Community Palliative Care in Spain: The Critical Role of Nursing in Its Development

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Introduction: Social and Cultural Considerations in Spain

Spain has had universal access to healthcare since the last century and palliative care has had a long history of nearly 30 years of evolution. Because of the idiosyncrasies of the nation and the existence of 17 autonomous regions governing their own competencies in health, there are a variety of programs and specialties that have been transferred to each autonomous government.

Palliative organizations were designed in the 1980s in accordance with the Social and Sanitary System (SSS) with a plan to interconnect the primary, secondary, and tertiary levels of health institutions. One priority was to address the insufficient continuity of care from hospital to home, the gap of time where patients are attended to at the end of life, usually at acute hospitals [1].

Palliative care was born together with the paradigm of oncology, which is currently undergoing a profound change; every scientific meeting that we attend shows that the use of social networks and digital information on the Internet as a means of communication is on the rise, echoing this new situation.

These new hopes are founded not only upon the personalization of the new therapies and initiatives that work in precise medicine [2] but also how professionals cope with all the new challenges.

Every type of cancer in this group of pathologies must be considered when we talk about the future. Beyond this point, oncology nursing is the art of caring for the "small details" regarding the patient's overall needs. And, in a large number of diagnoses, palliative care in cancer is a must when working in this field, from the very beginning of the diagnosis until the end of life.

Oncology and palliative nursing is one of the most important roles in caring for cancer patients, along with many other healthcare professionals who take part in this challenge.

Considering the existing demographic data, Spain could soon be among the countries with the oldest population in the world, with chronic conditions, multimorbidities, and disabilities that will continue to rise in number [3]. This will lead to a more complex social and health panorama requiring an urgent response from the government to ensure adequate health services.

Throughout the past 25 years, life expectancy from the time of diagnosis of virtually any type of cancer has evolved into survival rates hitherto

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M. Silbermann (ed.), *Palliative Care for Chronic Cancer Patients in the Community*,
https://doi.org/10.1007/978-3-030-54526-0_12

unknown. This fact is paradigmatic in the case of breast cancer, where every year we update the former rate of survival by 5–10 years from the time of the first diagnosis. On the opposite side and still in a slow process of change, the diagnoses of diseases with a high mortality rate, such as pancreatic cancer or cerebral astrocytoma, are within the first year of the patient's evaluation.

With these figures, we manage the care of the cancer patient. The reflection on how we do our work can be seen by the looks of health professionals in hospital waiting rooms, which pass from a patient with little hope of survival to others who can practically be assured a cure.

The introduction of monoclonal antibodies in combination with classic chemotherapy at the beginning of the twentieth century later added to molecules that inhibit tumor growth processes (tyrosine kinase synthesis, EGFR inhibitors, VEGF, etc.); today, immunotherapy and treatments with CAR-T (chimeric antigen receptor T cell) provide new hope for combating most types of malignant tumors.

We have seen in our own personal experience that precision medicine is here to stay and has revolutionized the world of cancer treatment. The personalization of medicine, much broader than just in terms of treatment, has turned precision in nursing care into a daily occurrence, utilizing all our human potential [2].

If we go back to our peninsular past, we find the wonderful case of *Benjamina*, named after the paleontologist who discovered her at the excavations of Atapuerca (Burgos, Spain). Benjamina, about 530,000 years ago, was a girl with a great disability, born with craniosynostosis, where the bones of the skull merge prematurely and do not allow the brain to adequately develop. She was cared for until late in childhood; the fact is that, without special care, she would not have survived long: *Homo heidelbergensis* put the time from birth until the moment of the girl's death at about 10 or 12 years. The chronicle of care has been widely recorded in the literature, and at every historical time, doctors have recognized themselves as being the first to establish a specific way of caring for the patient. The care, and more specifically, special care, provided to Benjamina shows that the act of caring is the key to survival [4].

