Palliative care between necessity and reality. Evaluation of the need for the development of palliative care services

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Abstract
Palliative care social work has emerged largely as a specialty health-related clinical social work on a global scale. Palliative care teams are relied upon to support patients and their families as a result of people living longer with serious illnesses and chronic diseases. An essential component of the interprofessional palliative care team are the social workers. In this study, I want to discuss the need for palliative care services to expand across the nation, with a particular emphasis on Galati County. The study's thesis is that because palliative care is currently underfunded and because socioeconomic developments provide significant obstacles, the state must take specific action. Additionally, this paper explains the role of social workers in hospital-based palliative care. It also examines some important statistical data about palliative care in Galati County.

Keywords: *Social work; Palliatives care; Involvement; Hospice care;*

1. Introduction

Palliative care, although an integral part of health services, is still a little-known concept at national level. In Romania, palliative care services appeared in the period immediately following the Revolution of 1989, in a period of profound social and legislative transformations. But it is noted that even today, the concept of palliative care is not sufficiently known, so that "addressability is paradoxically deficient, despite the fact that there are many people in a situation where they need such services" (Potra, 2021, p. 328).

There are families who face the illness and suffering of a dear member, and who do not know who to turn to and what to do for a terminally ill patient (Căruntu, 2012, p. 5).

In the specialized literature, there are several definitions given to palliative care, the reference being the definition given by the World Health Organization, as an *active, total care* given to patients whose disease no longer responds to curative treatment, which is given with the aim of ensure a better quality of life and by introducing medication to control the pain and symptoms related to the disease, also following physical, psycho-social or spiritual problems. The scope of palliative care also includes the family "facing challenges associated with life-threatening illnesses, whether physical, psychological, social or spiritual" (WHO, 2020).

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The European Association of Palliative Care (EAPC) has a definition of palliative care, slightly different from the definition given by the World Health Organization (WHO), specifying that it is an *interdisciplinary field* and includes the patient and the family and the community.

Palliative care does not address a specific disease, but addresses the human in its complexity, through a *holistic approach* aimed at improving the quality of life, by addressing the physical, psycho-social and spiritual needs associated with the life-threatening disease, from the moment of diagnosis and until the mourning period, through the assistance given to the family. This holistic approach to medical care was a necessity, as the multitude of specialties and sub-specialties in the medical field led to a sequential treatment, reducing man to the totality of his organs. However, it cannot be abstracted from the fact that man is a whole of body and soul, and that if an organ is affected by the disease, and is treated by a certain specialty, still the man suffers with his whole body and with his extension such as, the whole family. In the case of terminal illnesses, the patient and his family become "*a suffering unit*" (McLennan and Greenwood, 1987, *apud* Mândrilă-Lăzăreanu, 2014, p. 189).

Etymologically, the term *palliative* comes from the Latin *pallium,* and it referred to garments worn only by rich Greeks and Romans, being also assimilated into the clothing of the Catholic church, as an outer garment. The verb *palliate* comes with the meaning of protecting something by covering, by hiding and defending under a cloak, or under a mask (Chiorean, 2022). We note that the term palliative is itself a definition of palliation, respectively, it masks the symptoms, reducing the pain and although it does not cure the disease, it makes it bearable, bringing as much as possible a certain quality of life and dignity to the person.

The term "palliative care", was first used by Dr. Balfour Mount of Montreal in 1974, following his visit to the St. Christopher's Hospice center opened by Dr. Cecely Saunders in the south London, because he understood that the care activity that was carried out in that center represented a new medical specialty, and he needed a terminological attestation (Ignatieff, 2022).

In the worldwide trend of declining birth rates and its follow-up - the aging of the population, to which is added the change in the structure and functionality of the family, migration, the increase in the incidence of cancer and other chronic degenerative diseases, disabling for patients, as well as the fact that the affected age group no longer refers only to the elderly, but includes more and more young people and adults, Romania had to take measures to develop palliative care services.

Thus, Order of the Ministry of Health no. 253/2018, amended and supplemented in 2023 by Order no. 3514, brought the official regulation of unitary organization of palliative care by drawing a strategy for their progressive development, as an integral part of the health system.

