How doctors choose to die and what we can learn about it

In 2011, a doctor became famous for ensuring that his peers die with treatments that were less aggressive, quieter and less painful than the rest of the people. Some time later, studies have proven him wrong. Dying is difficult for everyone. Specialists demand that quality of death be a social value and want a radical reinforcement of the services of dependency and palliative care.

Jesús Méndez 12/10/2019 08:00 CEST

“As a doctor, you're always concerned about the number of patients you need to see. Now, as a patient, every time I go to my doctor's office, I know there's a little ticking clock in his mind.” The testimony of Paul Kalanithi, a neurosurgeon diagnosed with metastatic lung cancer, went around the world with his book *When Breath Becomes Air*.

> *“With what shift and pain we come to the world, we remember not: but ‘tis commonly found no easy matter to get out of it.”*
>
> Sir Thomas Browne. *Religio Medici*

“It’s not a frequent topic of discussion, but **doctors die, too**. And they don’t die like the rest of us. What’s unusual about them is not how much treatment they get compared to most Americans, but how little. For all the time they spend fending off the deaths of others, they tend to be fairly serene when faced with death themselves. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care they could want. **But they go gently**.”

That's what Ken Murray, a retired Los Angeles family doctor, said in 2011. He did so in an article entitled *How Doctors Die (It’s Not Like the Rest of Us, But It Should Be)*, in which he also said: “Of course, doctors don't want to die, they want to live. But they know enough about modern medicine to know its limits. And they know enough about death to know what people fear most: dying in pain and dying alone.”

That text continued to be shared and republished in subsequent years, giving rise to *discussions* about “why doctors routinely administer treatments to dying patients that they would adamantly refuse for themselves.”

His impression was personal, based on his own experiences and exemplified by that of a doctor friend who was diagnosed with pancreatic cancer. The surgeon who treated him spoke to him about a new technique that moderately improved the expectation of remaining alive after five years, but in exchange for a considerably worse quality of life. He refused treatment, decided to go home to spend more time with his family, and died there, without returning to the hospital.

After his article, objective studies were made and the data contradicted Murray. When healthy people are asked about the type and number of treatments they would like if they were close to death, doctors are clear that they prefer much less.

However, a 2016 paper analysed the deaths of more than 200,000 U.S. citizens, including nearly 10,000 physicians. Although they used **palliative care** a little more, they spent the same amount of time in the hospital during their last few months as the rest of people, even somewhat more in intensive care.

Another work of the same year with 600,000 people did see that doctors died somewhat less often in hospital, but only 4 percent less, and many of the differences had more to do with socioeconomic status than with the profession.

Is there any difference in how doctors live illness and death? What does a continued contact with both in their own lives entail? Why is it so difficult to die well?

And what is dying well, after all?

Pursuing death

“I had started in this career, in part, to pursue death: to grasp it, uncloak it, and see it eye-to-eye, unblinking (...) But in residency, something else was gradually unfolding. I was not yet with patients in their pivotal moments, I was merely at those pivotal moments. I observed a lot of suffering; worse, I became inured to it.”

These lines were written by neurosurgeon **Paul Kalanithi** in his book *When Breath Becomes Air,* shortly after being diagnosed with fatal lung cancer in 2013, at the age of 36. Kalanithi remembers his ongoing relationship with death and describes how he experiences it when he has to face it in person. Doctors may be better prepared for it.

“I’d say there’s no clear trend,” replies **Agustina Sirgo**, a psycho-oncologist at the Sant Joan Hospital in Reus and president of the Spanish Psycho-oncology Society. “There are no studies on the subject, and they’d be very interesting, but my personal impression is that the answer is no,” she continues.

“Perhaps the first layer of discourse, the first reaction may be different, sometimes through a scientific-technological escapism, but ultimately the core of the physician is a human being to whom the profession may or may not be of use. The question is not the level of one’s relationship with death, but the impact it produces and how one reacts to it. Many people not related to health may have such experiences and incorporate them in their favour,” Sirgo adds.

