SECPAL

(Sociedad Española de Cuidados Paliativos)

Constelación
de los Comunes

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Who are you and what is your relationship with SECPAL?

Elia Martínez: I am Elia Martínez, I am an attending physician. I have been involved in palliative care for a long time and we are now in Madrid. I work at the Fuenlabrada hospital and my connection to SECPAL is that I am on the board of directors. I am the president of the Spanish Society of Palliative Care.

Belén Martínez: My name is Belén Martínez, we are in Madrid and I have been a palliative care nurse for my entire professional life, which is practically 25 or 26 years. I am dedicated to this body and soul, not only in terms of care, but also in terms of teaching, research, and management. I was president of the Madrid Palliative Care Association in its time, in counseling, so a bit of everything and very enthusiastic about this field of care.

Does SECPAL have branches throughout the Spanish State?

Elia Martínez: Yes, SECPAL is really an association of regional societies. We have branches in most of the autonomous regions. In fact, right now one of the last remaining ones has just been registered, the Palliative Care Society of Murcia. We have regional societies spread throughout the country that make up what is our network, which is the national society.

In addition to the Society there is the SECPAL Foundation, what differentiates the Foundation from the Society? Do they have different functions?

Elia Martínez: The society is a group of professionals working within the same discipline. It's a scientific society. A group of people who have common knowledge, who try to develop it, to train people with that knowledge and to disseminate it, to promote research, education in the field of science. The Foundation was created in 2018 to accommodate this support that we needed from the scientific community for the development of Palliative Care. It is a non-profit entity that tries to facilitate connections to enhance that work that we do in palliative care and that, by the way, is very necessary work because it is quite invisible still with little public development in our country. And the Foundation was created to give a boost to this scientific community in some way.

Are there any contracted people working on a permanent basis?

Elia Martínez: Actually there are only two permanent employees, one person who is part of the European Palliative Care Association, of the APC, which is a member organization that is connected with

Spain. And then we have a project manager who is in charge of doing that more professional work or what is the more professionalized part within the society. Then there is a press office that is part of the society and works for it regularly, and for other entities as well. There is a legal office and another economic-administrative office, and there is an administrative secretariat that takes care of all the members. of quotas, of everything involved with training.

What is the profile of the members?

Elia Martínez: The profile is really nice, let's start with the passion, Belén. The beauty of SECPAL is that it embodies professionals from different disciplines within the both healthcare and also strictly non-healthcare fields, and who make up the palliative care team. Because the beauty of palliative care is that it is a part of science that is done as a team. The doctors can be of different specialties because there is no recognized medical specialty in palliative care in Spain, they are doctors who have been trained in these methods. The nurses do not have a specialty in palliative care either, but they have been trained by masters, via experts in some way. We have psychologists, who likewise do not have a specific accreditation, but they have worked or have carried out studies to deal with that type of patient in particular. We have social workers, volunteers, spiritual assistants and well, in general, what we have as members of SECPAL are people who participate in this type of care.

Belén Martínez: And also TCAEs.

Elia Martínez: Of course, of course the nursing assistants.

Belén Martínez: We also have nursing assistants. Recapping the whole team, we are missing some. Physical therapists and occupational therapists.

Elia Martínez: But it is true that there are very few members. In fact, there are very few social workers within SECPAL, we need more people.

What do you gain access to when you pay the Association's dues?

Elia Martínez: You get access to a series of resources. Newsletters are sent, information is sent to all the people who are members. There is access to everything that has to do with training, congresses, knowledge exchange and these fees are around 40 or 50 €.

Belén Martínez: Yes, I believe that a homogeneous fee was established, because before each autonomous community had different fees and I believe that last year was when the fees were standardized at 50 € per year and this gives you access to the journal with the research publications. You also have access to the European journal, and then to information on congresses.

Elia Martínez: Everything is on the web page. Importantly, Job vacancies.

Belén Martínez: And job opportunities, including guides that have been made in a multiprofessional way. I think you have access to a very interesting web page. Anyone who wants to can see it.

What other sister associations exist in the Spanish Spain for the democratization of palliative care?

Elia Martínez: As a fundamental soul mate in Spain we have PEDPAL, which is involved with pediatric palliative care. That would be our sister organization, so to speak, because it is a scientific society and encompasses the same work we do in adults, but for children. But then it is true that there are some foundations and associations that, although they are not part of SECPAL, collaborate very closely with it. For example, La Caixa Foundation has played a fundamental, historical role over the years because they have created social and health teams, each with a social worker and psychologist, which is one of the great deficiencies of palliative care teams, because the National Health System does not provide these professionals to the teams. And a private foundation is providing this support. The Spanish Association Against Cancer has also carried out this work and these are the two largest organizations historically.

Belén Martínez: Yes, they are the two largest. Then, obviously, all the scientific societies that in some way have to do with the end of life, the Scientific Society of Geriatrics, which shares a lot with us and also the Internal Medicine Family. In the end we often collaborate with them, even in the preparation of common documents. I believe that we have a good relationship given their support in our professionalization, that specialty that we have been pursuing for a long time as there is still no clear way forward and that the only thing we have achieved is a diploma of advanced accreditation. That for all of us seems very poor. There are many societies that are very involved and then within the society itself a specific nursing society was created in 2005 f specifically because nursing specialties arose in Spain that did not exist and also to establish the possibility of developing a specialty in palliative care. We were required to have our own society and although we are within SECPAL, it is a separate association.

Elia Martínez: Recently, the medical aspect has just been created: SEMPAL, the Spanish Society of Palliative Medicine. It has just been running for a year. There is also fairly good representation from all over the country, of palliative care team leaders from all the autonomous regions. And there is also PsicoPalis, a group of psychologists who carry out a lot of work, especially training, and have published documents of great interest. It is true that SECPAL is not a scientific society that has a very substantial income, it is a little poor, it must be said, but it is full of will and desire, a lot of will, people with a lot of vacation although it is not a rich scientific society. Because fundamentally, in scientific societies, income often comes from the pharmaceutical industry and here there is none.

