What ultimately matters

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Her eyes closed
And the world keeps going ...

Alfredo Le Pera, 1935.

The cold morning of December 19, 2018, while we were in my father’s funeral, in the East Cemetery in the city of Caracas, my colleagues and friends Jorge Sánchez-Lander and his wife Paula Cortiñas kindly approached to give me their condolences. As always, the affable conversation about our families, about Venezuela, about Spain, and obviously about our beloved Dr. Luis Razetti Institute of Oncology arose spontaneously. We call it ours, because at the end of our training as specialists in oncological surgery, we end up considering it as part of our lives.

Jorge, my mentor, taking advantage of the sensitive moment I was going through, recommended the reading of an enthralling book by the famous American writer of Indian origin Atul Gawande, surgeon oncologist from Boston and professor of Medicine at Harvard University.

Gawande, in eight chapters, narrates the limitations and incapacities of modern medicine to act properly when death is approaching. He does this recount through the analysis of many experiences in his medical practice, from interviews with geriatric doctors, but mainly from conversations with older adults, with terminally ill patients and their relatives. He tells us the modern experience of mortality as mere creatures that grow old and die, and in what sense medicine has transformed this experience, and in what sense has not been able to achieve it, scrutinizing whether our ideas are aligned to face our finitude.

He states with regret: "Modern scientific resources have profoundly altered the course of people's lives. People live more and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, into issues that have to be managed by healthcare professionals. And we, working in the world of medicine, have shown ourselves to be alarmingly ill-prepared for this task."

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In the first chapters of the book, the author crudely compares the aging of his grandfather Sitaram in rural India with that of Alice, his Caucasian American mother-in-law, who lived in the suburbs of Boston. While his grandfather grew old next to his family, being a reference for them, to finally pass away, with more than one hundred years, in his house, Alice, who is described as Jessica Tandy, the actress who played Driving Miss Daisy, lived her last years alone and "independent as is usual in the USA", while she could perform the activities of daily life, until little by little she could no longer fend for herself and was transferred to a nursing home, where after several years of a sad stay, and multiple visits to the hospital, she died.

At the beginning of the 20th century there were only asylums for the poor and destitute, which were dark and dreary places where people ended up dying of decline and without any dignity. With the birth of modern hospitals in the 1950s, these "patients" were transferred to hospitals, but sooner or later the health authorities realized that they could not stay hospitalized for so long as it was very expensive. The geriatric residences were born as a need to free hospitals from chronic and very sick patients who would not benefit from being hospitalized for longer. For that same time, most of the deaths occurred in the home, however starting in the 1980s, that only happened in 17% of cases.

The author makes multiple references of how doctors, especially in the area of oncology, treat with eagerness and vehemence, and by all means, to prolong the life of patients, sometimes not always well weigh the cost of suffering. He claims that we do not always tell patients the truth and what their real life expectancy is, he demands us to be more honest and limit our medical actions according to each patient and what they really wants. It teaches us to communicate difficult decisions, to know when to stop and let the patient get involved in their treatment. To move from being "an Information Doctor" to a doctor who inquires about what you really want the patient in his/her last days. Gawande tells how most of the elderly and their families resist taking their parents to residences for a long time, but then, due to the loss of independence and autonomy, all succumb to geriatric care.

Perhaps one of the most interesting aspects is how the author expresses the vision of the old man in front of the old age, as he describes the loss of physical strength, the emergence of gray hair, the diminution of vision, the fall of the teeth, the trophic changes of the skin, the spots, the chronic pains, the deterioration of the cognitive functions and finally the lack of control of the visceral functions. Without a doubt, this hit my psyche. When reading each line I seemed to be listening to my parents, when on Sunday afternoons we went to visit them. After the affectionate greetings, Giovanna my mother, began to enumerate us, one by one each of his ailments, with luxury of details and meticulous rigor, always said that once a new evil arrived he never abandoned it and rather added to the previous ones. She showed us her skin, increasingly thin, but she was still reluctant to take drugs and in fact she did not take them. Until the age of 90, she had never been operated or hospitalized. One day in December 2018, she stopped eating and decided to let herself die. Her loyal life-long companion, Vincenzo, my father, when he saw her delivered, undaunted, suffered a stroke and overtook dying before her. Giovanna, with the determination that characterized her, the following Sunday would reach him sweetly in heaven.
As the cases described by Gawande, most of the elderly are slowly going off, they are consumed as long candles, which eventually become extinct before dying, shrinking and blurring. In the end the author proves in his own flesh the sad agony of the painful illness of his father Atmaran, who suffered from a locally advanced sarcoma of the spine, recalls everything he had lived and learned in his long conversations with other elderly and sick people, the surgical intervention and palliative medicine. When applying what he has learned, then realizes how difficult it is to understand that each nadir is his own and sui generis. He makes us see how complex it is to apply knowledge without involving feelings. In the end he manages to have his father die at home surrounded by his most beloved affections, not before having gone through all the edges of the modern and technological medicine that had prolonged his life like most of the terminally ill.

We believe that medicine is about guaranteeing health and survival, but in reality it is much more than that, because those who suffer from a serious illness have other priorities, very often, very much apart from just prolonging their lives. Among its main concerns are avoiding suffering, tightening ties with family and friends, being mentally aware, not being a burden to others and having the feeling that his life is complete. People want to share their memories, pass on their wisdom and personal belongings, fix relationships and make sure that the people they leave behind are going to be fine. We must recognize with regret that our health care system, highly technological, has failed to meet those needs.

We do not really need a good dying, but a good living.


References