based on the resources available in the territory and the historical reality.

Another fundamental moment in the development of palliative care in Italy was the framing of palliative care in the Essential Levels of Assistance (L.E.A.). In this sense, the State and the Regions began to organize themselves in 2002 to provide a *Free Network* model of care to all citizens, guaranteeing quality of life and dignity to the people assisted.

Law 38/2010 represents a significant step forward in terms of the organization of the National Health System (SSN-Sistema Sanitario Nazionale), integrating palliative care and pain therapy into the LEA-Livelli Essenziali di Assistenza (Essential Levels of Assistance), which are guaranteed free of charge to all citizens throughout Italy. The law introduces the right of minors to palliative care at home, the first legal provision of its kind in the world.

The hospice network provides care both at home and in residential centers. Hospice care is funded by law and is dedicated to terminally ill patients who, for various reasons, are unable to live the last moments of their lives in their own homes (Marzi, 2004, p.90).

The structures for palliative care dedicated to the terminally ill in Italy are called Residential Palliative Care Centers - Hospice and have the following characteristics:

- Temporary hospitalization of patients for whom health conditions do not allow them home care;
- Temporary hospitalization of patients, as a support for their families, in order to relieve them in the terminal phase of their illness;
- Day care and assistance activity;
- Assessment and monitoring of palliative therapies for symptom control;
- Information and support point for beneficiaries;
- Special spaces for staff training.

According to ISTAT statistics (2023), the main causes of death in 2020 on the Italian territory, were caused by cardiovascular diseases (227.350), malignant tumors (177.858), Covid-19 (78.673) and respiratory diseases (57.113).

An article reported by "Il Sole 24 ORE" on October 31, 2023, shows that one person in three who died from tumor diseases during 2022 received palliative care, a total of 61.000 people.

The same source, indicates that in the last six years, the supply of palliative care both at the patient's home and in hospice has increased from 24% to 36% with major differences from North to South thus:

In Northern Italy among the people who died in 2022, in the Veneto region 57% received palliative care, in Emilia Romagna 53%, in Tuscany 50%, in Lombardy 28% and in Bolzano 47%.

At the opposite pole is Calabria, where only 12% of cancer patients who died were able to benefit from one of the types of palliative care, 15% of the beneficiaries were from Friuli and 16% from the Campagna region.

As regards the situation in Romania, the field of palliative care before 1989 was known as special type of care and was regulated by law 73/1969. This aimed to establish the treatment with opioids which were administered only in the treatment of cancer or post-operative patients. The emergence of migration after 1989 led to increased contact with Western Europe, as a result of which Romanian health specialists began to pay more attention to pain treatment and palliative care (Olăroiu, 2004, p. 9), also referring to good practice models (France) (Moisă et all., 2013).

Palliative care services in Romania are provided both at home and in outpatient and inpatient day centers. Due to the fact that the majority of health funds are allocated for curative medicine, the establishment of new palliative care services in Romania encounters numerous barriers, both from a bureaucratic point of view and in terms of the application of the legislation in force (Boggust, 2017, pp.30-34).

The National Palliative Care Program foresees the following levels of intervention:

1. The first level involves self-care support to patients, their families, their caregivers, provided by primary and community health care staff with basic training in palliative care.

2. The second level refers to basic palliative care - direct care provided to patients and their families/caregivers by health professionals with basic training in palliative care, certified by the completion of training programs accredited by the competent professional bodies; it is provided by family doctors and community care.

Specialized palliative care, or direct care of patients and their families/caregivers, is carried out by teams of professionals with in-depth training in palliative care: physicians with palliative care certification, specialized nurses, social workers, psychologists, therapists, clergy and other competent palliative care staff, according to national palliative care standards.

At present in Romania palliative care services are partially funded and are provided by interdisciplinary teams, made up of physicians with complementary studies in palliative care, nurses, social workers, psychologists, therapists, and other qualified professionals in this field. In terms of improving access to basic and Level 2 services, the involvement of family doctors and community care is required.

In Romania, the first palliative care service was established in Brasov in 1992 (Hospice Casa Speranței). The development of institutions offering palliative care services has been rather slow. Thus, the first initiatives in this field appeared at local level in the form of NGOs or SRL. From a legislative point of view, there was no legal framework providing clear specifications on how palliative care should operate, the provision of services, or the professional qualifications required by the human resources in the field of palliative care.

After 1995, the health authorities started to consider the concept of quality in this field. Standards for the functioning and accreditation of hospitals appeared, and in February 1999 the Law No. 146/1999 on the way hospitals are organized, functioning and financed was adopted.

