Telling the truth

Claudio Magris

How, when and to what extent is it acceptable, essential or improper to tell the truth, a terrible truth, to a sick person who is unaware of how quickly his or her condition is deteriorating? This dilemma impacts deeply and painfully on the life and quality of life of many people. I speak from experience having had to cope with this painful dilemma personally; the life I shared with Marisa Madieri, my wife for thirty-two years, lead me to share also this ordeal with her. For five years, day after day – the experience of disease and of knowing the disease, the experience of truth when truth is so difficult to accept, and the liberating and devastating power of that truth. Every general problem – as, in this case, informing patients about their condition and the manner and method of delivering information involving the essence of their life and their death – is concretely endured by each person, by each family. That was our experience, too. I say “we” even if the protagonist of this story is Marisa, because it is she who was stricken by cancer, who coped with it, fought it and eventually lost her battle, although she made this victory an arduous one as she confronted and hit back at her enemy step by step, calmly, blow after blow. She is the protagonist, because she lived every aspect of her story with her unceasing need to know the truth and with her questions on how to ask for it, demand it and listen to it – while the others, those who were questioned by her, certainly wondered how they could or should tell such truth. I am just a witness to this story, one who escaped to tell it, as the Bible says. However, given the intensity of our relationship, I was directly involved, too, all the time, second by second, step by step in this problem of requesting and delivering the truth – in this case a harmful and evil truth – and in the way of requesting and providing this information.

I can only describe what I lived through, without any claim to constructing a theory. Freud often quoted the Gospel’s phrase “The truth shall make you free”, in which he believed firmly, as I do. Without truth, there is no freedom, no intensity of life; the world cannot be crossed freely. Like any other instrument of salvation, truth is dangerous because it has to do with the essence of life; the great Jesuit and baroque writer Gracian said that nothing demands more caution than the truth: “tis the lancet of the heart”. If this operation is carried out hastily and driven by a rash albeit generous impulse, it could damage the aorta and kill the patient. It is one thing to love truth, it is quite another thing to be fanatical and obsessive about truth – an attitude against which the philosopher Benedetto Croce often warned. There are the right manners, forms, opportunities and times to tell the truth. If a person is ugly and ungenerously, telling them outright is not love for truth. A humane act lies in how the truth is told, on how we care for the person to whom we are telling an unpleasant truth. In this case, too, we tell the truth not because we want to demonstrate our frankness (and that form of frankness that may take the disguise of scientific language); we should not be focused on ourselves, but on the other person.

Moreover, we must be aware that given our finite condition, an exchange of absolute truth can never be achieved between two people, even within the closest of relationships. It is impossible to tell all the truth, to convey all its facets and possible shades; this is impossible due to the relative, imperfect and delimited nature of the human condition, and it would be wrong to believe that we can tell all the truth, that we can see everything clearly; as St. Paul maintains, we see “per speculum et in aenigmate”, through a mirror and in mystery, and it would be illusive to see ourselves as omniscient as God. Yet, we can tell almost all the truth, and this almost – if taken to its furthest possible extreme – is our all. When it comes to diseases (or news about diseases) that are serious, distressing and often fatal like cancer frequently is, there are people – Marisa, for example, or other people I was close to in similar circumstances now concluded, for the best or for the worst – who have by their intimate constitution a moral need, an existential, total, almost physical need to know and be told the truth, even a terrible truth about their condition. They need the truth to fight it, but they also need it to be able to live. Not knowing, ignoring, fearing to be deceived, even if for noble reasons, means to move in anguish through the mist, in an ambiguous darkness that erodes their life and destroys any opportunity for joy, pleasure, beneficial forgetfulness and abandonment that can be achieved in spite of the difficult or dramatic experience.

However, there are other people – as I have personally seen with other friends stricken by the disease – who do not want to know the truth, who try to hide it in every possible way, who manage not to read and understand even the most evident signs, who misunderstand even the most clearly worded communication. I have seen rational people, even deeply religious people, who would normally analyze reality and try to grasp its meaning, choose to deceive themselves about their tumor even though they were experiencing the burden of the disease day by day, actually manage to deceive themselves until the end. In a situation like this, I think that physicians are faced with a terrible dilemma: telling the truth or not revealing it, hiding it, softening it.

As I see it, there is no definite answer: of course, assuming that the protagonist is the patient, that his or her rights must be considered and not general principles and pre-defined behavioral models, and that the physician should pay attention to the patient’s requests, then it is (it should be) more appropriate to lie to a sick person who clearly asks for a lie, because this is what he or she wants and a doctor is there to serve the sick person, not to comply to a strict behavioral rule. It is a question for which I am not able to provide an answer, because a physician’s duty is not only to serve the sick person and
to meet his or her requests, but also to understand the innermost, real needs of the patient. If a person with liver cirrhosis asks for a bottle of whisky which he is really craving for, I do not think a doctor should give it to him, as a doctor knows better than his patient what the true needs of the person and of the patient as a whole are, from a psychological and physical point of view. And yet, there is a terrible implication (a necessary, but nonetheless terrible implication): that another person knows better than you what is best for your life, and has the power to make decisions for you according to his opinion.