The strategy in palliation at the national level is to develop according to the complexity of cases and needs, in three levels, namely level 1 which focuses on educating and supporting the patient in self-care, level 2 which includes basic palliative care, and level 3, which includes *specialized* palliative care. Thus, if the *basic* palliative care branch aids at home or in family doctors' offices, in general hospitals or in specialized hospitals, in day centers or outpatient clinics, *specialized palliative*

care aims at specialized assistance through multidisciplinary teams with in-depth training in the field palliation, in different care environments: at patients' homes, in palliative care centers, in outpatients or in day care centers.

Despite all the efforts made in the 32 years since Graham Perolls opened the way for palliative care in Romania for patients diagnosed with an incurable disease, we still have 9 counties where there are no palliative care services, the concept is still not well known to citizens, access to these centers is difficult, the need for care being bigger than the available places. The palliative care system is currently disproportionate to demand and unequally covered in the country.

From the data presented in 2024 by the National Association of Palliative Care, it follows that, currently, palliative services mainly consist of admitting patients in units with beds specialized in palliation or in wards established within public or private hospitals. Outpatient services remain very poorly developed, and home palliative care is supported exclusively by charitable organizations or private services (ANIP, 2024).

From the statements made by the Minister of Health Alexandru Rafila, the number of palliative care beds is approximately 3300, of which almost 3000 are under contract with health insurance companies (Neagu, 2024).

The other types of outpatient and home palliative services are underdeveloped, in 2023 only 7 home palliative care providers were reported (CNAS, 2024).

The result of this disproportionality between the demand for palliative services and the supply in the medical system, means that access to palliative care is limited or even inadequate, not being granted from the diagnosis phase, but to late, when the patient is already in the terminal phase.

In 2021, the Ministry of Health, together with the Ministry of Labor and Social Protection, the Casa Speranţei HOSPICE association and the National Health Insurance House drew up a Report, entitled *Analysis of the situation of palliative care providers in Romania in 2019*, following which - they found problems related to the fact that:

"In Romania approximately 176,156 people need palliative care annually. Most of them are patients with progressive chronic diseases (approx. 60%) and (approx. 40%) with oncological conditions. There are counties (10 counties, including the municipality of Bucharest) where the need is more than 5,000 patients annually and 13 counties with a need of less than 3,000 patients. The degree of coverage of the need for palliative care in 2019 was 18.71%" (Ministry of Health, 2019, p. 77).

There is a gap between existing services at national level and the need for palliative care. Since the number of IP centers is small and the demand is high, admission to these palliative care centers is made with difficulty, depending on the available places, after registering the patient on a waiting list. It is known that in incurable chronic diseases, life expectancy can vary between several years, several weeks or even a few days, so the intervention must be done as a matter of maximum emergency, not on waiting lists (Chiorean, 2022).

According to the Basic Principles in palliation, patient care must be provided from the moment of diagnosis of the disease, with the result that throughout the

disease there will be a permanent continuation of the assistance provided, a fact that cannot be applied in all cases in Romania, due to difficult access with this type of service. Palliation often remains only a care in advanced stages of the disease, in the last weeks of life.

A fair ratio between the offer of services and the real need, would contribute to avoid the unnecessary suffering of the patients, to eliminate the feeling of abandonment and the feeling that he has, that he is a burden both for the family and for society.

2. Factors influencing the need for palliative care medical services

2.1 Demographic aging

Demographic aging and the increasing number of elderly people is evident both at the European level and at the level of our country.

The factors that contribute to the increase in the relative weight of the elderly are demographic, social and economic, among which I mention the universal factors at the European level: increasing longevity, increasing the average life expectancy at birth and the "aging of the top" of the demographic pyramid, the decrease in the birth rate but also fertility, the increase in the average age at first birth, as a result of the priority aspect of the career, as well as external migration (Iosif, 2022, p. 6).

At the national level, according to the projections made by the INS, the number of active elderly population aged 65 and over will increase by +18.4% by 2060 (INS, 2018).

According to the INS press release, no. 83 / April 5, 2024, the phenomenon of population aging in Romania intensified in 2023. The elderly population of 65 years and over exceeded the young population of 0-14 years by 27.5%.