SECPAL is nourished by other foundations or associations that are collaborating to carry out initiatives within SECPAL. Right now the Dignia Foundation is working a lot with us, trying to promote palliative care at the end of life and they are helping us in different projects. The Pía Aguirreche Foundation, which is a foundation in the Basque Country, in Bilbao, is also doing a lot of work, in training, dissemination of palliative care, etcetera. And some others. The Fundaz Paixena Foundation in Aragon, which has just inaugurated a chair within the University of Zaragoza in Palliative Care, something quite pioneering. There are some friends who help us along the way.

Belén Martínez: And above all to make it visible.

Who were pioneers in palliative care in Spain?

Elia Martínez: That is a very nice question. It was founded in 1992, the pioneers in Spain I think are quite clear, Marcos Gómez Sancho, Josep Porta, Xavier Gómez-Batiste, Enric Benito. There are a number of people who saw that palliative care had developed, fundamentally in England, the Hospice movement was already well established and here in Spain there was nothing at all, so they got together and decided to form a society to carry out this work.

Belén Martínez: I remember that the unit where I work, which is the Gregorio Marañón Hospital, began in 1991 and some of the people who work there, Núñez Olarte and Eulalia López Imedio, who was the nurse, were part of that initial push. It is true that, for example, Palliative Nursing was trained in England and a little bit from Canada and I believe that those two philosophies of palliative care were merged there, in England more like Hospice and in Canada a little bit more like the hospital version. And that is where it all comes from. The truth is that I am still breathing that essence. Juan Manuel and Manolo Conti, who was also one of the pioneers, recently retired. And the truth is that we breathe a little bit of that initial essence that has nothing to do with what is being done now, because we started much earlier. It has nothing to do with those beginnings as they relate to end of life care as it was before and we don't deal with oncology patients only.

Elia Martínez: Fortunately, palliative care is now being extended to non-oncology patients. Before it was only oncology patients who received it. Only and exclusively. Very end-of-life. Little early palliative care, little joint follow-up with the pulmonologist, with the oncologist, with the cardiologist of a patient with an irreversible disease. The truth is that we must recognize that a lot of work has been done. We are still working hard because we have to raise awareness, especially among our own colleagues, nurses, physicians and other professionals who perhaps are not so aware of the benefits of palliative care and who see it as a disruption.

Belén Martínez: And they continue to misunderstand it despite the fact that palliative care has been in place, as I have said, since 91. It is like something that you have to keep impregnating, that you have to be that oil that does not go away, because there is no other way.

What is "dying"?

Belén Martínez: When in class I explain dying to my students, apart from the fear and taboo of death that exists in Western society, there is a reluctance to talk about it. People push one away when you ask what you would want for your funeral or they say, "What are you telling me? For me, dying is a process. I remember Camilo José Cela's phrase "Dying is sweet, death is, but the anteroom is very cruel" and it is true. Because there is a lot of suffering that we say can always be alleviated. And dying is not only the act as I often tell my relatives so that they understand why dying is not pretty, death is not pretty and you do not die like in the movies. And sometimes we have it idealized and it is not like that. And we have to educate society in an important way. But dying implies saying goodbye. We have lived, we have a biography and we have to close that biography. And that is the difficult thing, because sometimes we only think about the physical. The pain, the nausea, the vomiting, the choking. But there are patients who may not have any symptoms, but they have a very great spiritual or emotional suffering, because among other things, they have to say goodbye to their life partner, or to their children, or to their grandchildren, or vice versa, or to their mother. So that is a job that the person has to do. And so does the one who is left behind. And the remaining ones as well. And in that work, I believe that is where we accompany and try to help from all disciplines, each one contributing our grain of sand so that the road they have to travel until the end is as easy as possible. And this is what we do.

Elia Martínez: Yes, because in the end it is a process just like that birth. Enric Benito said that it was the “morimiento.” But it is true that birth can also be tremendously complex. And there are women who do not exactly have a beautiful memory of their births or of how their children have come into life, because it is a process that can be complicated. But this is different, because this is what Belén says, that in this process there may be absolutely no complications from any psychological point of view, but it is true that you change places. Let’s leave it there. Each one will believe that it changes from one part to another, depending on the beliefs and a number of things. But what is clear is that there is a moment in which we pass from one sphere to another and it is that we have to say goodbye, we have to close that circle, in some way, and that has complexity, a lot of complexity.

What does “dying badly” imply?

Elia Martínez: For example, look here if I am going to give you a very personal opinion and in my day-to-day role, do you mean how would a patient of mine or one of the patients I have seen this morning die badly? They would die badly if they were poorly informed, if they had not been given enough time to be told about the times, the possibility of complications, the possibility of not maintaining home care because the situation merits hospital admission due to complexity, they would die badly if they were not allowed, as Belén said so beautifully, to close their goodbyes, to have their own time, to manage their own times. If we were to give her something that she didn’t really want. That is why shared care planning is very important and that is why early palliative care is very important, I insist again. I treat mainly palliative patients, they are oncology patients, they receive chemotherapy, but they are not going to be cured of the disease they have and they know it from the beginning. For me, for those patients to die badly would be in some way a failure in some of these matters, in the management of what I always consider to be theirs, their time, their will, their decisions. It is that kind of thing. Because it is true that dying badly from the point of view that there is no symptomatic control, that there is no psychological care, that there is no such care, that is something that unfortunately continues to exist in Spain, f because there is no full development of palliative care.

Belén Martínez: It is difficult, it could happen, but it is complicated. For me, sometimes a bad death is not listening to the patient’s wishes and preferences. Sometimes if those wishes and preferences are not possible, the patient has to understand that they are not possible because otherwise he or she will die a bad death. And just as I talk about the bad death, there are also very good deaths and peaceful and quiet deaths. And I don’t know if you’ll have a question later on whether they always have to sleep sedated. I say not necessarily. And this is one of the issues that we also have a hard time working with the population. The vast majority of inter-consultations, in line with what Elia said about planning, lately in our hospital have to do with those patients who do not have a specific pathology, but are multi-pathological, with advanced age, who are admitted, readmitted with many complications and we have to work on that planning now. Because up to what point does this constitute a quality of life for them, for their family, for their environment. And they call us a lot in that planning, because it is more difficult for the internist, the oncologist, to work and he is not so used to that moment and it is much more difficult for them. Just as we talk about the bad death, I talk about the good death and from a personal experience. I took my parents home with me because it was their wish. It is also true that I was a palliative care nurse. It is easier for them. Sometimes providing the resources is the complicated part. That is to say, 24-hour care in a home, hopefully. Because I think all of us palliative nurses are very pro-home. Being surrounded by your things, by your environment, is a more peaceful death for the family member. But we also have to count on the family to be able to assume this, because sometimes it is not easy to die at home, of course.