Florence Nightingale (1820–1910), nurse and former epidemiologist, was the first woman admitted into the British Royal Statistical Society. She was called "the lady of the lamp" for the night walks she took visiting the English soldiers that she attended to during the Crimean War. In her work, she highlighted two major and important points: the first, the quality of the care, based on the first epidemiological studies on hospital infections resulting from the poor conditions she observed in the field work – poor hygienic conditions and unscrupulous practices during the process of treating patients injured in war, who did not die from their wounds in battle, but rather from hospital infections. The second point is the explanation for the use of the lamp: the continuous attention to the patients as a novel method of care. This is one of the milestones in the so-called humanization of care in modern times and considered to be the cornerstone of palliative care [5].

If medicine has classically been considered as the art of healing, nursing, on the other hand, could be defined as the art of caring, with technique, with evidence, and, of course, with humanity. In the art of healthcare, the quality of care must be holistic, incorporating all the bio-psycho-social aspects of the patient, not forgetting any one of these areas. Three fundamental factors worth reiterating, with respect to patient care, are education, knowledge, and learning, followed by a continuous commitment to that care.

The United Nations' Sustainable Development Goals (SDGs) strategy guarantees equal access to healthcare, treatments, vaccinations, and food for all people of all ages, regardless of purchasing power [6].

This last statement, in reality, is subject to change, primarily due to not only economic reasons but also political reasons. The high cost of cancer treatments lowers the expectations of patients who must assume responsibility for part of or all of the expenses of their therapeutic procedures, so, in many cases, the only treatment that patients can afford is palliative treatment, many times in suboptimal conditions, especially in developing African or Latin American countries [7].

The Present-Day Palliative Care System in Spain

Many primary care professionals and specialists from hospitals were involved in and contributed to the development of the current palliative care system in Spain, with a lot of hard work and dedication. It was in 1984 that the first Spanish palliative unit was established, in Santander within a general hospital, followed by the *Canary Islands*, the Basque Country, and Catalonia in around 1986 [8].

Considering that all patients, as well as their relatives, have the right to be attended to during the dying process, various home care programs with different models and dependencies have been created in Spain since the 1980s. On December 18, 2000, the Foundation for the Development of the National Palliative Care Plan was approved at the plenary of the Inter-territorial Council of the National Health System in Spain, where palliative care was recognized as a health priority throughout the entire country, not distinguishing between the original diagnosis of the tumors, the type of cancer, and/or under what condition the cancer is to be treated [9].

In 1991, the Gregorio Marañón Hospital in Madrid created the biggest palliative care unit of any hospital, working jointly with community primary care teams under the umbrella of the national health service (INSALUD). They began with home care support teams called ESAD (Equipos de Soporte de Atención Domiciliaria).

However, primary care teams are not always the best trained and may not have the expertise, the necessary resources, or the means to attend to palliative patients who are treated by home hospitalization teams or home care support teams (ESAD) [10]. Their purpose is to support primary care professionals in the comprehensive and ongoing care of the following patients and their caregivers and families: (a) those who are in the advanced stages, (b) complex patients, or (c) those who have functional limitations [8].

Catalonia: The PADES Teams

The Catalonian network of social and sanitary services began in 1986 within the framework of the deployment of the program Vida al Anys (“Life in the Years”), contrasting the past focus which was adding “years to life.” This program initiated the development of a range of services that integrated social and healthcare services in a single model for the benefit of advanced cancer patients. One of these services was the home care programs designed to support primary and community teams known as PADES (Programa d’Atenció Domiciliaria i Equips de Suport) [11].

In addition to giving individual attention, they are primarily there to control symptoms, to provide comfort, and to promote the well-being of the advanced patients, of their caregivers, and of the surrounding family, promoting the best care and death at home, when possible [12].

They play an important role in the management of complex cases, in the coordination of resources between healthcare levels, and also in training other professionals of the primary care network in the field of palliative and complexity care at the end of life [13].

The PADES’ mission was to act as support for the other primary care professionals, mainly in the following circumstances: geriatric and/or chronic diseases that have been decompensated or are at an advanced stage, some conditions at the convalescence phase requiring specific care supervision such as endovenous treatment at home, advanced and palliative patients that express their desire to be at home instead of being hospitalized, and those patients with specific therapeutic or complex symptoms needing direct support at home from health professionals [14].

Types of Conditions and Support for Palliative Care

The PADES teams try to ensure that patients receive the best care, at any time or stage and in the right place or, at least, the most suitable one. The teams mainly focus on adult patients, but also there are some for onco-pediatric, in cities or rural areas. Multidisciplinary teams work on connecting the three different levels of health: primary, secondary, and tertiary.