The INS data also show that the accentuation of the demographic aging process is clearly demonstrated by the demographic aging index, which was on January 1, 2024, 127.5 elderly people for 100 young people (INS announcement, 2024).

Another marker that attests to the phenomenon of population aging is given by the increase in the values for the average age and the median age of the population. The average age of the population was 42.5 years. The median age was 43.2 years (INS, 2024).

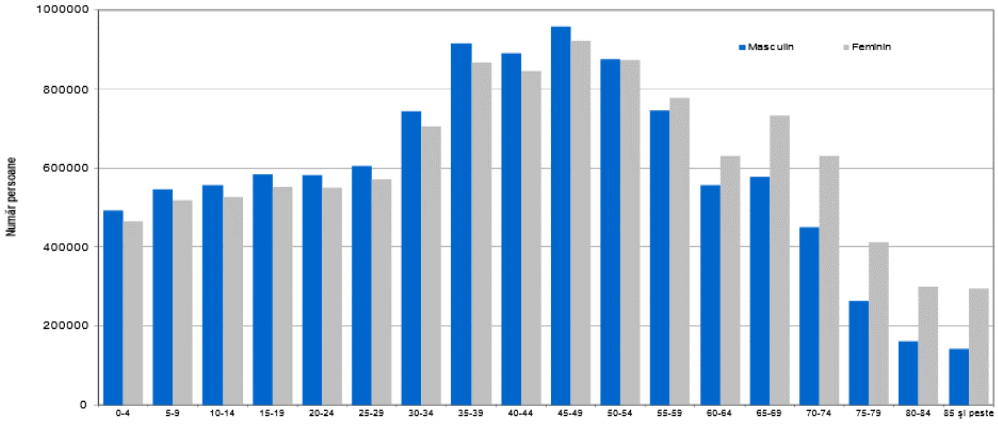

Figure 1. Population by residence by age group and sex, on January 1, 2024.
Source: INS, 2024.

This aspect shows that the aging of the population stems from the low birth rate. In the next 10-15 years, the demographic aging process will be acutely felt, as the people who now constitute the middle age segment will become elderly people, without having the support of the category that is now 0-14 years old.

Although non-communicable diseases and chronic diseases that require palliative care cover all age segments, a large proportion of patients belong to the 65 plus age group. Life expectancy without disability after the age of 65 (i.e. healthy life expectancy) is lower in Romania than in the UE, and is manifested by the loss of autonomy in carrying out basic daily activities.

In conclusion: old age is not considered a disease, but it brings with it a sharp degradation of the whole body, and the health system must be prepared to deal with the care needs, which are currently high and not sufficiently covered, but which according to the statistics presented will be increasing in the next period.

2.2 Life expectancy at birth

Life expectancy at birth is an important indicator in the evaluation of the quality of life, relating elements related to the degree of development of the population both from an economic and social point of view. Life expectancy also brings information about medical services in the analyzed area, bringing information related to the efficiency and quality of services, as well as the degree of access of the population to these services. In 2023, the European Commission conducted, through the OECD, a study entitled "Romania country profile in 2023, in terms of health". The conclusion of this study is that until 2019, this index grew faster than the index registered as an average in the UE, but it fell sharply during the period of the COVID-19 pandemic, reaching an index of only 72.8 years. In 2022, the life expectancy index increased to 75.3 years, but in relation to the other member states, Romania is the third country with the lowest life expectancy. The difference compared to the UE level is -5.4 years below the average (OECD, 2024, p. 4).