Elia Martínez: And there can also be a bad memory. Recently, at the education day we held in Madrid, a daughter of a patient who died at home spoke. Partly because there were no resources in her area, partly because she was at home, she described how they were unable to manage the situation at home between her and her mother. So this situation of having reached the end in such a traumatic way, with discussions in between, with relevant doubts as to whether we are doing it right or wrong, this should be avoided. There should be a professional who should be advising that family, saying that you are exhausted, it is all right, we are going to go in. It was not what your father wanted, he wanted to have died at home, but we have to look for the least bad thing. Sometimes you cannot do the most good thing, unfortunately. And I remember that our dearest Juan Pablo Leiva, often said to alleviate suffering, we alleviate it up to a certain point. Many times it is not possible to stop suffering, so we have to start from that basis as well. We are going to help you as much as we can, but there may come a time when we have to make a decision that is the least bad, not the good one. So, I believe that these are points that also have an influence.

Belén Martínez: This is caused, I think, also by the distance we have from death, because we have to go back years, where death, even in the rural world, I think is more common to die at home than in the big cities. It is rare to die at home. Rarer. But it is that distance that we have from death. In the past, it was taken care of, it was seen as normal, that the end came, the farewell and the family surrounded the one who was in the bed to say goodbye to him and he would even leave with more pain, because we did not have the measures that we have now. I also believe, or this is my perception, correct me Elia if I am wrong, that today there is little tolerance for suffering. There is little tolerance to that suffering that is going to exist and that can be alleviated, but that on many occasions we cannot avoid it and leave it at zero. The phrase "I want my father or my mother not to suffer," what does it mean to you that he or she should not suffer? To see him or her asleep? But I can't see him asleep because otherwise he won't listen to me. Yes, but he is in so much pain that maybe he needs to sleep. In other words, it is complex, especially the information we give to patients and families.

Elia Martínez: And what you said is really prevalent or frequent. The non-acceptance of death as a natural process. Sometimes I am on duty or I am working in the morning and I see that there is a patient in "last days situation" that we call when he is close to death and you go into a room that is a single room complying with the normative law. But I find one son there, the other son there, the other son there, the other son there, the patient sedated in bed, but not surrounded by them. So you tell them we are going to approach your father, we are going to shake his hand, we are going to touch him. And they say, "No, I can't do that." And you have to push them towards this physical approach and I find it hard to see where the problem lies. We have made a mistake in that we have not been able to convey to them how important it is to accompany that person physically. I always tell them that we, the team, are going to help them a lot to control the symptoms, but the most important role is played by the family. The accompaniment of the family is the key for that person to leave with peace and in turn that family will be left with peace. But it is curious, because I see that each child is sitting in a different place in the room and the patient is in bed and no one is shaking hands with him. What happened there? That is a problem we have in society, a problem of values, a problem of expectations.

Belén Martínez: And suffering. Sometimes, when it is prolonged a little bit, instead of three days, that end-of-life situation is prolonged for five days, they tell you “This can’t go on like this,” “We can’t go on like this.”

Elia Martínez: Or they say “Can’t we do something to make this shorter?”

Belén Martínez: This is what they tell us.

We cannot forget that in many families the option of home care is not possible, what alternative can we offer these patients in these cases?

Elia Martínez: Well, it also depends. I think there are many times when there is no option. You have to die in a hospital because who is going to take care of you at home? I am no longer talking about specialized care, I am talking about basic care.

Belén Martínez: I wish we could provide resources so that they could have 24-hour care, but that is unfeasible.

Elia Martínez: People need to be cleaned, they need to be changed, I am not talking about fusion pumps, I am talking about more basic things.

Belén Martínez: Man, just giving resources, but that is not easy.

Elia Martínez: What happens on a daily basis is that they die in hospitals alone.

Belén Martínez: Yes, they die alone in hospitals. I always put a lot of effort into my students. The patient who is at the end of life continues to live. Please go to the room because they may not be able to call.

Do we have the Anglo-Saxon hospice model in Spain?

Elia Martínez: Yes, we do. There are medium-stay palliative care units, as they are called. Many of them are private or have an agreement with the Social Security. There are also a series of requirements. We have units here in acute hospitals, which can be palliative care units in hospitals or support teams that attend the rest of the hospital services. They are “interconsultational.” We have the mid-stay units, which is that Hospice model. And it exists. It exists in Spain, in Madrid and in other autonomous communities. And then we have the home care support teams, which is a team of professionals who go to the patient’s home and take care of the patient at home with the help of the family.

What other end-of-life resources and services are there in Spain?

Belén Martínez: We have a very important service, which is a 24-hour palliative telephone hotline, for those families who are in the situation of a loved-ones last days and have doubts about the medications that have been prepared for them, or about the care or symptoms that begin to appear and that upset them, for example, rhonchus. This team works to contain, to provide telephone support and I think it is very important. Since it was created, almost 12 years ago, it has been in the emergency department and then, if they consider it necessary, they mobilize a specific ambulance team to make an on-site assessment. Or an admission to a specific palliative care unit without having to go through an emergency. I believe that the Community of Madrid is very well equipped. The problem is that there is a lot of disparity in the development of palliative care in Spain. And that is a problem which society has been insisting on a lot.

Elia Martínez: There is so much diversity that right now we are trying to assemble a map with the updated resources and we have had to do a lot of surveys to be able to collect data that reflects the reality. Not what the politicians on duty say about the resources we have, because for example, the politicians would say that what Belén is talking about, the PAL 24, which are really emergencies, 24 hours of palliative care, maybe in another autonomous community the conventional emergency rooms do it and they say that they are also palliative care emergencies. And it is not real. They go to the emergency services that take the patient to the hospital emergency. That is the idea. But it is true that it is so complex, palliative care in Spain is so heterogeneous that you don't know what it is costing us to do our own survey of professionals and collect resources, because there are home care support teams that depend on home hospitalization. We have this in Galicia, for example, or in Lanzarote, or in different places. Home care support teams sometimes depend on primary care.

