

Featured Innovation

Palliative Care in Spain - an Evolving Model

An interview with Carlos Centeno, MD, PhD
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In the following interview, Dr. Carlos Centeno, an oncologist and a consultant in Palliative Care in the Pain Therapy and Palliative Medicine Regional Center, Los Montalvos Hospital, Salamanca, Spain, describes the development of palliative care services in Spain since the early 1980s and offers perspective on the opportunities and challenges that faced the innovators of several models of care in that country. His remarks are grounded in a review of the Spanish model of palliative care delivery, which he and Dr. Marcos Gómez Sancho, who founded the Palliative Medicine Unit at El Sabinal Hospital of Las Palmas in the Canary Islands, report in a forthcoming publication.¹ Dr. Centeno and his colleagues in the Spanish Palliative Care Association (SECPAL) are involved in a variety of efforts to build on, expand, and sustain the most promising and effective aspects of palliative care delivery in the context of a changing Spanish health system. [Citation: Centeno C. Palliative Care in Spain - an Evolving Model: An interview with Carlos Centeno, by KS Heller, *Innovations in End-of-Life Care*, 1999;1(5), www.edc.org/lastacts]

Can you tell us about how palliative care services were started in Spain?

In the early 1980s, there were several physicians working with terminal patients in various parts of Spain, who were concerned about how best to treat pain and other symptoms of terminal disease and how to improve the way care was provided to dying patients. These people included Dr. Sanz Ortiz, an oncologist from Santander; Dr. Xavier Gómez Batiste, an oncologist, and Dr. Josep Porta, an internist, from Catalonia; Dr. Marcos Gómez Sancho, an anesthetist from El Sabinal Hospital of Las Palmas in the Canary Islands; and Dr. Juan Núñez Olarte, an internist from a very big hospital in Madrid, where many cancer patients were treated. All of these physicians were excellent clinicians, very advanced in their fields, and some were university professors. These highly skilled professionals began to look beyond the borders of Spain to find appropriate models of care. Over the next few years, they made trips to work with palliative care experts in several other countries.

Dr. Núñez Olarte, for example, went to work with Dr. Balfour Mount at the Royal Victoria Hospital in Montreal, Canada. Dr. Sanz Ortiz made a short trip to England to see how hospice worked there. Dr. Gómez Batiste and Dr. Porta also went to England and spent time at the St. Christopher's Hospice in London. Dr. Gómez Sancho, from the Canary Islands, went to Milan, Italy where he worked with Dr. Ventafridda and his group. Thus, in just a few years we had a very complete vision of how palliative care was being conducted in four or five countries around the world.

When they returned to Spain, these physicians, working at first independently and alone, founded palliative care units or teams in their own hospitals. But these individual initiatives also stimulated actions by the health authorities, the most important and well-known of which was that in Catalonia, in northeast Spain. Under the leadership of Dr. Xavier Gómez Batiste, the Catalonian Palliative Care

Planning and Implementation Pilot Program provided an integrated, wide-ranging solution to the problem of incorporating palliative care into the public health system, through a network of home care and hospital-based care. Conducted as a pilot project of the World Health Organization from 1990-95, this program has influenced the development of palliative medicine throughout Spain and in Europe.²

When these physician innovators returned to Spain from their visits abroad and sought to initiate a palliative care program, what kind of support did they receive?

It was very different for each of them. For example, in Santander, Dr. Sanz Ortiz worked totally alone, without any support from the government health authorities, for fifteen years. Dr. Núñez Olarte had very good support from the director of his center, and Dr. Gómez Sancho, had good support not only from his hospital but also the regional health authorities of the Canary Islands. Dr. Gómez Batiste in Catalonia had the support of the regional authorities of health, as well as the sponsorship of the World Health Organization.

Part of the difference in the kind of support these physicians received for their work has to do with the fact that the health care system in Spain is becoming decentralized. Now we have different regional health systems in, for example, Catalonia, Galicia, and the Canary Islands, but in other places, we still have the old centralized, national health system, which is called INSALUD. I think that when there is a regional system, when the authorities feel close to the patients and to the health care professionals in their own region, they may feel closer to the problems and more committed to resolving them. In that situation, one can begin to work more quickly than when one is working under the old national health system.

