FROM THE INSIDE

Subtle trajectories

Fabrizio Elia* and Andrea Verhovez

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A man is lying on a hospital bed. Next to him, a woman is holding his hand.

The man is well past his 70s, and a long history of disease stands behind him. Chronic obstructive pulmonary disease constrains him to be connected to an oxygen tank for most of the day. He has now been admitted to the hospital for another episode of exacerbation. He is connected to a ventilator through a tube, and a mask covers most of the face. Things are not going in the right direction. He is more and more drowsy and his blood is increasingly acidic. Notwithstanding our efforts, we are failing to wash away the carbon dioxide, which is accumulating in his body. Blood pH values are too low, and we are almost at what we believe is the point of no return. We have long been discussing whether to proceed to more invasive treatments. The woman, his wife, is a little bit younger, and has spent all of her life beside him. We sit down together with her in a distant room and start our talk, as though it were a ceremony.

“Things are not going well”

“This has already happened in the past”

“This time is different”

“I’m prepared”

We outline the situation, the treatments delivered, the natural course of the illness. We share with her the

absence of indications to endotracheal intubation and invasive ventilation.

“It wouldn’t change the course of his illness”, we say.

“We talked about it many times. He wouldn’t agree”, she replies.

We try to explain that her husband is dying and what the next steps will be. The deepening of the consciousness, the breathing gradually slowing, and so on. We add that, at a certain point, we will turn the monitor off (a source of alarms and noises, useless by that time), which may help the patient not to perceive any disturbing symptoms.

“I agree with you, but do not take off the mask. Do not take him off the ventilator”. We explain to her that keeping him on non-invasive ventilation wouldn’t offer any advantage. On the contrary, we could prolong the suffering. But she insists, and we believe that we should respect her will.

Our shift comes to an end, and we say goodbye to the woman, in tears as she is going to tend to her husband’s last night.

The day after, as we set foot in the ward, a man’s voice wishes us good morning. Here he is, wide awake in his bed, a little oxygen flowing through his nostrils and a cup of tea in his hands...

“I did nothing”, the night doctor tells us. “At a certain point he just woke up, and a little while ago he asked for the mask to be removed”.

“He is alive” the woman says, as she comes across us in the corridor. The tone of her voice reveals both happiness for the news and reproach for our failure to understand the situation.

Modern medicine displays powerful therapies to cure patients and increasingly precise instruments to monitor their clinical evolution. Most likely, this gives us the illusion of being able to fully control the biological aspects of our patients’ existence. It almost appears that their lives depend on our interventions and decisions. We tend to

*Correspondence: fa.elia@libero.it
High Dependency Unit, San Giovanni Bosco Hospital, Turin, Italy

think that if something goes right, this is thanks to us and to our choices, and on the other hand, if something goes wrong, this is because of us and our bad decisions (or worse, our colleagues' bad decisions). A sort of self-certification of almightiness.

This and similar episodes remind us that this is not the case (at least, not always), offering us a lesson in humility. Things can go right despite our pessimism, or go wrong despite our optimism. In much the same way, a patient can die even though our decisions are correct, or he can live on notwithstanding our wrong decisions.

Over the years, we have striven to understand our patients' trajectories of disease. In spite of all our efforts, we are still far from possessing instruments precise enough to exactly predict the course of the illness and the degree of response to treatments. Trajectories lie elusive for the most part, and the results of our interventions

continue to be uncertain and unforeseeable. Most probably they will always be so. A first step forward is accepting the uncertainty; the next is finding a means of explaining it to the patients and their family.

As for our patient, he lived a few more months, together with his wife, until he passed away during another exacerbation of his pulmonary disease.

We believe we made the right choices, and we would do the same again. But there is one thing we learnt: patients can live or die, despite us. Most probably, we are less important than we deem ourselves to be.

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