Belén Martínez: Other times they are mixed and provide hospital and primary care support. In other words, there is no standard model. Since the strategy came out in 2007, the autonomous communities have been told that they have to comply with a series of indicators and objectives while each one develops its own palliative care. And the data is what the politician of the day wants to give you, and we know that care is not the same everywhere.

Elia Martínez: There is no homogeneity precisely because we do not have someone from above telling the autonomous communities that they have to do all this in this way. They are not doing it, so they should do it. There should be acute care units, in units of short stay, there should be home care units. Because we do not have a national law.

Why don't we have a palliative care law in Spain?

Elia Martínez: Well, because they have not considered it appropriate. There have been several attempts to legislate.

Belén Martínez: There are autonomous communities that have passed a law. For example, the Community of Madrid has it, Andalusia has it. I believe that practically almost all the autonomous communities have legislated. But what we are saying, so that there is no inequality, is that there should be a national law that obliges you to have, for example, specific palliative care with a specific palliative care professional. Because that professional is going to be required to have training, he or she is going to be required to have knowledge and will also be trained in how the organization works. And then that professional will be there to see. In fact, when PAL 24 is created, a specific clinical record is created where everything is stored and where they have access to this information in order to be able to attend to the patient well. This access is not available to the emergency department. In other words, specific resources would be created.

In the interview for the Constellation of the Commons with the Right to Die with Dignity we talked about the Euthanasia Law, what is SECPAL's opinion about the acquisition of this right?

Elia Martinez: Well, SECPAL's position is the same before and after the euthanasia law was passed. We are in charge of the development of palliative care, of attending patients in palliative care regardless of whether or not they have the desire to bring forward death or request euthanasia. Our behavior has to be the same. We cannot enter into the personal decision of patients. Our goal must be and our mission must be to accompany patients who have palliative needs. SECPAL is not against it. That is a right that patients have acquired by this law. But obviously, if we are against the fact that there are not enough resources to guarantee something that is part of the euthanasia law, which is to guarantee complete, complex and accessible palliative care to all patients who request euthanasia. If we don't have the resources, how do you want us to be able to bring this to patients? I will accompany my patient if that is their decision, but as president of the Spanish Society of Palliative Care, I have to say that if there is a lack of palliative care, do not pretend that we can accompany all patients who request euthanasia. That can interfere in those decisions.

Belén Martínez: Furthermore, this request for euthanasia cannot be mediated because there are no resources. That is what cannot be. We attend patients on a daily basis and the professionals also feel overwhelmed when there is a request to bring forward their death. And we deal with these situations and sometimes there are many things influencing them. I don't have an effective caregiver at home, I don't know how to organize myself, I don't have help, I am losing functionality. I don't want to live like that. And there is no one to accompany you. The professional who receives that request gets scared because that's how it is, he gets scared and calls us. And we, well, we have that background to explore, well, in all its dimensions, not only the physical, but also the emotional, the spiritual to see what is going on. And we have patients who of course have wanted to continue with the process and we have continued to accompany them in all that symptomatic control. And then we have also had patients who, upon exploration, have decided that they prefer to be in palliative care even though they have that trump card. They always say well, I have that there. Okay, perfect. As Elia says, it is an acquired right. And there are patients who make use of it, but I don't think it is at all in opposition. I think they are two things that we have been working with for a long time and they are fine.

Elia Martínez: The only thing that does cause concern is that this examination must be carried out by well-trained, qualified personnel, interdisciplinary teams. In other words, the patient should not be able to receive this examination.

Belén Martínez: Exactly, because there are no resources like this.

Elia Martínez: And the patient says "look, I am being a burden for my family, I am getting out of the way".

Belén Martínez: In one of the tests that has been implemented, which is the complexity test, the IDC-PaL, precisely one of the items is this, a highly complex patient. When a patient jumps out as highly complex, a specific palliative resource is necessary. If we do not have that tool, we have a problem.

Why do you think that in Spain we have an Euthanasia Law before we have a Palliative Care Law?

Elia Martínez: The truth is that all this has a lot to do with politics, with ideologies, with certain social pressures that have existed, and also with the concept of dignified death being equated with requesting euthanasia. And so I see it fundamentally as an ideological issue. I believe this, without being against the fact that this law has been passed. It certainly does not make sense that there should not be a palliative care law beforehand, and I will say this as many times as necessary and in the places where it is necessary. I have not said that they do not have the right to ask for euthanasia, whoever considers their end to be more appropriate, but not without a palliative care law.

Belén Martínez: That guarantees resources that can reach everyone equally.

Why do you think it is taboo to talk about death in the developed capitalist model of society?

Elia Martínez: There are many factors. From a more professional point of view, I would say that we have witnessed a boom in technological scientific development that has made us lose perspective. Questions such as “But how can there be no more treatment for my father?”; “How can that be possible if they are making so much progress…?”; “Everything can be cured”; “If oncologists are coming out with drugs…? If the oncologists are coming up with drugs…? I can’t get my head around it…” Well, we have to assume that people continue to die even with available treatments, because we lose functionality, we lose capacity and the treatments do not arrive because they should not be given when we are not in a position to do so. From a strictly scientific point of view. Then, on a social level, we have developed a kind of society in which death must be hidden. And we have to show only the good.

Belén Martínez: The beautiful. Beauty. Power. Success. And then death, which is a success, because it is called exitus, is part of life, it is part of life. So, of course, we don’t want to see that. Because also, as I said before, death is not beautiful, death is ugly. So we are outside the canons. And then, of course, what Elia was saying, because all these technical advances and drugs are still coming out. Sometimes for the professionals themselves, the media are sometimes another threat. For a medium that has found a cure for I don’t know what disease. And maybe it’s a trial or who knows what. And that is what the population is clinging to. We have more and more people, we here in Madrid, especially those who come from surrounding provinces, because here there are trials, trials that may be in phase one. We are not talking about them curing you, not even. But well, people cling to that. In oncology, especially in oncology, there is talk of looking for treatments and you generate this expectation in the chronic patient. Because it is true, cancer is not what it used to be, and so you generate those expectations until there are no more. We always come in saying of course there is and can continue to do, but until that transition does not happen, that is the difficulty we find. And because they always think that palliative care equals sedation, it equals the end and in the end it equals the last week of life. So that is why we have very bad press.