For example, Dr. Sanz Ortiz's program in Santander, which is under the national system, remains smaller and less well-supported, in comparison with others that are being developed under a regional system. In Catalonia, by contrast, we have a very complete system of palliative care with home care teams, support teams, hospital teams, and palliative care units.

More recently, in 1998, a Regional Program of Palliative Medicine was approved in Castilla y León, which is a very large region. This program features the use of telemedicine techniques in training, information and clinical support for palliative care teams working with dying patients. Planning measures have been adopted in Valencia and in the Canary Islands, where in 1998 a strategy was designed to extend the work of the palliative care center set up by Dr. Gómez Sancho at the El Sabinal Hospital to the rest of the Islands. These innovations have taken place primarily in regions where the health system has been decentralized. INSALUD, the central national health administration, has adopted only some local initiatives in Madrid, the capital of Spain.

So, to date, palliative medicine in Spain has evolved from the personal efforts of several innovators working independently, and has not resulted from any government planning or special financing in the majority of cases.

What developments followed these first personal efforts of individual physicians in various parts of Spain?

These first steps by individual innovators were followed by the creation of the Spanish Palliative Care Association (SECPAL) in 1992. This organization has spread the philosophy of palliative care throughout Spain and has contributed to education and research in palliative care. SECPAL has close to 1,000 members from different specialties, including medicine, nursing, psychology, physical therapy, religion (priests), and other fields. The society publishes a journal, *Medicina Paliativa* and for

the past two years, an annual Directory of Palliative Care Programs. It has sponsored two National Congresses and conducted many training activities in palliative care in different parts of the country. In meetings with the Ministry of Health, SECPAL has contributed to the development of new rules for prescribing opioids and narcotics. The organization is working on training standards and program organization and plans to publish recommendations for health care authorities on the training and organization of palliative care teams.

To me, the most impressive role the Association performs is that every year, the founding physicians, who were the original innovators in palliative care, as well as others, travel to many places in Spain to speak about palliative care to physicians and nurses and to recruit new people into the field. This is a very important factor in disseminating the message about the need for and value of palliative care and in expanding the numbers of people and services in this specialty. (For more information, visit SECPAL's website (<http://www.secpal.com>).

At the same time that SECPAL was being formed, two private organizations, the Spanish Association Against Cancer (AECC) and the Order of Hospital Brothers of Saint John of God (*Orden de los Hermanos Hospitalarios de San Juan de Dios*) also were pioneering in the field of palliative care in Spain. In 1991, the AECC, a private charity, launched its first mobile home care unit for terminal cancer patients, a model which extended palliative medicine to many provinces in the country. They were influenced to do this by Maria Miranda, a nurse who trained in hospice care in England. Dr. Pablo Sastre is now the coordinator of this effort and has extended the home care teams. The teams consisted of doctors, nurses, and drivers to transport them to patients' homes (because it is very difficult to find parking in Spanish cities!). The teams also have the support of psychologists, who generally don't go out with the team but are available as needed. The teams always work with the family physician and are beginning to work with the support of a hospital-based service, as well. Today, there are nearly 40 AECC mobile palliative care teams providing care to terminal cancer patients at home. Their work is supported through a campaign known as the "day of the little flag", when a big collection of donations is held in Spanish cities. We call it that because when you give a donation, they give you back a little flag. The AECC raises a lot of money through this campaign. This model of delivering care through mobile home care teams gave rise to many more complete programs within the public health system in a number of areas of Spain.

The other organization, the Order of Hospital Brothers of Saint John of God, provides care for patients with chronic degenerative diseases and terminally ill patients in its hospitals. In 1991, the first palliative care unit was established at St. John's Hospital in Pamplona, through agreements with the health authorities there. Now there are 10-12 such units providing medium or long-stay hospital care for dying patients in Spain under the auspices of this Order.