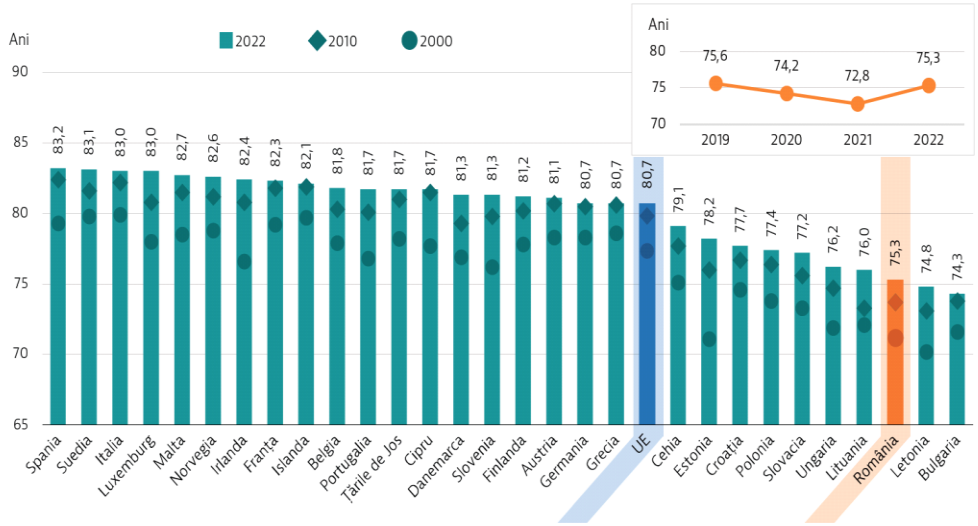

Figure 2. Life expectancy at birth in Romania and UE. Source: OECD, 2024.

The fact that life expectancy at birth is low in our country sends a signal regarding the quality of life and the quality of medical services. This indicator is a requirement to develop curative medical services and palliative care.

2.3 The incidence of chronic incurable diseases

Although the initial perception towards palliative care is that this type of medical care would mainly serve the elderly, unfortunately, statistics show that incurable diseases strike all age groups.

In this sense, G. Rahnea-Niță in the work *Practice and ethics of palliative care* (2022), mentioned "We do not grant IP only to patients with cancer in the final stages or to the elderly in the last moments of their lives. IP is also granted to children and pregnant women and young people" (p. 181).

Even though life expectancy has increased in the world, as a reverse, cases of oncological diseases have appeared in young people up to 40 years old. In 2023, at the annual meeting of the American Society of Clinical Oncology - "specialists warned that the rate of colorectal cancer has increased rapidly in people under 40, risking becoming in the coming years the main cause of death in people between the ages between the ages of 20 and 49" (Cox, 2024).

The OECD study, regarding health in Romania, notes that the incidence of chronic diseases is very high in our country. Of the total deaths recorded in 2020, more than half of the causes of death are due to heart diseases (OECD, 2024, *apud* Eurostat database, p. 5).

Regarding oncological diseases, I present below the graph of the estimates of oncological cases.

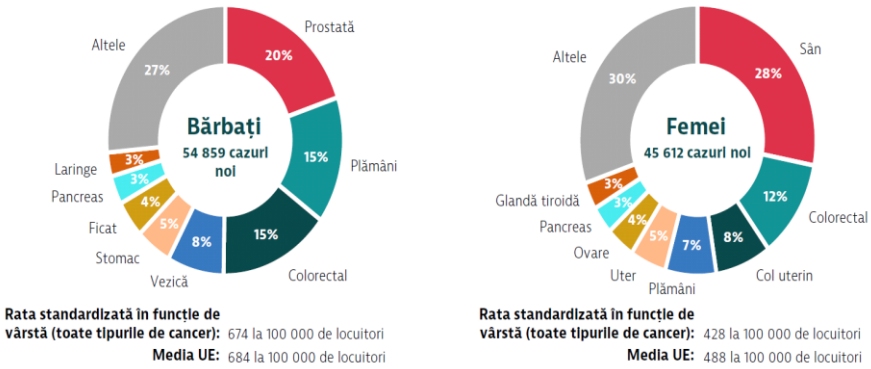

Figure 3. Cancer incidence trends in Romania. Source: OECD, 2024, January 20

The OECD estimated, based on disease incidence trends from previous years, that there would be "more than 100,000 new cases of cancer... The main types of cancer estimated among men were prostate cancer (20%), lung cancer (15 %) and colorectal cancer (15 %), while among women, breast cancer would be the main type of cancer (28 %), followed by colorectal cancer (12 %) and cervical cancer (8 %)" (OECD, 2024, p. 6).

It follows that the growing need for palliative care services is a challenge for the health system around the world, including in our country.

