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THE NATIONAL PROGRAM FOR PALLIATIVE CARE – AN IN-DEPTH ANALYSIS

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Abstract. *Health is a priority for all states and obviously for the European Union, concerned with achieving convergence of all states towards equal or at least comparable systems. The analysis of health systems in Romania and France provides a picture of the vulnerabilities that should be considered by the Bucharest administration. The paper sets out a series of strategic recommendations that can contribute to the improvement of health services in Romania, as well as a number of directions for action that will bring them closer to those of the European Union. The level of quality established at national level must meet the needs of citizens and their rights to a better life.*

Keywords: healthcare, public policies, strategic management, quality of life.

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1. Introduction

The health of any individual is widely regarded as being the most important “possession” one can have. Your state of health determines what you can achieve and it is also capable of inhibiting you from achieving your goals. The private healthcare service market is still one of the most invested in markets worldwide. Yet, the state owned hospitals and healthcare providers lack the funding to properly adhere to the needs of the working class or individuals of a lower socio-economic level. Having the appropriate equipment to deal with emergency situations is crucial in defining the infrastructure of a hospital or clinic [9].

Unfortunately, there are exists a vast number of health care systems in Europe, particularly Eastern Europe, where the public health sector is neglected in favor of more profitable resources. It is inevitable, every person on this planet has been sick at least once in their lifetime, so therefore they will at one point or another visit a doctor, whether or not they choose to access medical help in the private or the public sector depends strictly on them, but the amount of money you make should not prevent certain members of the public to gain access to more expensive/efficient treatments over others.

The first step to gaining an efficient and balanced healthcare system is having a well-designed and concise policy outlining all the necessary actions and equipment required to carry out your plan. Establishing a budget in order to

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implement your program and following a schedule are key in bringing your ideas to fruition [16]. The purpose of this paper is to evaluate the already existing palliative care programs for children and the elderly with chronic disabilities or life-threatening disorders and suggest methods of improvement. It also aims to establish quality control mechanisms for palliative care services in the public and private system, to legislate for quality standards and specific clinical protocols.

2. What is Palliative Care?

Palliative care is the active and total care of patients whose disease is no longer responding to curative treatment. Control of pain and other symptoms, psychological, social and spiritual issues are of major importance. The goal of palliative care is to ensure the best quality of life for the sick and their families.[6]

According to the Oxford Textbook of Palliative Medicine, palliative medicine is: The medical care of patients with active, progressive and advanced diseases, for whom the prognosis is limited and the care should focus on ensuring the quality of life [4].

The World Health Organization has defined palliative medicine as follows: Palliative care is an approach that improves the quality of life of the patient and their families facing problems associated with life-threatening illness by preventing and eliminating suffering through early identification, correct assessment and treatment impeccable pain and other physical, psycho-social, and spiritual problems [23].

In a recent paper by the National Consensus Group, eligible patients for palliative care are:

- Children or adults with congenital illnesses or injuries that lead to dependence on life support or long-term care for the daily routine;
- People of any age with severe and life-threatening illness (severe trauma, acute leukemia, stroke), where healing is a realistic goal, but where the illness itself or the associated treatments bring with it significant suffering;
- Individuals living with progressive chronic diseases (peripheral vascular disease, cancer, renal or hepatic impairment, severe functional impairment, advanced cardiac or pulmonary disease, age-related fragility, neurodegenerative disorders and dementia);
- Patients with terminal disease;
- People living with chronic and life-threatening illnesses resulting from severe accidents or trauma [13].

Palliative care: is a total, active care of patients and their families, usually when the disease no longer responds to potentially curative treatment, although it can be applied early during the disease. It provides relief of pain and other symptoms. It aims to achieve the highest quality of life possible for patients and their families. Palliative care should respond to physical, psychosocial and spiritual needs and should be flexible when needed to provide support during mourning [13].