“I wouldn't know what to say,” admits **Fernando Marín**, a doctor specializing in palliative care and president of the association Right to Die with Dignity (DMD, from its Spanish initials). “My impression is that it depends on the person and his or her way of thinking, his or her fears and previous close experiences.”

Marcos Gómez, honorary chairman of the Spanish Society for Palliative Care (SECPAL) and one of the promoters of this discipline in Spain, feels that “there are no big differences. I don't know what will happen when it affects me, although I would say that right now, with experience, I'm less afraid.”

A few pages later, once the diagnosis of his lung tumour was known, and as a personal answer to Marcos Gómez's question, Kalanithi writes: “Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable.”

There wasn't largely because, despite the ongoing relationship with patients, “you don’t appreciate the mounds of paperwork that come along with it, or the little things. When you get an IV placed, for example, you can actually taste the salt when they start infusing it. They tell me that this happens to everybody, but even after eleven years in medicine, I had never known.”

(...) Simply, “racking back pain can mold an identity,” Kalanithi says.

Is there, then, any way to be prepared for death from the standpoint of health? Assuming, as **Cicero and Montaigne** once said, that “to philosophise is to learn how to die,” Irish physician **Seamus O'Mahoney** wrote an article raising the question of whether philosophers died better than doctors. The bottom line is that, generally speaking, they do not do so especially well. Their choice, therefore, is to forget it until it is near and visible, preferring to think about what he will cook for dinner. Another way to think about it is to bear it in mind as a rumour that does not interfere with one’s daily life, but allows one to recognize it as it comes nearer.

“That may be an option,” Sirgo notes, “but bearing in mind that thinking too much about it can tangle life and that, until then, no one knows how they will react. The here and now will be the one corresponding to that moment.”

The other big question is how to do it once the time has come. And what not to do.

What it is to die well (and all obstacles)

> *«Just before he died, Tolstoy said, “I don't understand what I'm supposed to do.” »*
>
> Anatole Broyard. *Intoxicated by My Illness (And Other Writings on Life and Death)*

Anatole Broyard was a literary critic diagnosed with advanced prostate cancer in 1989. His reaction was strange and particular, and he included it in an e-book entitled *Intoxicated by My Illness*: “It seemed to me that my existence, whatever I thought, felt or did, had taken on a kind of meter, as in poetry, or in taxis.” (...) “In this phase I’m infatuated with my cancer. It stinks of revelation.” This reaction is not common, but it shows the variety of ways of facing illness and that there is no exact way to describe what “dying well” is, although for Marín it could be summed up as “dying the way you want.”

What seems clear is that we die worse than we should. For example, “up to 25% of patients with advanced cancer receive aggressive, objectively defined end-of-life treatments,” says Marín. Without going any further, among a sample of 1,001 patients at the University Hospital of Santiago de

Compostela, 19% received doses of chemotherapy in the last five days of their lives.

“Quality of death is not a social value,” continues Marín, who is alarmed to explain that “25% of doctors do not even know if the **living will** is regulated, which is almost like saying they do not know about insulin.”

“Hospitals are built to diagnose and cure. Death is an intruder in them,” assures Marcos Gómez. This may be borne out by the fact that up to half of Spanish universities “do not even offer the subject of **palliative care**,” and at the hospital level "we rank 31st out of 49 in the European Union in this area.” According to Gómez, this means that “75,000 people die each year in Spain with suffering that would be avoidable, including 1,100 children.” Palliative cures are not an end in themselves, but “a means to die well,” concludes Marín.

The image with which healing at the end of life has sometimes been compared is that of a train that advances with the inertia of healing and from which it is very difficult to jump. “That, along with the fact that people change their thoughts in desperate times, could explain why even doctors don't die better,” Sirgo reasons.

Right now, in Spain there are ten autonomous communities that have a **specific law of dignified death**, but “in reality there is a lack of political will,” says Marín critically. “It’s basically a pedagogical law, a catalogue of good intentions. In real practice there are no differences between those who have adopted it and those who haven’t.”