In pediatric palliative cases, there is a multidisciplinary team (doctor, nurse, social worker, and psychologist) that treats the patient and his/her family as a whole. These teams move throughout the region so that the geographical dispersion increases the number of face-to-face visits, which are mitigated by telephone calls and telecommunication consultations [15, 16].

This provides the pediatric palliative services with data for unique research in the investigation into cultural and sociocultural aspects [17].

The Critical Role of Nursing Advocacy

Spain's regional reality is that access to treatments outside the community of residence is diminished by the administrative inconvenience that entails being able to receive the best treatment for a specific diagnosis in a hospital outside the autonomy of residence [13]. Sometimes it would be easier to go to an emergency room to get a cardiac monitor or, in some cases, to be admitted to an intensive care unit. Receiving the palliative care support in the community or at home can be very difficult.

Nursing care goes beyond physical or clinical needs and is often realized in the form of the emotional and supportive care that it brings to patients. The vital element is communication. The nurses' support is based on the communication skills of the professional nurse, who considers the patient as the center of the therapeutic dynamic. Communication is identified as the most positive and recognized element of palliative care and the most valued, both by patients and families.

In Spain, the main activities of the ESAD, PADES, and other team nurses are shown in Table 1.

The obstacles that the patients must face occur at multiple levels [18]. For instance, challenges at the bureaucratic level are often greater than those that can occur at the clinic or hospital. Another is related to the time of the medical referral and when to begin at the community level [19]. Another aspect is the cost, although it has been largely demonstrated that end-of-life home care is less expensive than hospital bills [20].

Table 1 Activities developed by palliative care community nurses

To work within a team with other medical and social work professionals with a patient-centered model and with a palliative philosophy
To work in a coordinated manner with other social services, primary care, and secondary or tertiary/acute health centers and hospitals in accordance with the patient's needs
To monitor the patient's condition with a therapeutic plan and establish a calendar of programmed visits according to the objectives established for each patient. To guide and advise patients and relatives, respecting their values and preferences and acting with ethics
To identify, assess, and address the patient's needs in a holistic and comprehensive manner and with a multidimensional vision
To train and teach caregivers and family members and to oversee techniques, such as subcutaneous administrations, to provide them with the most complete care guidelines to facilitate care at home by providing support and ensure safety
To provide individual and personalized medical, social, and emotional support
To resolve family and patient doubts that may arise with regard to their condition
To provide emotional support to patients, families, and friends pertaining to the environment at home
To prepare and facilitate the bereavement process at home or any other intervention required by the family. To follow-up grief and family after death

Bekelman et al. compared the costs at the end of life vs. place of death in seven different countries, for patients 65 years and older who died from cancer. They concluded that the costs in more hospital-centered countries – Canada, the USA, and Norway – were higher than the costs in Belgium, Germany, England, and the Netherlands and that intensive care admissions in the USA were more than double the cost of those in the other countries [21].

One explanation for the above statistics could be the fact that indirect costs are mainly assumed by the families, though, when hospitalization occurs, the costs are assumed by the National

Health System. In Spain, there are many examples of complementary therapies such as supportive care medications, physical rehabilitation, psychologists, and grief counselors to cope with end of life that are not included in the national health coverage, although their use is widely prescribed for cancer patients, especially at the advanced stage [22].

The guarantee of equity in access to treatments in our country is compromised in many communities due to budgetary imbalances and inequality in policies. These barriers are provoked more from political decisions than from the medical need of patients and the population.

Inequalities are clear, palpable, and demonstrable and we need to reverse the situation; scientific societies have already made statements denouncing the situation and calling for a reversal of the circumstances for many patients who live in our own country [23].

The Nurses' Role in Palliative Process

To "accompany," as an active verb, can be enumerated by the number of hours that health professionals, nurses, and doctors spend alongside the patient; this fervent accompaniment focuses on efforts to prevent a painful or distressing death, where the patient feels cared for and not abandoned to their fate. It has less to do with prescribing more medical interventions (which is easier for some professionals than listening to needs of the person at the end of life) and more to do with the effort required to order and provide compassionate care for patients and families.