In the care of a patient an interdisciplinary team is needed (to meet the complex needs of the patient and the family), the patient communicates with the family and the others interact with them, but also with each other depending on the complexity of the case or the evolution of the disease: medical, social worker, nursing home, psychologist, priest/pastor, physiotherapist, occupational therapist, game therapist, dietician, pharmacist and, last but not least, the volunteer. Beneficiaries of palliative care are not only cancer patients but also geriatric patients, neurological diseases, organ failure, AIDS, congenital malformations and other chronic diseases that require continuous care or where the symptoms are unpredictable.

Care of dying patients extends beyond the control of pain and symptoms. It includes support: The patient as he adjusts to lower physical abilities and mourns anticipated loss of family, friends and all that is familiar to him/her; The family that adapts to the fact that someone close will die [6].

Caring for these patients becomes a form of partnership with the patient and his family. In palliative care, we are not only concerned with the physical aspects of the patient but, above all, with the patient as a person, with all the inner conflicts related to his illness (psychic, social and spiritual in particular). Questions about the religious issue that are considered too intimate in other specialties to be addressed to the patient, in palliative terms, are only of a general nature at the onset of a "warming" conversation: How do you deal with the illness? What do you hope for? What significance do they have? Where do you find resources? (material and spiritual) What is the most important thing for you?

Communication plays a particularly important role in the complex patient assistance to the terminal. The news of the worsening of the disease and the inability to stop the degradation of the general condition produces a strong emotional burden on both the patient and his or her patients. But shared truth can contribute to awareness of the remaining time, which is becoming more and more limited in order to use it as efficiently as possible.

Communicating bad news is a process that is more like negotiation. The patient has the right, but not the obligation to find bad news. Pain is a symptom, a subjective experience. Every individual learns the meaning of his own experience, acquired from his first childhood, as a result of accidental trauma, because an unpleasant sensation is always associated with an emotional reaction. The higher the emotional aura (depending on the individuality of each individual and the culture from which it originates), the more the real pain (physical or mental) is greater. You do not get used to the pain. The longer it lasts, the stronger, the more traumatic it is, the inevitable change in personality.[1]

The concept of total pain encompasses all the factors that cause pain: biological (physical), psychological (emotional, mental, behavioral), social (relationship with others) and spiritual. Against the background of the general decline in birth rates and implicitly of population aging, the increase in cancer incidence, neurological and cardiac disabling conditions for patients, Romania has been experiencing an increase in the number of patients with progressive and incurable chronic diseases in the last few decades specialized health care system is not prepared. The considerable increase in the population's need for access to palliative care services has been highlighted in the context of a nationwide sociological research on the population's preoccupation with palliative care.

The study showed that 20.7% of the population (about 4.3 million people) faced or faced the problem of incurable patient care at advanced or terminal stages; of these, 76% were exclusively family-cared for, 11.8% by family doctors, 1.2% in specialized services for these patients. Corroborating the study data with the estimation of the need for palliative care (calculated on the basis of international recommendations), in Romania 5.9% of the persons who should receive specialized services for the improvement of the quality of life in advanced stages of incurable disease have access to specialized services. Palliative care provides the patient and his family with specialized multidisciplinary assistance (nursing and health care, psycho-emotional, social and spiritual support) to improve the quality of life and alleviate suffering [22].

It is currently estimated that about 160,000 patients/year need palliative care (over 59,000 of them are cancer patients), and coverage of needs through existing palliative care services (in the public, nongovernmental or private system) is only 5.4% [20]. Romanian authorities recognize the need to offer palliative care to the population, but their actions are uncoordinated.

The Sustainable Development Strategy of Romania Horizon 2013-2020-2030, published in MO 824 bis/12.2008, provides for 60% coverage of palliative care needs for eligible patients by 2020, but does not foresee ways to implement it objective [20].

In 2008 the Health Ministry signed with the Hospice House of Hope and the Federation of Associations of People with Cancer a partnership to develop a national strategy for palliative care partnership that has brought some regulatory adjustments:

- Defining the staff regulations for palliative care services in 2010.

- Definition of palliative care services at home (distinct from home medical care) and how to finance them, starting with the 2010 Framework Contract;

In 2011, at the request of the Ministry of Health, „Hospice Casa Sperantei‘ started the project to develop a national strategy for palliative care. Benefiting from the voluntary consultation of two former experts [12].