As far as I am concerned, this attitude would be unconceivable; I need the truth, like Marisa did. Not because I am a brave person – Marisa was brave, much more than I am, and not only regarding diseases or death – but because truth is like a shield to me, the comfortable warmth of life against my fears or my weaknesses. Marisa always wanted to be told the truth, and in fact she was always aware of the truth, all the truth, about her condition. I am sure of this, because at each visit I spoke at length with her doctors and I witnessed the conversations she had with them: I know what she asked them and what they replied. When, on a couple of occasions, we went to different hospitals from usual, even abroad, after every conversation with her doctor or doctors, Marisa would write a brief yet detailed and exhaustive description of her condition and of the state of her disease, and then show her report to the doctor to be sure that she had not written inaccuracies. And I can confirm that her report was perfectly in line with what her treating physicians wrote to describe her case to their colleagues. It is not without reason that she was a great writer, whose books are appreciated in many countries, and one of her characteristics was the clear-cut, accurate style, the ability to use the most appropriate words that reflect true poetry.

Throughout the five years of her illness – five years marked by alternating phases, with tumor exacerbations that were very hard to manage followed by long periods of good health and vitality – I have seen this continuing process of truth, as those years were characterized by frequent clinical tests, examinations, procedures, visits with doctors, questions and answers. I could see that this continuous “link”, as I call it, with Marisa’s own truth was an anti-anxiety factor for her, a sort of safety net (the little safety remaining under those circumstances), a sort of guarantee of normality.

Marisa managed, for herself and for the others who lived with her, to keep a “normal” atmosphere until the end; she did not allow the disease (which she fought strenuously) to control all her life, to become a nightmare or a fixed thought that would make her life a black hole. She devoted the necessary time and energy to her fight against the disease, but then she moved on to other things, and even if at times she certainly was scared and sad about her probable death, she never projected her anxiety onto the rest of her life; she did not become neurotic, did not lose her taste for life or interest in the personal and collective affairs of others; she kept her love for the sea and for all other pleasures or passions until the end. Not to mention her loving relationship with our two children, with her friends, and with me. I think that this knowledge of the truth, this gazing into the face of Medusa, this tearing off the mask of a terrible disease and looking it in the eye without fear or humble submission, allowed her to deprive the disease not of its destructive and ultimately triumphant

“Red shoes” by Marco Ceruti.
power, but of its dark nature. And it is darkness that more often and most of all scares us. This attitude was also made possible by the health professionals we were so lucky to encounter: humane people, who showed their wisdom and great ability in telling the truth. Not because they softened it, but because they placed it, frankly but very tactfully, within the general context of her condition, with an emphasis on all possible options available.

To be specific, I can quote the words of one of her doctors, Guido Tuveri. A month or two before the end, when her condition was rapidly worsening with the insurgence of an ascites, he described the likely fatal consequences to us – I was present with Marisa – without complacency, just the bare truth. Then he added “All this can happen an hour from now, in six months’ time or perhaps even never. It is unlikely, most unlikely, that it will never happen, but it is not to be excluded”. He had told the truth, because he had yes given the bare facts of the new threat, but also because it was quite true that the devastating effect of the ascites could have occurred at any time or even, based on medical history, never – because not only in life itself, but also in those processes which threaten to destroy that life, or do destroy it, nothing can be absolutely certain. Of course, that ‘never’ was improbable compared to the other two possibilities; Dr. Tuveri did not hide the fact that these were more probable, but his tone when enumerating the three possibilities did convey the sense that after all ‘perhaps’ (perhaps never) was faint but not impossible. He was able to tell the unveiled truth in such a way that the dreadfulness of it was clear yet not totally damning.

I believe those words are an example of how a negative and destructive truth can and should be told to a patient; with no omissions but without brutality, with delicacy but without reserve. Perhaps, also, it is only right to clarify the truth, as it does not only regard the disease or the therapy or the psychotherapy, but existence itself; the truth in knowing that we die anyway – even without a fatal illness we are destined to die – but that we also live. Life is a deadly disease, but it is possible to live it happily, without dwelling too much on death, without letting the Grim Reaper cast too long a shadow.

That was how Marisa lived her life in those five difficult years, allowing those around her to live a better life too, and this, I believe, was due to her capacity and need for the truth but also to the ability of those who knew just how to impart that truth.

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