According to Marcos Gómez, honorary chairman of the Spanish Society for Palliative Care, "75,000 people die each year in Spain with suffering that would be avoidable, including 1,100 children." / Adobe Stock

What is called for is a law accompanied by budgets that would make it possible to "increase palliative units and design appropriate plans for each place, giving much more importance to the value of the living will and **the right to die in a single room**," he adds.

He also insists on improving home-care services, because "everyone's home is the preferred place to die. And the cheapest," says Gómez, for whom right now the way to die is almost "a matter of luck that depends on the region, the hospital and, ultimately, the unit that happens to deal with you." It is clear to him that "it couldn't be easier to programme an operation than a help to feed them and clean up in their own home."

Ethical conflicts

> *"What a critically ill person needs, above all, is to be understood. Dying is a misunderstanding that must be cleared up before the end".*
>
> Anatole Broyard. *Intoxicated by My Illness.*

In **Tolstoy's** novel *The Death of Ivan Ilych,* what tormented the protagonist most "was the deception, ***the lie***, which for some reason they all accepted, that he was not dying but was simply ill.” This phenomenon, which has been called ‘the conspiracy of silence’, affects “50% of situations in palliative care,” explains Marín. This is largely due to families, who generally act with the good intention of “protecting” the patient. But it is also due to doctors, “for whom it is often not a priority and whom it leaves in a more comfortable position.” However, “this is an irresponsible attitude that hinders the process of dying well. Although there are people who disagree, **there is no right not to know**.”

For Marcos Gómez “there is a very serious communication problem. It is sometimes a question of lack of time, but also of training. Doctors have not been taught, and it is not only a very important medical act, but possibly also the most difficult.” An act that, according to Sirgo, must be done “with the right time, respect and generosity. And without prejudice on both sides.” Kalanithi was lucky with his caregiver, and thus described a moment of that stage together:

“There we were, doctor and patient, in a relationship that sometimes carries a magisterial air and other times, like now, was no more, and no less, than two people huddled together, as one faces the abyss.”

That was also Broyard's quest, that of “someone who is able to go beyond science and reach the person... who is able to imagine the solitude in which critically ill people live,” because he could see “no reason why he has to stop being a doctor and become an amateur human being.”

In this relationship at the end of life, other types of conflicts also appear, such as that of the possible **induction of death** when the time comes and the case arises. There is a fine line, a very important one for some, between **non-intermittent palliative sedation** and **active euthanasia.**

The former consists in putting the patient to sleep with the added possibility of interrupting his nutrition and hydration, which leads to death within a short time. This “is done more often than is said,” says Marín. In the latter case, a **lethal dose** of some substance is administered, which is the direct cause of death. “Deontologically it's something very different,” says Gómez, who, unlike Marín, is opposed to this second practice.

Gomez prefers to focus on the absolute need to improve palliative care and end-of-life care. “Putting the focus on euthanasia is like putting the cart before the horse. Every day a hundred people die in Spain waiting for the dependency help to which they are entitled. Euthanasia could be a solution for approximately 3% of us, for up to 50% we are going to need palliative care,” he laments with astonishment.

Although he is against euthanasia, he has been asked to give his opinion on the latest media case, that of the now-accused man who helped his wife, who had multiple sclerosis, to die. “I would have done the same!” shouts Gómez. “They'd been applying for a nursing home for ten years, that's what’s disgraceful!”

The epilogue to Kalanithi's book was written by his wife shortly after his death in 2015. She tells of what happened at home, without any therapeutic obstinacy, controlling the symptoms: "He knew he would never be alone, never suffer unnecessarily.

Paul Kalanithi with his baby, Cady, born after he was diagnosed with incurable cancer in May 2013. The doctor died at home in March 2015, when Cady was eight months old. His testimony of those years overwhelmed patients and colleagues.

TAGS PALLIATIVE CARE | EUTHANASIA | MEDICINE | DEATH |