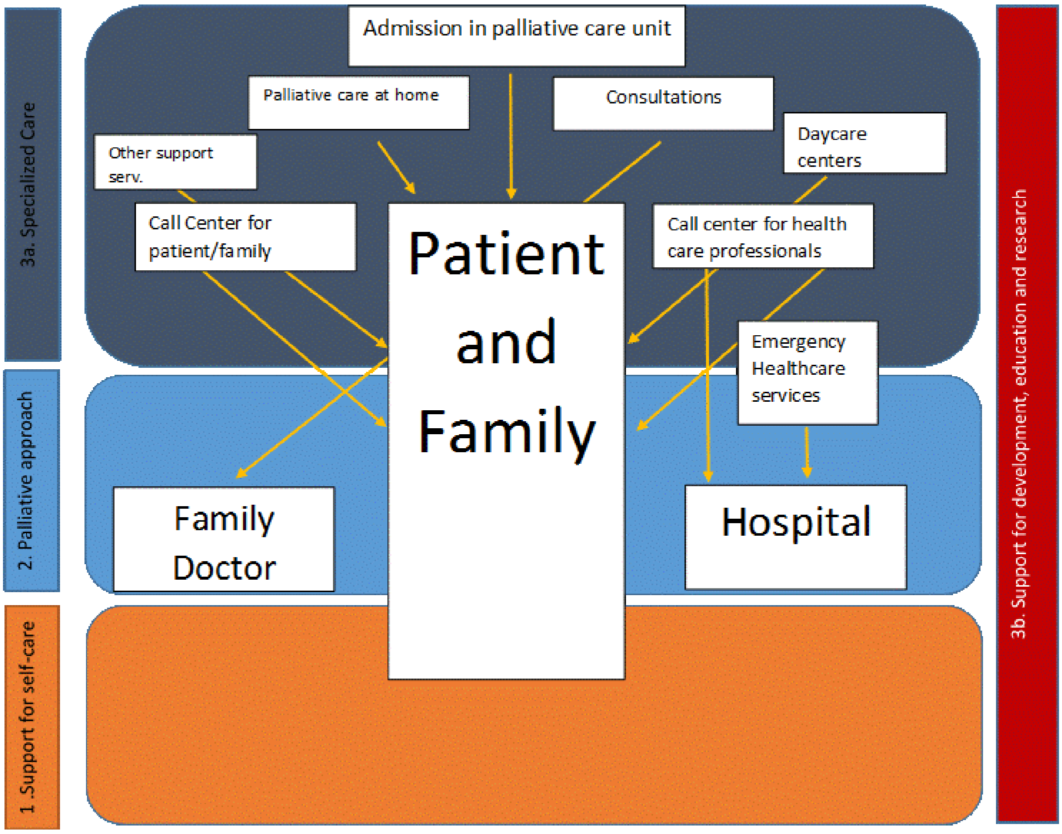

Fig. 1. Structure and links in palliative care.

Source: based on the National Coalition for Hospice and Palliative Care (NCHPC) model, readapted for the Romanian Healthcare System [21]

Level 1. Support for self-care

The National Institutes of Clinical Excellence (NICE) in the UK, with the support of professionals involved in public services and charitable palliative care and under the umbrella of the National Association of Palliative Care (ANIP), the National Strategy for Palliative Care in Romania was developed and presented to the Ministry of Health. In 2013, The Ministry of Health approved the establishment of a palliative commission between the specialized committees of the Ministry. The role of the commissions, among other things, is to "identify and propose to the Minister for Health the short, medium and long-term national priorities corresponding to the field of expertise within his sphere of competence" and to "participate in the elaboration of the national health strategy” [22]. The special features of evaluation include a characteristic concern with cost, comparisons, needs, ethics, and its own political, ethical and cost dimensions; and with the supporting and making of sound value judgments, rather than hypothesis-testing [19].