Elia Martínez: Recently in an interview I said that sometimes death is seen as a failure for professionals. And I would say that for me a failure is not accompanying my patients to death, for me the death of my patients is part of my work. I have to accompany them from the moment the diagnosis is made and they come to the office the first day scared until the last day when they are in a very final situation and I go up to accompany them and I go up to greet the family, with whom I often have a strong bond. Well, because they are patients who have been with me for a long time. Death is not a failure and it is true that it is not. Death is part of life.

In your experience, what is usually the perception of terminal patients of the medical system?

Belén Martínez: Many times the patient feels abandoned by that oncologist, by that physician who has followed him or her for so long. And I am not saying that he or she does not want to accompany that patient, but sometimes the day-to-day, the frenetic activity at work does not allow it. The other day a patient told us: "Well, look, my doctor told me that there was nothing more to do and he was so calm and he never called me again." And they feel that sense of eviction. I think that's why it has to be what we say, that transition or that integration that has to exist between the different professionals is not black and white, but there is a range of grays that has been going on for a long time. That range of grays, because we begin to have losses and from that very moment we should begin to connect with palliative care from wherever it is, from an outpatient clinic, from a support team. It does not have to be an admission to a palliative unit, which is perhaps more relegated to complex or end-of-life situations, but there has to be contact beforehand so that they are aware of our work.

Elia Martínez: I do not know, I think that these patients are so complex that the more people attend to that patient and the more united it is and if the same objective is in mind, the better it is for the patient. That is to say, I believe that the patient with metastatic pancreatic cancer, who receives palliative chemotherapy, lives longer and his symptoms improve. That is true, this person is a very complex patient and if he is seen by the palliative care team and by the oncologist, it will always be better. We are going to try to see if we can adapt the concept that patients are nobody's masters. That is very important. It is not that this patient is mine and no one else sees him. And this happens. Let's look at it together, I'm sure each one of us will contribute something.

Belén Martínez: I am sure we all contribute. We always contribute something different, a different vision, because the vision of palliative care has nothing to do with the vision of oncology treatment, even if it is palliative. The oncologist wants to give more life and sometimes to oncologists, I say, but they should be left alone, from the perspective of being left alone, please.

Elia Martínez: Earlier we were talking about the people who make up the PALs, in the palliative care teams, the nursing assistants. For many years at Laguna I was on call and I would go in in the morning. Chelo, who was one of the cleaning assistants all her life, would come in and tell me, "Come on, Elia, go see so-and-so, I don't like the way I see him today. How right Chelo was, because she was told by the patient "I'm not going to make it through today." We all contribute, because maybe they don't have the confidence they have with the doctor because they think it could entail a series of decisions, but they do have it with a nursing assistant and I am interested in that.

What are we talking about when we speak of "palliative care?" What sort of care does it include?

Elia Martínez: We have a patient who has a disease that is not going to be cured, that is irreversible, that is slowly progressive, that is chronic, let's call it whatever we want. The fact is that this disease and the patient are going to go together until the patient dies. This will entail symptoms of many types and problems of many kinds: physical symptoms, emotional symptoms, social problems, because logically, when there is a disease there are a series of problems associated with the disease. So what does palliative care do? They look at the patient. What do you have? "I have pain" "I have a very complex social situation because I have no one to take care of me." Well, that is what palliative care tries to do, to address the patient in all his or her dimensions. As Belén said, the theoretical definition is the real definition. We look at that person who does have a disease, but that disease is causing a lot of things around him. And a doctor alone can't take care of it. A nurse alone can't take care of it. It has to be the whole team because otherwise we would not be effective in caring for that person.

Belén Martínez: It is always said in palliative care that just as one person alone cannot do much, neither can one resource alone do much. That is to say, it is the group of all those who come and I am going to capitalize the word PERSON. Because now full attention to the person rather than to the disease is so much in vogue. I am talking again about my students, when they come into practice and they say, "seven is a lung cancer," I ask "What did you say?" It is not "7, it is Antonio Perez, he has a life, a biography and on top of that he is ill and maybe he will close his biography here with us. So, do not repeat what you have said."

Historically speaking, how did the incorporation of palliative care in hospitals occur?

Elia Martínez: Well, support teams begin to be set up in certain hospitals, especially in the larger ones.

Belén Martínez: In the Canary Islands, it began, then in Vic, and also at the Gregorio Marañón Hospital. I think there is a book that tells the whole story of how they started. In 1989 it all started a little bit and from there it was like an impulse, everywhere things began to be done. For example, here in Madrid, the Spanish Association against Cancer had teams already going to homes. They also had very well-equipped teams because they had a psychologist and a social worker. In the public sector, there were also four in the old area that also began to have some things. It was a little by little growth that it was worthwhile, that it made sense for these teams to exist because they saw the patient in a different way from what was usually attended to by other teams.

Palliative medicine is a recognized specialty in many universities and has been named as a right by the World Health Organization and the United Nations. What is the situation of palliative care education in Spanish universities?

Elia Martínez: In Spain, of the 50 faculties, less than half, 23, have a division dedicated to palliative care. That's something, because I didn't do anything. I left the Complutense with zero knowledge, but they are not obligatory.

Belén Martínez: And the rectors do not see it either.

Elia Martínez: There is a bit of everything. That is to say, the deans of medicine seem to be in favor. It is true that it is complex to make a change in studies, but I think that with what is coming in terms of changes in aging, we had better make the changes and bring out well-prepared future professionals, because otherwise they are going to be naked in the face of reality. Really. Knowing about molecular alterations is all very well, but knowing and managing and not being afraid of a patient is quite important.

Belén Martínez: And knowing how to inform. In nursing it is true that yes, there is a little more development. In the end, care is like the most basic aspect of nursing, it is the essence of nursing and in the end palliative work has a lot of care, it's more basic more about attention. Well, because nursing also has a vision that is not so much based on the disease and the treatment or the diagnosis, but a little more holistic. And it is true that there is even more professional development, but it is not a homogeneous development, it is professional development that depends on the faculty. Well, yes, it is becoming more and more obligatory, perhaps within subjects, not as a specific subject, but well, there is a little more professional development, which is not 20 hours at most, about 40 at most throughout the degree course.

Why do you think there is no palliative care course in medical schools?