2.4 The place of death and the implicit need for the establishment of palliative care centers

It is worth noting that statistically, the place of birth and death of a person takes place most frequently in institutions (they are, somehow, public events).

It is obvious that most patients want to receive care in their home environment. Studies show "that around 75% of respondents want to spend the last stage of life at home" (European Association for Palliative Care, 2022). But in practice, the place of death for most patients is the hospital, nursing home or hospice. This is due, on the one hand, to the fact that the patients are single, unmarried or widowed, and on the other hand, to the fact that there was no longer a strong social and family network (Iosif & Pop, 2023; Iosif, 2024). Institutionalization is a correct decision, considering that the patient's condition becomes very deteriorated, and home care is no longer effective, but on the other hand, there is also a tendency of modern man to run away from discomfort, and thus death is outsourced from the family, starting with the transfer of the dying person to institutions, and continuing with everything related to funeral services and rituals. It is an escape from all that is sad and uncomfortable.

2.5 Migration and the disappearance of the traditional extended family

The INS press release shows that on January 1, 2024, "the population by domicile reached 21,833.2 people, down 0.5% compared to January 1, 2023", which

proves that the phenomenon of migration continues (National Institute of Statistics, 2024).

International migration had a double effect in Romania. In addition to the positive effects of reducing unemployment and economic growth, there have also been negative effects related to a sharp decrease in the resident population and the aging of the population. The migration was felt especially on the labor market, where "as the share of the active population decreases, the pressure on the one left to support the elderly population increases" (Logofătu, 2021).

A negative consequence of migration is the worrisome demographic evolution, with the total or partial depopulation of some localities, which remain inhabited exclusively by elderly people who do not have family support. These single elderly people, whose children have left the country, are very vulnerable, not having family support. They represent a growing social problem that will have an impact on society, involving social service systems and the health system.

Consequently, no matter how much the elderly person wants to have a socially active old age, to retire as late as possible, not to be a burden and to be able to manage his life autonomously, at some point he becomes vulnerable, and dependent on the help provided by the state, through its social institutions, in the context where the family of belonging is no longer in the country or is unable to take care of the problems related to the care of an elderly and sick person. All this new context that society was facing and that will intensify in the future, forces society to take urgent measures to develop social services and medical care.

3. Assessment of the need for palliative care in Galati County. Presentation of the existing situation

In 2023, in Galati County, palliative care was provided in the Geriatrics-gerontology department, within the "St. Apostol Andrei", ward that has only 10 beds, related to a population that, according to the December 2021 census, was 496,892 inhabitants (INS, 2024).

At the level of 10 beds, compared to the number of residents, to which patients from neighboring counties are also added, Galati County, although it is among the 30 counties in the country that have established IP services, faces an undersized development of services, in a negative relationship between demand and supply. This conclusion is supported by the fact that the Ministry of Health, in the Regional General Plans of Health Services for the period 2021-2027, established a rule that provides for the provision of a minimum number of "25 IP beds for a population of 125,000 inhabitants" (Methodological norms for the application of GD no. 521/2023, 2023).

To assess the need for palliative care in Galati County, we analyzed the statistical data provided by the Galati Public Health Directorate, with the limited purpose of preparing the study.

In the period 2014-2023, the situation of admissions and deaths in the palliative care department of the County Hospital "St. Apostle Andrei" from Galați, was the following:

Table 1. Status of admissions/deaths - palliative care ward, 2014-2023. Source: DSP Galati

Section/ Department	The year	Number of beds existing	Number of hospitalized patients	Number of patients who died in hospital
Palliative Care	2014	10	149	63
Palliative Care	2015	10	246	73
Palliative Care	2016	10	336	86
Palliative Care	2017	10	255	72
Palliative Care	2018	10	221	69
Palliative Care	2019	10	213	59
Palliative Care	2020	10	54	21
Palliative Care	2021	10	43	21
Palliative Care	2022	10	242	140
Palliative Care	2023	10	227	136
TOTAL			**1986**	**740**

From the table regarding the situation of hospitalizations and deaths registered in the palliative care department, in the period 2014-2023, it can be seen that we register an annual average of hospitalizations of 198.6 patients per year, an average that has a margin of error, given the decrease "forced" of the services addressed to the chronically ill during the Covid 19 pandemic. The deaths recorded in the hospital are an average of 74 patients per year (that is, 37% of hospitalized patients died in the hospital).