A proposed model, based on the retrieved data, was created in order to outline the development of structures which can ensure the access of the population to palliative care services. More importantly, patients can benefit from these services without obstruction and in the desired location, by efficiently using the current resources and gradually developing new structures and assets. These structures comprise different levels of proficiency as presented in figure 1.

It is given to patients and their families or caregivers by community healthcare teams with basic palliative care training as well as specialized palliative care services; this level ensures that the patient and family acquire the knowledge, skills and confidence for self-care and to provide adequate care during periods between medical staff interventions.

Level 2. Palliative approach

It is the direct care given to patients and their families/caregivers by medical staff with basic training in palliative care, certified by graduate training programs accredited by competent professional bodies: primary medicine, community care, acute hospitals where there are occasionally hospitalized patients with palliative care needs.

Level 3a. Specialized Care

Provides direct care to patients and their families / caregivers, as well as level 1 and 2 advisory services. It is provided by interdisciplinary teams of professionals with in-depth palliative care studies: physicians with palliative care, nurses, social workers, psychologists, therapists, clergy and other competent palliative care staff, according to national palliative care standards.

Level 3b. Support for development, education and research

Development of palliative care services and increasing coverage of care needs in all counties, human resource education and research to develop and promote palliative care. It is provided by the professional palliative care association and reference centers in the field of palliative care.

The program should be built in a ―hands-on” approach starting from the in a bottom-up. Beginning from what exists as structures and acquisitions in the legislative, educational and service fields, with consultation and engagement of the stakeholders and with the support of the national authorities. Tolerance, flexibility and adaptation will be required in the implementation of the program, with constant evaluation of the results and focusing on employing quality service providers. First, if evaluation is to be useful and usable, it needs to be seen as an integral part of decision making and management – and indeed the entire process of democratic accountability. Second, evaluators and those who commission and use evaluation findings always need to balance best available methods with the demands of pragmatism. One of the core competencies of evaluation is to gather information from different stakeholders or publics. This is especially important at the program design stage [19].

3. SWOT analysis of the objectives

The objective of the program is to improve the quality of life of adults and pediatric patients with progressive or incurable chronic diseases (cancerous and non-cancerous) through coordinated and enhanced distribution of palliative care at a national level as well as providing access to basic and specialized palliative care. The term effectiveness concerns whether the objectives formulated in the program are being achieved, what the successes and difficulties have been, and how appropriate the solutions chosen have been and what is the influence of external factors that come from outside the program [2]. The term efficiency is assessed by comparing the results obtained or, preferably, the impacts produced, and the resources mobilized. In other words, are the effects obtained commensurate to the inputs? (The terms ‗economy‘ and ‗cost minimization‘ are sometimes in much the same way as efficiency) [18].

3.1. Short to medium-term objectives

The short term objectives should be established by a delegated committee, organized by the National Association of Palliative Care (ANIP) with the assistance of the Ministry of Health and other private external investors and partners such as the European Association for Palliative care or the Worldwide Palliative Care Alliance. Firstly, there needs to be a concise plan based on the needs of patients and the quality of care received, second there needs to be sufficient funding in order to carry out these reforms, seeking European funds from certain organizations like the World Bank Group, is essential in completing the tasks at hand. We feel that the objectives listed below are key in establishing and running a successful Palliative Care Program.

Objective 1. To assume the national strategy of Palliative Care by informing and consulting the interested parties in order to shape the national strategy; support and to create an opinion favorable to the implementation of the national palliative care strategy.

Objective 2. Normative and legislative adjustments in order to create the structure necessary for the implementation of the national palliative care strategy (including functional palliative care devices and equipment).

Objective 3. Development of human resources capabilities on the three levels of palliative care. Macro – National policy, judicial/legislation framework, financial aspect); Meso – Implementing activities, such as education, tools, research and service models; Micro – Delivery of palliative care services [7].