In addition, in the last couple of years, some private palliative care programs were started in Seville, Barcelona, Madrid and other cities; this care is paid for by the patient or by his or her insurance company.

In 1998, there were 143 palliative care teams of various kinds working in Spain. These programs are of three main types: integrated systems (as in Catalonia), programs for hospitalized patients, and programs providing care for patients at home. Based on a couple of recent national studies, one can conclude that at least 25 percent of the 80,000 people who die of cancer each year in Spain now receive care in the final stages of life from some sort of a palliative care team.

Is there any kind of home care supported by the public health system for terminally-ill patients without cancer?

In the old national system, they are beginning to support palliative care teams at home, not only for terminal patients, but also for chronic patients, for example, those with diabetes, or bleeding problems or respiratory problems. These teams are very new. In all of Spain, there are probably ten or fifteen teams under the national health system, but their focus is not terminal care, it's home care. These began the year before last as an experiment, but now I think that the national system is beginning to expand these kind of teams throughout the territory where INSALUD remains in place.

So far as the health authorities are concerned, it is a successful approach, because with one team they have found a solution for three or four problems -- the problem of very full hospitals, not enough beds, the problem of treating patients with diabetes and other chronic diseases, and the problem of caring for terminal patients. But I don't know if it is a very good solution because we need very well-trained doctors and nurses to care for terminally-ill patients. Caring for the dying is not the same as caring for someone with diabetes or other chronic diseases; it is a specialty. Similarly, as a specialist in palliative care, I don't know if I would be as effective in treating people with all kinds of chronic diseases. I think that the best approach is not to combine the different forms of care in one team; palliative care should be kept separate.

However, it is too soon to say whether these teams are a good design for caring for terminal patients, among others.

What about palliative care teams based in hospitals?

In Spain, there is a wide network of high-tech hospital centers designed for acute care patients. In these hospitals, there are palliative care advisory teams, similar to those in other countries such as England, Canada, or recently, the United States. These teams do not have their own beds, but monitor terminally ill patients on units, such as Oncology, Internal Medicine, or even a Palliative Care unit, wherever they are needed, and they continue to monitor and coordinate the patient's care upon discharge.

The integrated model of care undertaken in Catalonia has been very successful and widely copied in Spain and elsewhere. What can you tell us about their approach?

In Catalonia, the palliative care program has three components: home care teams, acute hospital teams or an acute hospital unit with palliative care beds, and also beds in long-term care facilities, what we call social sanitary environments. My impression is that now we have in Catalonia probably the best program in Europe. This program cares for more than 60% of cancer patients in that region.

I think that the principal factors accounting for the success of the Catalonian model have been the support from both the regional health authorities and the WHO, and the very good design that the Dr. Gómez Batiste put on the table. He began to think about how to provide palliative care in Spain based on his observations of how palliative care was delivered in England. He saw the problems in England arising from having hospice outside the national system of health, and the problems in financing hospice care, so he thought that in Spain we need one plan from the health authorities that would provide an integrated net of palliative care services, from top to bottom, and across the settings in which care is provided.

A key difference between the Catalonian model and other places, I think, is that the kind and array of palliative care services offered derive from a plan, which is based on an assessment of what kind of care is needed,-- including what kind and how many physicians, what kind and how many teams,

how many palliative care beds, and so forth. With planning, it's easy to develop palliative care.

Another difference is that having an integrated net of services helps to resolve the problems of coordination and continuity of patient care across settings. In Spain, we have an excellent health system, but one which is organized more in terms of structures than functions, which makes coordination and continuity of care more difficult. Community-based health services are under the direction of one authority and specialized care in hospitals is under another authority. Often there is little communication between hospital-based care providers and family physicians in the community.

For example, one of my patients, in my unit here in Salamanca, lives in a little village about 30 km from the city. One family physician serves that village. When my patient was discharged from the hospital to home, I checked my book for the phone number of this doctor, because my patient would be at home for probably two or three weeks, and then would return to my unit. When I called the family physician, he was very, very surprised and told me it was the first time in all his experience working in that village that a doctor from the hospital had called him about a patient.