The first regulations at the legislative level regarding palliative care in Romania were implemented by Hospice Casa Speranței, NHPCO (National Hospice and Palliative Care Organization) and ANIP (National Association of Palliative Care), which in 2002 developed the National Standards in Palliative Care. In 2009, the existing standards were added to those for

Bedside Units, the latter constituting the basis for calculating the costs of palliative care services in both bedside units and in patients' homes.

In 2006, through Law No. 95 on health reform, the procedure for accreditation of hospitals to be granted by CNAS (National Commission for Hospital Accreditation) is established.

In 2018 is approved by the Ministry of Health the Order No. 253/2018, aiming at the implementation of palliative specific services in the public, private and charitable health system. At the same time, the order is correlated with the National Authority for Quality Management in Healthcare (ANMCS), thus exposing the necessary conditions in order to obtain accreditation, as well as details on service providers, the necessary qualification of specialists, categories of beneficiaries, the necessary conditions for palliative care at home, as well as in outpatient or in hospitals or in independent Hospice type units (Catalog of Palliative Care Services in Romania, 2017, p.14).

According to a report provided by the State of Health in the EU in 2023, our country ranks first in the European Union in deaths caused by preventable and treatable causes, such as ischemic heart disease, stroke, pneumonia, this is due to the lack of prevention in the health system. At the same time, reports from 2023, show the incidence of cancer as the second leading cause of death in Romania, accounting for 16.7% of deaths. The most prevalent types of cancer are lung cancer (3.2%), colorectal cancer (2.2%) and breast cancer (1.2%), with a different incidence according to gender as follows: prostate cancer (20% of cases), lung cancer and colorectal cancer (15%) predominate in men, while breast cancer is the most prevalent in women (20% of cases), followed by colorectal cancer (12%) and cervical cancer (8%) (State of Health in the EU Romania Country Health Profile 2023).

3. RESEARCH DESIGN. METHOD

Considering the situation of the two countries in terms of the way palliative care is organized and functioning, in the following, we will analyze the need for this type of intervention in the two countries. To carry out this study, it was necessary to be physically present at one of the first hospices that appeared in Italy-Hospice Antea-Rome-which contributed to a better understanding of the situation on the ground. Another factor of great importance in this respect was the support received from the hospice Antea's specialists, who have improved the methodology of this approach.

In this sense, based on the interview guide built, an interview was conducted in March 2024, in Monte Mario - Rome area. In order to concretize this comparative study, for the situation of palliative care in Romania, we used secondary sources, based on the content analysis of an interview broadcasted on April 13, 2024, on the TV channel Digi 24, on the activity carried out by Hospice Casa Speranței.

In carrying out this study we used a global view of the actions of the two organizations, due to the fact that Hospice Antea is one of the palliative care providers in the Lazio Region, while Hospice Casa Speranței is the largest palliative care provider in Romania and the only one that offers all types of specialized care in the field. In terms of the year of their establishment, the proximity in time of the emergence of hospices can be observed, the late 1980s for Italy and the early 1990s for Romania.

The aim is a common one, namely to provide free specialist care to all people diagnosed with an incurable disease for which a cure is no longer possible and to promote these services at national level through education programs. As a result, the main objective of the two palliative care providers is to provide all eligible persons with the best possible quality of life. Also, the care of the beneficiaries is holistic, giving particular importance to all aspects of life, considering the person in his/her complexity and taking into account his/her physical, psychological, social and spiritual states. This type of complex care is carried out by a multidisciplinary team, with the following specialized professionals present in both centres: palliative care physicians, nurses, social workers, psychologists, spiritual assistants, volunteers and auxiliary staff who complete the care offered by the two organizations. In the two organizations, palliative care is provided both at the patient's home and in hospices, supplemented by the assistance provided by Antea's Telemedicine Centre and in Romania by the assistance provided in day centres, outpatient care or care provided by mobile teams.

To be eligible for palliative care, patients in Italy and Romania must be eligible, meaning that a referral from their family doctor or specialist for specialist care is required. The host institution also has its own eligibility criteria to accept the patient. In both Hospice Antea and Hospice Casa Speranței, the multidisciplinary team is responsible for the final confirmation of the patient's acceptance for care. All decisions regarding the patient are made only with the consent of the patient or legal guardian. Both Hospice Casa Speranței and Hospice Antea Roma have made a remarkable contribution to the emergence of the legal framework for the smooth running of palliative care services at national level.

4. RESULTS

In Romania, the credit for the approval of Order 253/2018 on the organization, operation and authorization of palliative care services was due to the Casa Speranței Hospice Organization and in Italy, Hospice Antea actively participated in the introduction of palliative care, in the category of levels essential assistance but also with the emergence of Law n.38/2010, provisions for guaranteeing access to palliative care and pain therapy. Regarding the financing regime, in Italy palliative care is a right of the sick person, it being granted free of charge. Law 38/2010 and successive decrees assign the responsibility to the Local Palliative Care Networks to guarantee the right to care for the patient and his family.