3.2.Objective 1 SWOT analysis

Strengths and Opportunities: The strengths and opportunities of this objective are the same, because it appeals to all people, whether they are stakeholders or investors or beneficiaries: patients, families, relatives, friends and even professionals: who offer a palliative approach or specialized palliative care or even other medical or social professionals (professional associations, non-profit organizations, etc.). Institutions such as; public, private, donors & international agencies and even local and central authorities; but specifically politicians who see it as an opportunity to use the media in order to sway the vote of the general population.

Weaknesses: Preparing and publishing a reference document is key in laying the foundation for a good program. This reference document should include: A national strategy, executive summary, and should have a clear key message and position adapted to each audience but at the same time remain consistent and compatible. Choosing the way of communicating the message (audio, video, and writing) and preparing the necessary materials is also extremely important. In this instance, since your target demographic is elderly, disabled individuals or their families, it probably would be a good idea to resort to social media or the internet to promote your message, instead maybe try a more old school approach. Meetings with stakeholder groups and establishing a communication strategy and making sure everyone is on the same page is crucial and shows you are dedicated to the cause. The reason that all these elements can be considered weaknesses is that if they are not thought out and executed correctly or at the right moment it could throw your plan off track or even terminate the project all together.

Threats: Product messages and printed materials promoting other programs or existing palliative care institutes. Not being able to fund or develop a functional website.

Lack of promotional materials which in turn may not generate enough public interest. Educating the public is essential in order to gain support, if there is not enough invested in informing the masses then there will be negative feedback and no public support.

3.3.Objective 2 SWOT analysis

Strengths: The creation of working groups including representatives of the Ministry of Health, the National Health Insurance (CNAS), the Ministry of Labor, Family and Social Protection, the National School of Public Health and Sanitary Management (SNSPMS), the Romanian College of Physicians, The National Association of Palliative Care (ANIP), representatives of patients and pharmaceutical associations, are all organizations that have been set up by the Ministry of Health and the Governing body at that specific point in time, which have the right to propose certain laws and regulations which they consider as beneficial to the public.

Opportunities and Threats: The reason opportunities and threats were introduced into the same category was based specifically on personal opinion. For example, establishing working group meetings to draft normative/legislative proposals produced and submitted for approval or potential draft regulatory acts, which can include: Ministerial Order for the definition of palliative care services, approval of national standards, approval of clinical protocols, nursing specialization, etc. can be viewed as an opportunity by others and a threat by individuals who have certain conflicts of interests and therefore may not be as objective.

Weaknesses: The most significant and probably the only weakness in implementing a plan for provisions of approved acts is rejection. A plan or strategy can be rejected based on two factors: either the proposal is incomplete and does not have sufficient evidence of an existing need for the program or it needs to be reviewed because there are major visible flaws in the implementation process and the most significant weakness, if the proposal passes the selection criteria is the economic infrastructure, meaning does the country have the necessary funds to implement and sustain such a program.

3.4. Objective 3 SWOT analysis

Providing palliative care is conditioned by human resource training at 3 levels:

Strengths and Opportunities

1) The patient and his/her family (In 2008, according to the Official Monitor, a survey shows that 20.7% of the respondents had or had a person suffering from a disease in the terminal phase, and in 76.5% of cases the family was the only one caregiver of the sick person at home) (MO824). *Macro – Opportunities for laws*

and proposals to pass based on national surveys and statistics showing evidence of a need for a more comprehensive palliative care program with quality healthcare a and experienced caregivers.

2) Families and community care physicians need basic courses to acquire the knowledge and skills needed for patients with palliative care needs. *Meso – Implementing education programs for the masses and for palliative cares service providers.*

3) Palliative care services: Clinical and administrative training of interdisciplinary teams (doctors, nurses, psychologists, social workers, therapists, nurses, volunteers, and management/fundraising staff). *Micro – this component will not be able to function without firstly executing the other two. In order to effectively put together a training course for specialized personnel there is a great deal of time and effort that has to be put in, not only by the instructors, but also by the trainees who have to be willing and able to learn. In order to properly secure a higher standard of quality the trainees need to be motivated and also makes sure that they do everything they can to uphold that standard.*

Weaknesses and Opportunities: Each program should focus on its strengths and weaknesses, the reason we chose to categorize the components of a program we have outlined as a possible training program in the weakness category is once again based on human understanding and appreciation, which is more of a variable then a constant. Nevertheless, the success of the program is based on the success of the how comprehensive the trainer is and how willing to learn the trainee is. However, if the courses are carried out efficiently then they can also represent an opportunity to investors as well as beneficiaries of the provided services.