Elia Martínez: I think that this is basically a problem of concept. In other words, if a dean of a medical school is not aware of the importance of including a compulsory course in palliative care, he or she has a problem of concept. Basically. Because he sees it as banal, because he does not see it as relevant, because he does not see it as necessary. I believe that right now, they are not really included because they require a series of changes in the curricula that have not been able to be developed. But I do believe that the need has been seen. Not 25 years ago, but today I think that this is already quite clear.

If a medical career does not seem to be the place for this type of training, where do people in the palliative care sector receive training?

Elia Martínez: By pursuing a university master's degree, fundamentally, an expert, advanced training courses and then seeing patients. It is the best way to train.

Belén Martínez: The same in nursing. I started at the Marañón in 2000. Imagine, it has been years since then. I had taken ome courses, because I had always been attracted to the world of palliative care, and I began to put into practice what I had learned in the courses and with my colleagues who helped me to understand a little more. In the end, it is a background and an experience that you acquire and then you say hey, I am going to do a master's degree, because at the end of the day, maybe someday they will ask you for something. As I say, since there is no major, we are going to do it. And what we were saying before, the Ministry of Education has approved the Advanced Accreditation Diploma, which, as always, depends on the development made by each autonomous community. This is what we have in Spain, because it can be like in the United States, the states that each one then legislates in its own way and everything goes at its own time. I do not know how the rest of the autonomous communities will go. Here it seems that they have started to take a few steps because they are already asking us what we have. Especially because I am at least one of those who say that in summer, I am sorry, the quality of care in the palliative care units decreases, because the people who are hired have no training and perhaps they do not even like what they are doing, because working in palliative care is something you have to like, you have to choose it because otherwise it is very hard even for the professional. So it is not possible to hire from a labor pool as it is done today. The first one you get because you have a longer or shorter leave of absence. This cannot be and we have had experiences with this and the patients notice it very much.

Who should be able to request this type of care?

Elia Martínez: Well, depending on where we are, the person who diagnoses you should refer you to the palliative care team in question. Within the hospital, for example, let's look at ALS. Here in Spain in Madrid there are ALS units that have an integration of all the professionals, the pulmonologist sees them for the respiratory issue, the endocrinologist sees them, because perhaps they have a need for enteral nutrition and these issues have to be adjusted, the neurologist sees them, and the palliative care unit sees them within the ALS unit hospital. Not all of them, but they are being treated. If the need I have is a need for something that is going to be slower and more progressive, I can stay at home and go to consultations. They may have to refer me to primary care so that they can make a referral to the home care support team. There are patients who may go a long time without very frequent visits, who may have very few symptoms at the beginning of the disease, but they can start to make the link with their palliative care team, who will give them a phone call from time to time. Is everything going well? Yes. So we'll talk again. Well, look, now this symptom has come up. It requires a visit and the same in the hospitals, there are also consultations and beds assigned.

Belén Martínez: When the patient is able to move, I think it's better. It's better because, in the end, since resources are scarce, we have to try to ensure that the palliative care team goes to the home when it's needed, when the patient can't travel, but they still establish that link with those teams. For example, we have an activation process at the hospital, where for each patient in the Tumor Committee, which is a group that decides treatments or whether palliative care has been determined, they are directly referred to the palliative care consultation and an appointment is made right away. So, it's a way of directly capturing those patients. And there, in the first appointment, we assess whether the patient will be able to come to the hospital or if we have already had a conversation with them, and then we determine the need, contacting their primary care team. This is a patient who might need closer monitoring. They may not need an ESAD (Specialized Home Care Service) because they are not very symptomatic and it seems that their social or emotional situation is more or less stable, but they do need more follow-up. Palliative care should be part of the foundation for all professionals. We should all have basic knowledge to care for these patients. Just because someone has an advanced, progressive, untreatable illness doesn't mean they should only be seen by a specific type of professional. Here, we're talking about complexity, and it's so important to keep that in mind because resources are limited and we need to optimize them. That's when we decide who is the most well suited.

According to the information on your website, palliative care teams reach less than 50% of the population in Spain. What needs to happen for palliative care to be a reality available to everyone?

Elia Martínez: In reality, hospital managers are always linked to positions associated with political parties, and the managers are the ones who organize the direction of a hospital, a health area, or whatever we want to call it. So, well, if the manager in La Rioja is highly sensitive to palliative care, they will make everything available. But if in Castilla-La Mancha they're not, then perhaps half of Castilla-La Mancha will lack home care, for example. I'm just saying this because it's a reality.

Belén Martínez: It's true that families are requesting it more and more. Right now, I wouldn't be able to quantify it, but let's say in the last three or four years, family members have been requesting more palliative care. This used to be unthinkable. It was very rare. Today, it's a reality because we have this tsunami of chronicity, as our friend Rafa Mota said, he mentioned it in "The Monograph on Chronicity"—we have a tsunami of chronicity, and that's the way it is. I see it daily in the hospital. The hospital is full of complex chronic patients, and we need to start planning, making decisions, and this is upon us, and we don't know how to address it. It's not being addressed well, and resources are limited. And that's the reality, and we have to work with what we have.

Elia Martínez: Yes, but it's also true that, although it has improved, I agree with you, Belén, the stigma surrounding palliative care is still very present. It's somewhat linked to what we said earlier, how we want to be successful—how are we going to accept people requesting a treatment that is all about doing nothing? Because this is what we're told every day. And then they understand that yes, much has been done, but initially, it's about doing nothing. So, it's true that raising awareness and educating society is important; that the people are the ones who demand it—that's a bit what we're repeating continuously now, it's important. Starting to say, "I have this problem, I have this social illness situation, etc." Who can resolve my problem better? Well, I'll ask my primary care doctor for a palliative care unit, for example. I still don't know if it exists, in fact, I don't think it does, I'm going to stick my neck out, because I still encounter patients who are confused, especially families, about the difference between euthanasia and sedation. Every day, or every week, or once a month, I have to explain the difference between palliative sedation and euthanasia. That's a bad sign. As for the understanding of what palliative care is.

Belén Martínez: Just as they ask you about palliative care, "When will they sedate them?" and we answer, "Is there any reason to sedate them?" I mean, they confuse palliative care with sedation, with euthanasia. Even our own colleagues, when there's a request for euthanasia, they call us. We go when they call us, no problem, and we explore the situation, but one thing is not the other.