Regarding the situation of admissions and deaths in the period 2014-2023, in the Oncology and Oncological Radiotherapy departments of the County Hospital "St. Apostle Andrei" from Galati, the situation was as follows:

Table 2. The situation of admissions and deaths registered in the oncology and oncological radiation therapy department, in the period 2014-2023 Source: DSP Galaţi.

Year	Number of beds existing	Number of hospitalized patients	Number of patients who died in hospital
2014	45	3474	229
2015	45	2576	250
2016	45	2363	243
2017	45	2058	258
2018	45	1894	288
2019	45	1998	317
2020	45	1062	251
2021	45	835	228
2022	45	1219	221
2023	45	2245	230
Total		19,724	2515

From the chart regarding the admissions and deaths recorded in the oncology and radiation oncology department, in the period 2014-2023, we register an annual average of admissions of 1,972.4 patients per year. The period of the Covid 19 pandemic distorts the result, the patients not having access to the hospital during that period. The deaths recorded in the hospital are in a linear average of 251.5 patients per year (12.8% of hospitalized patients died in hospital).

Table 3. Records of cancer patients registered (Oncology) in Galati County, 2014-2023. Source: DSP Galati

The year	Total cases	Women	Cases from the urban areas	Cases from rural areas
2014	15560	8084	9867	5693
2015	16253	8524	10413	5840
2016	17259	8989	11056	6203
2017	17083	8775	11009	6074
2018	16651	8728	10789	5862
2019	16470	8761	10750	5720
2020	15870	8566	10454	5416
2021	15341	8422	10177	5164
2022	15404	8495	10135	5269
2023	16026	8695	10614	5412
	161917	86039	105264	56653

Analyzing the collected data, we notice that of the total number of patients with oncological diseases, more than half are women, respectively a percentage of 53%. We also find that the number of patients with oncological diseases represents 3.2% of the total inhabitants of Galati County, and as a zonal distribution, 65% of the patients are from the urban environment.

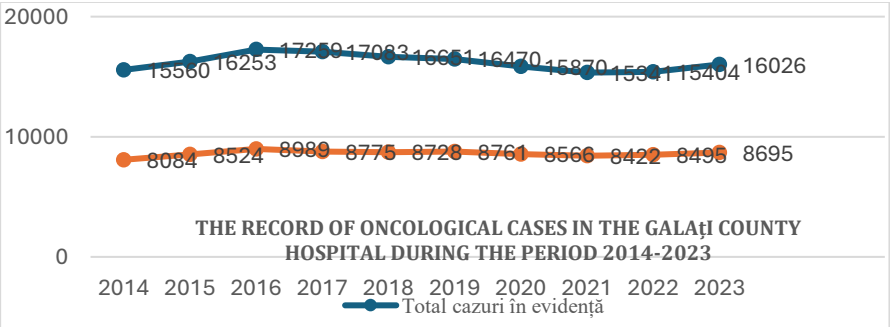

Figure 4. Evolution of oncological cases in the Galati County hospital in the periods 2014-2023

4. Determining the need for palliative care in Galati County

To calculate the need for palliative care, the Stjernsward method or the Irene Higginson method can be used (Higginson, 1997, *apud* Negoescu, 2020, p. 46). I chose

to use the Higginson method, as this was the method used in the study " Romania - Assessment of the need for palliative care", initiated by the Ministry of Health (2017).

This method uses mortality data, estimating that approximately 90% of patients who die from oncological diseases and 2/3 of all those who die from non-oncological diseases, would require palliative care services in the last year of life.

To determine the number of patients who annually need palliative care in Galați County, the population data for the year 2022 were used, since at the time of the study, the data for the year 2023 were not published.

Analyzing the natural movement of the population that took place in 2023, according to the data provided by the INS, we can conclude that:

Table 4. Natural population movement. Source: INS, Demographic evolution Galati, 2022-2023.