The model is broken down into 4 different components each coordinated by a different institution. First we have the physician training which will be a modular program of 12 modules in 12 months. The estimated capacity is at minimum 50 doctors and at maximum 100 doctors enrolled in the program annually. The institution(s) responsible for the training of the physicians will be the National School of Public Health and Health Management/Ministry of Health/Education.

The second component consists of the nursing training. This program is another module program consisting of 4 theory modules and 4 practice modules, with an optimal running time of about 8 weeks. The estimated capacity should be a minimum of 100 nurses and a maximum 200 nurses enrolled in the program annually. The institution responsible should be The Order of General Medical Assistants, Midwives and Nurses or Romania (OAMGMAMR).

The third component is the interdisciplinary team training – The course deals with organizational and clinical aspects and has as its objective interdisciplinary team formation, understanding team roles, working procedures, documentation. It will be composed of 15-20 annual courses with a maximum of 30 participants. The institution(s) responsible for this program are palliative care institutions which have the necessary funding and resources to successfully implement and complete the program.

The fourth and final component is training the Palliative Care Trainers – The course is supported by the National Training Center; the aim is to master the techniques of adult education. These courses should generate, on average about 15-20 new trainers annually. Training will be done face to face as well as virtually (Skype, face time, etc.) Each provider will receive the materials and curricula and will train at least 100 patients and 100 attendants, if this occurs then there will be an annual total of at least 10,000 patients and directly trained personnel. These types of numbers will surely generate a national TV education program through national channels, a weekly educational video clip and on-line television programs. Potential beneficiaries - all affected/potential population.

Threats: There can exist an infinite number of risks and threats when establishing a national program which requires the support and financial backing of many implicated individuals. Making sure you have the appropriate course curriculum creation and materials – responsible for: lecturers from the certified program plus members, is the first step. Then making sure that family doctors and general practitioners (GP) want to participate as providers of palliative care services is also a task in itself. In order to facilitate this, preparing current family physicians starting from the recommendations of the European Association for Palliative Care doctors' education group, a curriculum is developed to educate family physicians in a palliative approach. The way of implementation foresees combined course support techniques: online and face to face to allow easy access but also to maintain quality. Another risk is the selection of practice centers, mentors – selected physicians or teachers with palliative care at work in palliative care services will be selected. 40-45 in-house trainers will be selected, to which 15-20 new trainers will be added annually. Specialized palliative care services will be selected as practice centers. Start with 10 centers and increase them each year by 3-5 until there is at least 1 center in every county, 2-3 in the bigger counties and at least 5 in the capital city of Bucharest.

Implementing GP education courses. Preparing future family physicians: Including a palliative care course in family medicine residency. If not implemented correctly can be considered a risk if it is not well received or unsuccessful. In order for the program to be successful establishing the minimum necessary skills and creating a work group for curriculum preparation is the foundation. Identifying the current level of care, care practices and improvement areas for self-care and care by family and caregivers as well as identifying the required minimum competencies will help to design curricula training.

Providing financing is without a doubt the biggest risk, but if you manage to secure the necessary funds you can use them to appoint and educate trainers who can then teach the healthcare professionals. Last but certainly not least, the program should be under careful surveillance and effective monitoring, that way any situation can be immediately detected and dealt with promptly. The final graduation diploma of the palliative course will be received after the completion of both the on-line course and the face-to-face course. The target we want to reach is 10 General Practitioners/county or district, which equivalents to 470 participants for the whole of Romania (41 counties and 6 districts in Bucharest). That figure should increase by 50% within the first 3-5 years.