Is being a subject in a clinical trial compatible with receiving palliative care?

Elia Martínez: In the end, science cannot advance without clinical trials, but I don't think it's unreasonable for patients who are in phase one of a clinical trial, which will help advance oncology or any other specialty, to also receive palliative care. I believe this is what we need to strive for. This is the excellence we should offer our patients. And it's about recognizing that "Wait, palliative care also involves a lot of science." Let's not think it's just about holding the patient's hand. Nothing like that. It's about the fact that we are also advancing in palliative care. I talked about this a lot with Borja Mújica, who is a psychologist, and we discussed how to manage the ambivalence between the hope of a clinical trial—the possibility that the experimental drug might work—and the sadness of being in palliative care. That ambivalence is difficult to manage in a normal mind because it's challenging. But this is exactly where we have to work and say that there is no such thing as ambivalence here. On one hand, we are doing science, as long as we don't harm the patient. That's important, very important, and we must be careful in measuring the benefits. That's crucial, because sometimes it's true that professionals who focus on research lose sight of the person. I have to say it because it's a fact: they're thinking about the pharmacokinetics of this or that, side effects, whether the patient meets the inclusion criteria for the trial, and the patient tells them they have pain and they don't even acknowledge it, because that happens. So let's try to be more holistic as professionals.

Does the type of palliative care change depending on whether it is provided in the private or public sector?

Elia Martínez: In the specific case of Spain, the private healthcare system doesn't have a well-developed palliative care service. It is in the public sector where we have the majority of the resources.

What would need to happen for a Palliative Care Law to be approved?

Belén Martínez: The stars would need to align because we've been waiting for so long. I think the population has to demand it.

Elia Martínez: Exactly... What would happen in this country, and this is something my friend Borja Quiroga, a nephrologist who wrote a great book called Palliative Care, said—if of the 160,000 heart attacks that occur every year in Spain, 80,000 didn't get a catheterization, people would be out on the streets right now. And what happens with palliative care patients? Well, in the end, because they die, families don't feel as motivated to advocate for it.

Belén Martínez: And when they ask us, "What should we do?" we tell them to go to patient services and submit a letter of appreciation so that the manager sees that this is valuable, because we're always in the spotlight and under threat. Because palliative care in a large hospital doesn't seem to have much weight, despite all the savings it generates. Although we don't like to talk about the fact that they appreciate us because we save money, that's not our goal.

Elia Martínez: But, well, it also saves suffering. When we talk about saving in economic terms, we save, because there's less therapeutic escalation, fewer inappropriate interventions, and a better alignment of therapeutic pricing. That saves resources, saves money, and saves suffering.

What happens when palliative care does not intercede?

Elia Martínez: It's really bad, very bad. Pathological grieving. Uncontrolled, avoidable suffering. Burnout in professionals, let's not forget about this. Because a professional who is unable to handle such a situation ends up with a huge load of frustration. There's even abandonment of jobs; this is documented and published. So, a lot of suffering at all levels.

Belén Martínez: We see it when our patient is out of place, when they are not taken in by a team that has that philosophy and approach. As she says, the professional feels that they don't know how to tackle these situations. I'm talking about the professionals, I'm talking about everyone. And the phrase "When are you going to take them away?"

Elia Martínez: Or the phrase "Get them off my hands, I don't know what to do."

Belén Martínez: Or "I'm not capable," or "We don't know how to approach this." And even if you're there supporting them 24/7, it's still complicated, they suffer. There's poor symptom control because symptoms aren't always easily controlled. You need knowledge on how to do things, not just pharmacological knowledge, but also techniques, etc., which is why we've made so much progress in palliative care. And then there's the emotional and spiritual approach, which is not done, because the hospital is seen as a place where you arrive, get treated, and leave. And they only see the disease. So when a family member starts crying and tells you about their social situation at home, people tend to flee. Or they give empty or cliché phrases, and of course, the family and the patient don't feel supported.

Elia Martínez: I'm very rebellious within the world of medicine. I'm going to get criticized a lot for talking about my life because many doctors think we can manage symptom control on our own. And then I refer the patient to the psychologist and the social worker, as if we're integrating the patient in parts. We break the patient into pieces, pieces that haven't communicated with each other, and that haven't shared information. This is very common, for example, in oncology, where continuous care is promoted. The oncologist manages the morphine, the treatments for insomnia, constipation, whatever it is, but doesn't realize that, for example, pain can have a huge emotional component that you'll never manage as a doctor unless you have the support of the team. So, that humility that, sometimes, you only learn after many years of realizing that this approach is wrong—that's something we sometimes lack.

Belén Martínez: Sometimes it's another professional. For example, the oncology nurse, who forms a different kind of trust with the patient and uncovers things the oncologist has never explored because it hasn't occurred to them. So, there always need to be more professionals. Like you said earlier, always more professionals who attend to and see more aspects of the patient to help them from all angles.

Would you agree with the hypothesis that a lack of palliative care somehow encourages the desire to resort to euthanasia?

Elia Martínez: I would say, look, human suffering is so complex that I wouldn't dare to be so definitive about it. The complexity of suffering is very profound.

Belén Martínez: It's true that if we had resources to address and alleviate that suffering, logically, alleviating that suffering wouldn't lead you to the desperation of saying, "I want this to end now." We do share that. That's why, in fact, we always advocate as a society for a law that ensures everyone has equal access to professionals who know how to address this. There will always be a minimum number of patients who, regardless of having the best possible resources and the best possible palliative care, would still request euthanasia. And we have to say that. It's true, we're not going to deny it.

In what areas has SEPCAL been developing its activities?

Elia Martínez: SECPAL is working hard on outreach. We are working a lot on training. We try to do this, of course, at the scientific level with our congresses, our courses, etcetera, but also by trying to bring training to students, to MIR to EIR, which is in the case of Nursing, or PIR, who are already professionals who are in specialty training. We are trying to promote research and it is true that we cannot do anything in terms of resources. It is not in our power to promote resources, but it is in our power to give value to the existence of these resources. So that is what we can do as a scientific society, value science, value development and try to promote research and show that this is good. Try to develop it because it is something good and it is something necessary. That is what SECPAL can do. I believe that SECPAL is the scientific society that works the hardest of all.