	2022											
	Jan.	Feb.	March	Apr.	May	June	Jul.	Aug.	Sept.	Oct.	Nov.	Dec.
live births	353	242	295	274	346	315	436	456	488	377	332	324
deceased	706	749	726	562	593	523	579	622	520	538	566	717
Natural growth	-353	-507	-431	-288	-247	-208	-143	-166	-32	-161	-234	-333

In the year 2023, a negative natural increase was registered in Galati County (the number of live births minus the number of deceased), the excess of the number of deceased over the number of live births being -3103 people.

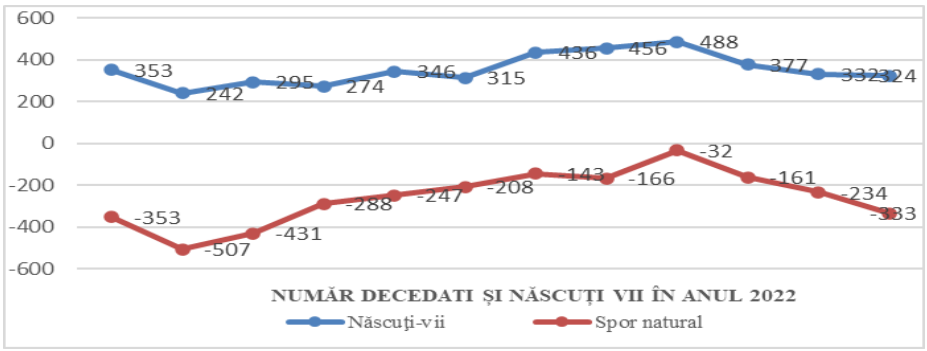

Figure 5. Number of deaths and live births in 2022

For the year 2022, INS reports that in Galați County, 7,401 deaths were recorded, of which 49% were in rural areas and 51% in urban areas.

Of the total deaths, 6077 (82%) had non-oncological causes, 1177 (16%) oncological causes, and 147 (2%) acute causes (accidents or suicide) (INS, 2023).

From the calculation of the assessment of the need for palliative care, we excluded acute causes, as being irrelevant. We estimated that approximately 66% of

all deaths with non-oncological causes were presumed to need palliative care, and for the cases of deaths with oncological causes in a percentage of 90%, palliative care was needed.

Following this methodology, it follows:

- 66% * 6077 (total non-oncological deaths) = 4011 non-oncological patients need palliative care annually;
- 90% * 1177 (total oncological deaths) = 1059 of the oncological patients need PI annually;
- Total: 4011+1059 = 5070 patients in need of palliative care annually.

Thus, at the level of Galati County, the need for palliative care is 5070 patients annually, compared to the average of 198.6 resulting according to the analysis made previously in table no.1.

The reduced or insufficient number of these services "puts this category of patients and their families in difficulty, there is a risk of death due to the lack of care" (Căruntu, 2012, p. 5).

The quality of life of Romanian citizens depends on the way the state, through its policies, will act in this field of health, and develop services according to need, because: "The quality of life of the elderly...as well as of other age groups, is strong dependent on the macrosocial framework: on the level of economic development, adopted social policies, the level of development of services, the degree of social cohesion, etc." (Mihalache, 2021, p. 4).

5. Conclusions

This study supports the scaling of palliative care services to the capacity required by the actual existing need, so that patients can benefit from specialist palliative care at the appropriate time, avoiding unnecessary suffering and human degradation.

The right of citizens to benefit from health protection is a right guaranteed and regulated by internal laws and international laws to which Romania is a signatory party.

The current legal framework certifies the right and the possibility of any sick person to benefit from appropriate medical assistance in state or private medical institutions.

Palliative care is a mathematically and statistically proven need and by no means a luxury, it is a human right that, although it does not prolong life, brings it a certain quality and dignity. Obviously, there is a difference between a right and an ascertained need. A need is not the equivalent of a human right, but it is an entitlement to it. And this right is void if the necessary socio-economic resources are missing.

Starting from the old hospital, the millennial philanthropic ethos of the Church has been perpetuated until today. The Romanian Orthodox Church succeeds through the centers and medical facilities that it has established next to the archdiocese in the big cities, to support and complete the Romanian medical system, something that should also be achieved at the level of Galaţi county.

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