4. Palliative Care: European Practice and Opinions

In 2008, as a response to a request by the European Parliament in November 2007, the Task Force on the Development of Palliative Care in Europe, European Association for Palliative Care (EAPC), published a study ranking the development of palliative care in each of the 27 EU member states. The used a series of criteria in order to rank the efficiency and level of quality of palliative care offered by each European country. These indices were based on specific resources, i.e. Number of hospital units, support teams, home care teams, specialized beds and full-time physicians [3].

Indicators of vitality where also used to evaluate the movement of palliative care. These indicators measured; the existence of a National Palliative Care Association in that country, the existence of a Palliative Care Service Directory, the amount of people who attended the EAPC general congresses, the existence of certification or specialty for palliative medicine, publications of the national development of palliative care and the existence of palliative care teams for children [3]. A point system was then implemented for each country from 0 (meaning non-existent) to 10 being the maximum score possible.

The global rank of palliative care development was then established by joining the two components; available resources which accounted for 75% and vitality indicators which accounted for 25% [3]. Out of the 27 EU member states involved in the study, Estonia was regarded as being the country with the least development of palliative care while the United Kingdom clinched first place, by a long shot, scoring a perfect 100%, followed by Ireland and Sweden rounding out the top three spots. Romania ranked 22nd beating out Greece and Malta, but still behind countries such as Bulgaria, Slovenia, Hungary and Lithuania [3].

The European Association for Palliative Care (EAPC) was first established in 1988 with its main objective being the promotion of palliative care in Europe as well as being the focus of professionals who worked or were interested in the field of palliative care. Every second year the EAPC organizes congresses and uses them as platforms for research groups to implement and share ideas, prepare palliative care curricula to train nurses and healthcare professionals, as well as organizing task forces to monitor and maintain a sustainable development for palliative care [15].

The EAPC, in collaboration with other national associations, will then use all the gathered information to establish norms, which will then have to be agreed upon by the various associations using the ―Delphi procedure”. After the norms are accepted the EAPC will then attempt to implement them through various projects. This is where the support of other European committees such as; The European Council and European Parliament come into play, without their backing such national programs would not even get passed the planning stage [15].

5. Conclusions

According to the WHO report 2014, by 2030, there will be 25 million new cases of cancers worldwide per year. In Romania, the most recent studies (2016) estimate 1 million cancer patients diagnosed with cancer and specialists in the field say the number of oncologists in our country dropped to 250-300. Unfortunately, the percentage of deadly or disabling diseases in Romania has been increasing rather than decreasing within the past years. In more than half the cases these illness are due to an unhealthy lifestyle and diet, which is usually brought on by the bad economy and society forcing you to make certain choices to survive.

On the other you have genetic disease or congenital malformations which you have completely no control over. In any case, this is an ever prevalent matter and a problem that can have a potentially very easy and efficient solution. By implementing a national program which can provide a high standard of care to improve the quality of life of terminally ill or disabled patients is something that at least 1 million people in Romania alone would like to benefit from, not even mentioning the family and friends that will be willing to support and help their loved ones. Each program starts with a clear and concise plan, it requires support on all levels and the necessary infrastructure. Romania may not have the appropriate infrastructure as of now to support such a program, but there are other means to obtain funds; The European Union, private investors, even online sites like ‗gofundme.com‘ and ‗youcaring.com‘ will be able to support such a cause. If everyone gets involved in a national program then they will be able to spread awareness and receive donations and medical equipment.

We strongly believe that following the above mentioned steps and implementing a palliative care program following these parameters will decrease the mortality rate as well as greatly improve the quality of life of severely ill patients as well as all the people around them. As we could see from the EAPC indicators of PC development, economy plays an integral part in the development of such programs.

The Eastern European countries ranked among the lowest while the top spots were all held by Western European countries. Having the necessary resources when developing national programs is undoubtable the most essential component, at least from what we have seen statistically, but we believe that having a concise plan, being able to implement different ideas from other models, using the resources you already have and receiving the support of the local government as well as public and private organizations and healthcare professionals can ultimately resolve in implementing a program that might not be as efficient as one with a higher budget, but at least it has a strong foundation which could always be built upon and taken to even higher levels.

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