Belén Martínez: I was president of the Association and I remember that those two years were tremendous, because you go wherever you are asked to go; you are always there, because your intention is to spread the word that this is good, that it is positive, that it is good for the patients, for the families, for society. So you go wherever you are called. Besides, I remember I was there during the years when the euthanasia law came out and, of course, it was like a kind of bombardment, because it seems that we were against it and it was not the case.

Elia Martinez: Now we are carrying out a kind of plan that is to approach patients' associations. Today I have to sign an agreement with CEAFA, which is an association of patients with neurodegenerative disease. We are going to sign one with another of the most important ALS associations. Although I am an oncologist, I try to work and promote the Oncology Center because I think it is essential and that it is in deficit right now. What are we going to do with these agreements? With these agreements we are going to try to nurture each other. We try to explain what palliative care is because they can ask for it. For example, when we met with AdELA, we realized that they knew nothing and the same with CEAFA. They didn't know what shared care planning was. So that's a big issue. The patient associations, which in turn are the voice of the patients, do not arrive. That is a mission that is ours and we have to reach all of them if possible. Let's see if this time it happens, one after the other.

Is it important to include death in early childhood education?

Belén Martínez: How important! I have been saying it all my life, because I educated my children in death, as I say. My children went to the funerals of their grandparents, of their uncles and aunts, they were at the morgue and absolutely nothing happened to them. In other words, the distance we have between children and death is brutal and I think that in schools there should be talks about dependence, also about that loss of functionality, about that old man or woman who is going to be there, who in the future is going to be you too, and that we have to have a society where we wrap ourselves around each other. And not to talk about individualism and competitiveness continuously and that death exists, that it is part of life. And that simply opens a teenager's eyes, I think.

Going back to the subject of resources, I imagine that many families are unable to care for terminally ill family members because they cannot take time off work to attend to them. Have you come across such situations?

Elia Martínez: Of course. In Madrid there is already a fund in the case of pediatric palliative care for parents to take paid leave for the care of children in palliative care. That is a tremendous social advance. And that would be fabulous for patients that I see who are at the end of their lives, in the last months of life, and their children are doing real barbarities in order not to miss work, to be in the hospital, to come to the doctor's office.

Belén Martínez: Of course, in the end, if you have a job that allows you to take time off, many times the primary care physicians themselves see the saturation of that person and give him or her time off to be able to take care of those relatives. But sometimes you are self-employed, you have your own job and you cannot do it. So, if the Dependency Law were developed and if the resources that have to be put in place were put in place, it would be a blessing. But it takes months and months and months. And there is an emergency procedure here when it is palliative, but it still takes a long time. Also because I believe that it took us too late to arrive. And then, as it was already there, but we see that forecast much earlier and we start to say, But do you think I have to look for it? Yes, start moving it, because probably in a short period of time this will be necessary and then, when it is too big for us, we do not have time to do anything and we are already overwhelmed. So, well, it is true that the Dependency Law should be developed 100%, especially in the case of these patients who have months to live.

From the Constellation of the Commons (CC) we are working on a useful and propositive collective imaginary that encourages civic participation in the transformation of the hegemonic system. Can you share with us some good news?

Elia Martínez: I believe that the perspective we have ahead of us is good, it is positive. "Evangelization," which is a very appropriate expression for palliative care, is already a fact and a lot of people have worked hard and thanks to God we have reaped its fruits, a job very well done and which is now going to take off because society is also ready for it to take off. And I believe that on the other hand, this is like everything else, the fact that society is going to start demanding things from us, it is going to make the resources stronger, that a law will appear, which will surely happen. As so many other things have fallen by their own weight throughout history, the horizon is going to be more positive than what those pioneers have done, to whom we have to be infinitely grateful for having raised the first stones.

Belén Martínez: I think like her, that the population is beginning to ask for palliative care is something very positive and what we have always said in palliative care, that a good and peaceful death is possible. That is to say that this is also something very positive but above all that society tries to integrate this process as something natural is so important so that there are also calm and peaceful deaths. I think here is our role as a scientific society that is doing a lot, supported by foundations for dissemination.

What fuels your desire to fight daily for the right to palliative care for everyone?

Elia Martínez: I first studied internal medicine, which is exactly what I am trying to improve, the oncology patient, organ failure. And I had not had any personal experience with death or any real situation. I had no training in palliative care, but I saw a lot of suffering and a lot of incongruity. I saw very advanced patients who had extraordinary circumstances and no one stopped to ask them or relieve them of their symptoms. And from there it was born, I was quite young, I enrolled in the master's degree at the Autónoma, which opened my eyes, it changed my life. I, of course, am a vocational doctor. But I love science. I love reading articles about medicine or so on, but what I love is people and helping people. Without that, my work would be meaningless. And without palliative care, my work would be meaningless.

Belén Martínez: Well, I am passionate about it. I started working in a place for chronic patients when I was 23 years old and there I began to see palliative care courses and I said, this is what I want. That is to say, I never liked big technologies, I always fled from ICUs, from equipment, because I did not like it, I liked the person and I began to do an internship in oncology. I loved the oncology patient and I loved the geriatric patient. And when I went to sign my first contract they said "What do you want: emergency, ICU, geriatrics, internal medicine, oncology?" they looked at me like that, with a strange face, because I like to take care of people and connect with people and I think in that end of life you connect very well with people, you connect with the essence of those people and for me that helps. I always say, and I don't remember who it is that says it, but helping to give life and to heal is no less important than helping to die, to die well and in peace. And I go on like that. And we always say hey, we must take into account compassion fatigue. Be careful, we have been doing this for many years and we may have it. Well, I think that working in palliative care has made me, because I had never had any experience with death beforehand. Already working in palliative care, I expericned traumatic death of my brother and it helped me to work in palliative care, to overcome everything that was coming to me, to overcome what was coming to me with my parents. And she has helped me a lot in everything. In a recent death, also of a niece, also very young, it has helped me to understand that this happens, that we don't like it. Of course we don't like the loss, you have to live it, but it helps me to get up every day if I want to go to work, which is very important for me.

Elia Martínez: It is important that you are not looking at the clock and saying it is still half past one.

Belén Martínez: On the contrary, I lack time.

Elia Martínez: I think that the luckiest thing in the world is first of all what patients teach us and secondly, that the hours at work go by and you really say "what a great job" ....

Belén Martínez: .... and you go home satisfied.