Generally, all the professionals involved in the process – in the hospital and in the community context, from the people in charge of cleaning to the caregivers, auxiliaries, and technical staff to the rest of the experts – are proactive in their efforts to provide the best care. However, sometimes the lack of medication or technically sophisticated devices dedicated to managing symptoms and pain is supplemented in some way by accompanying the patient with genuine human care.

Finally, considering the patient as a whole and providing a comprehensive package of humane care should be the routine and not the exception.

Palliative Needs for Advanced Chronic Diseases Other than Cancer in the Community

Almost all National Care Plans of the 17 autonomous regions in Spain include palliative guidelines and have demanded that palliative care embraces all patients with life-limiting disease, irrespective of their diagnosis, in an equal manner [24].

Regarding access to palliative care, chronic patients should be referred as early as possible and not limit care to the last days or weeks of life. We know from previous research that palliative care, if integrated earlier than at the last moments in life, can offer better support and control of symptoms and has a more positive impact on the patient as well as on the family's grieving process after death [25, 26].

Among complex chronic patients, those who have advanced chronic conditions other than cancer may have multiple needs due to the life-limiting prognosis – on one hand, palliative care and, on the other hand, that they may also need curative and preventive measures from the health professionals [13].

These patients often have severe pain and a diversity of symptoms that necessitate supportive treatment and a palliative care approach. The physical and psychosocial needs of patients with chronic non-malignant lung disease are comparable to those with lung cancer.

Blay et al. found that 1% of the adult primary care population have advanced diseases. His study of advanced-disease patients was conducted in three primary care teams in Catalonia, with 251 patients mostly affected by dementia and chronic diseases; however, all presented with palliative needs, and the median age was 85 years old with an average survival rate of 23 months. For 47.3%, the place of death was their home, and 37.2% died in an intermediate care hospital and 15.5% in an acute care hospital; these findings coincided with the data reported in the literature in other regions of Spain and in other developed European countries [27].

Quality of Life and Future Challenges

Patient participation is the key issue in the palliative process, although it must be accompanied by the support and professional decisions of each of the disciplines that make up the team. Now, the patient is an active subject as far as the treatment is concerned. And above all, the patient must be asked what he/she wants to do and how far he/she wants to go.

Translating this last statement into the language of cancer patients, in the context of Spain and in general, means to facilitate the best and most appropriate treatments, as well as gaining access to the most advanced clinical trials. We try to provide the patient with the best supportive treatment when no therapy is indicated for the stage of the tumor, although we still have a long way to go.

It is well-worth considering the trend that has been booming in recent years – the idea of involving the patient in clinical decisions regarding medical and nursing care and techniques.

Another common issue concerning palliative care in oncology is the characterization of each of the diagnoses, molecular subtypes, and final classifications for treatment, which require a fine and precise differentiation so that, from the moment of diagnosis, the best and most appropriate therapeutic approaches to the disease are offered as options to each individual patient [5, 7, 26].

The relationship between human development, human rights, and bioethics can be debatable in the reality of an imperfect world, where bioethics must continue to respond to the different challenges of the evolution and development of technology [27].

It is important that professionalism includes the capacity for clinical judgment in decision-making, be it medical or nursing care, as we have the tendency to confuse patient autonomy and empowerment with decision-making. Some clinicians have defended a position to qualify the patient's empowerment, provided it is accompanied by clinical and critical judgment. That is, without the appropriate clinical perspective, the patient's critical view of his/her illness can be accompanied, among other things, by fear of pain, suffering from side effects, and, finally, death, whereby making an inadequate final decision perhaps causes harm to their health and well-being.

The classic example of the above lies in the treatment of lung cancer: treatments based on platinum salts in combination with radiotherapy, a traditional treatment in care procedures, have some harmful side effects including poor general condition and vomiting. Despite the unfortunate consequences, the short-term quality of life improves as the patient recovers ostensible respiratory capacity, pain levels decrease, and quality of life increases; with less pain, the patient moves better and his/her daily life activities (AVD) become more independent.

Greater initiatives regarding the training of professionals, in all areas of treatment and care, should be implemented. We need projects that help enforce better care [28].

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