In Romania, Hospice Casa Speranței obtains financing from campaigns organized for the purpose of raising funds in a percentage of almost 90%, and the remaining 10% is obtained by financing palliative care services from public funds. Following the comparative analysis between the interview given by the Antea hospice specialists and the information about the Casa Speranței Hospice, it follows that the principles of palliative care are the same, namely ensuring the best possible quality of life, for people suffering from a disease for which there is no cure is still possible. At the same time, palliative care is provided through a multidisciplinary team that offers the patient holistic care. Also, when asked about the criteria for access to this type of care, it emerged from both interviews that the services offered by the two hospices are provided free of charge to all eligible patients, both: oncological and non-oncological, pediatric and adult, in based on the recommendation of the family doctor or specialist.

Another common aspect in the analysis of the two organizations is represented by the fact that both in Italy and in Romania, palliative care providers are insufficient, this leads to a selection of people who need specialized care and the drawing up of lists which often turn out to be very busy. This explains the phenomenon often seen in hospices, namely the fact that a good part of the people who end up being hospitalized cannot fully benefit from an individualized care plan, due to the advanced stage of the disease and the poor clinical conditions, losing thus the little precious time they have. As for the most appropriate care environment, the patient's home is preferable, but when the state of health does not allow this, a different setting can be chosen according to the patient's needs. All decisions concerning the patient are made only with the consent of the patient or the legal guardian. Communication represents another common point of the two interviews, this being of major importance both within the multidisciplinary team and between the specialists, the sick person and the family, being considered the key element in establishing the relationship of trust between them.

Regarding the differences between the two systems of providing palliative care, of major importance is the fact that in Italy it is offered free of charge to all people who are in the territory and are declared eligible, palliative care being considered among the essential levels of assistance. At the same time, each region in Italy has legislative autonomy regarding the provision of socio-medical services. Another distinct aspect between the two systems is represented by the intervention of local health units in granting the certificate of eligibility to the sick person.

In Romania, we have a fragmented financing system regarding the provision of palliative care and at the same time many of the people declared eligible cannot benefit from this type of care. This is due to both insufficient funds in the health system and the lack of service providers. In both interviews, the reason behind the choice of the professionals to carry out their activity in such a fragile environment as that of the hospice was surprising: each chose this path following their own experience, which motivated them enough to give aid to those in distress.

Table 1. Share of deaths and their main causes

Country	Tumors	Cardiovascular diseases	Covid 19	Respiratory diseases	Deaths from preventable and treatable diseases	Other causes of death	Total number of deaths 2022
Romania	45.823	50.640	-	29.612	112.670	33.738	272.483
Italy	177.858	227.350	78.673	57.113	117.701	87.627	746.322

Source: Author elaboration based on the data reported in the INSEE and ISTAT database

Table 2. Total number of units with beds and care beds in 2022

Country	**Units with beds**	**Care beds**
Romania	66 UP	1435 P[1]
Italy	306 UP	3220 P[2]

Source: Author elaboration based on the data reported in the INSEE and ISTAT database

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Table 3. The need for palliative care related to care beds and the number of inhabitants

Country	**Number of inhabitants**	**Care beds**	**The need for palliative care**
Romania	19.053.815	1435 P[3]	176,156[4]
Italy	58.997.201	3220 P	450.000[5]

Source: Author elaboration based on the data reported in the INSEE and ISTAT database

5. CONCLUSIONS

From the data presented in table number 1, it appears that tumors are the second cause of death both in Romania and in Italy. Another worrying aspect is represented by the number of annual deaths, caused by avoidable and treatable diseases (heart disease, pneumonia, vascular accidents, Covid 19), which represent 112,670 in Romania and 117,701 in Italy. Following the comparative analysis between the population of Romania (19,053,815 inhabitants) and that of the Italian state (58,997,201 inhabitants), related to the incidence of deaths caused by avoidable and treatable diseases, it can be concluded that in our country the number of deaths due to mentioned above is very high. In this sense, a decisive factor is the lack of prevention and screening in the Romanian medical system, as well as the high costs for carrying out medical investigations.

In the tables with numbers 2 and 3, you can see the ratio between the need for palliative care that exists at the level of each state (176,156 in Romania; 450,000 in Italy), the population of the country (19,053,815 in Romania; 58,997,210 in Italy), the number actually of palliative units (66 UP in Romania; 306 UP in Italy) and beds (1435 P in Romania; 3220 P in Italy), intended for people who need this type of care. This study demonstrates the fact that both in Romania and in Italy, palliative care services related to the need in the territory are insufficient.

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