Based on the Spanish experience over the past several years, what advice would you give people who want to set-up a palliative care service somewhere in the United States, for example?

First, Spain is a country of 40 million people, who share a common culture, religion, and family traditions, so it is difficult to generalize from our experience to a more diverse social setting. Also, in Spain, all medical care, including palliative care, is paid for under the national or regional health system (with the option to add private fee-for-service care, as well, if you prefer). This includes home care as well as hospital care. But in the United States, palliative care services are not necessarily covered by government or private insurance or there is difficulty in defining the care in such a way that it will be covered. In my view, palliative care is a right, and therefore it is obligatory that it be paid for like any other kind of medical care.

Even with the differences between our countries, I think that our experience might be helpful. For example, we found that in order to develop palliative care quickly, you have to have physicians working in this field at the very highest levels. You need doctors with very good training. I think that this is a problem in countries like the United States, where much of palliative care is provided by nurses and for that reason, physicians may see it as not part of medicine, but rather as a second level of care. So, it is important to communicate to physicians that palliative care is a medical specialty that requires excellent training and the interest and support of physicians to be done well.

At this time, if someone needs palliative care anywhere in Spain, can they get it?

We are working towards that. It is not possible in all of the regions of the country, because we have many places with difficulties. We are now treating 20-25 percent of patients with cancer in the terminal stages of disease. But another eighty percent don't receive palliative care, because palliative care is not yet incorporated into the national system or the regional system throughout the country. It is primarily available only in cities, for example.

I think that the national system is working to get the idea, but unlike the United Kingdom or France, Spain does not yet have a national plan of palliative care. There are regional plans only in Catalonia, Valencia, and Castilla y León. But in the rest of the country we have little teams in many places, but no national or regional plans.

What is the greatest area of challenge right now in Spain, as you move forward? What are

the things that you need most to do now?

I think that we have several pressing problems. The first one is for the national authorities to take a position about a single plan or design of palliative care for all the people. We need the intervention of the national authorities, as the first step for the future, to make palliative care services accessible to everyone throughout the country. Another important problem is to increase the credibility of palliative care in the health care environment. We are not yet well recognized as a specialty and the importance and value of this field are not yet well understood everywhere.

Third, we need to do more advanced scientific research in palliative care. In Spain, we are providing palliative care now to nearly 20,000 people, enough to conduct sound statistical research on a variety of aspects of care, for example, different systems of delivering medication.

Finally, I think that we need more university professors to provide training in palliative care. At present, we have only a handful of palliative care experts working in the university. For more credibility, we need more professors to provide better training to future physicians, because we don't just need more palliative care programs. Many of the dying will be cared for by family physicians and nurses in general practice. So, we need all physicians and nurses throughout the country to know how to care for dying patients. We need palliative care teams for the more difficult problems, but for the general problems, these teams would not be needed if all health care professionals knew how to take good care of the dying.

We are working now in Spain, not only in my city but in other cities, on improving communication between the hospital and community physicians and coordinating care between all the areas. I think that the new home care teams of INSALUD, the national health system, are one solution to bridging the worlds of specialty and primary care and between the hospital and home.

In Spain, we have very good acute care hospitals, whether national hospitals, or university hospitals, with very good teams and specialists with very good training. But we haven't many medium or long-term care facilities for chronic patients. Many times a patient does not need to be in an acute-care hospital, but rather, could be better cared for in a place like a hospice, or a long-term care facility. We need more beds of this kind, in order to expand and develop palliative care more quickly. We are beginning to build this other kind of hospital in Spain, but we do not yet have enough.

Palliative care is growing throughout Spain, more slowly than in Catalonia, but growing. Every year there are ten more palliative care teams started. I think that palliative care is impossible to stop now in Spain because the people know that it is useful. For example, the Organizacion de Consumidores y Usuarios, which is the most important consumer organization in Europe, is undertaking a public survey about palliative care and euthanasia in five countries, Belgium, France, Italy, Portugal, and Spain. People may see that palliative care is a useful alternative to euthanasia. They may recognize it as the better solution to the problems experienced by patients who are dying in pain.

References

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