

editorial

“There was a boy...” - the importance of narrative Medicine in Paediatrics

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I am a paediatric neurologist, an avid reader since I was a child and a storyteller. Why write? Not exactly because I enjoy it. Pleasure is to be in the sun, to lie on the sand after a swim in the sea, to taste the first spoonful of a delicacy, to feel the touch of a beloved hand on the nape of our necks. Writing is for me a necessity. Experience remains chaotic, formless inside me, until being represented. I write to understand myself and others, to exorcise thoughts, emotions and sufferings.

Many physicians share a passion for medicine and literature. What else do they have in common? Tchecov, a Russian physician and writer who lived in XIX century, said that medicine and literature were for him like the wife and the mistress: when he was tired of one of them, he slept with the other... I think that we can stilly cohabit with both, they do not exclude each other, because both are nourished by the same: narratives.

It is not by chance that there are many medical writers. The great themes of literature are love and then, sickness and death. As doctors, we have direct access to stories from many lives. In order to hear them, we just have to let the patient tell his/her story... But, why do patients tell some doctors about their stories and do not do it with others? Is it because some doctors listen to them, while others do not? The most precious thing we can give to others is our attention. I have always treated my patients as people with their particular history. That is why I listen to them very carefully, and then, sometimes after more than twenty years, I write some of those stories. Knowing the people's histories helps us reaching out to them, treat them, comforting them, being at their side with all their dignity.

If we do like stories, we will go to each consultation with enthusiasm, because we know that day we are likely to learn something new. We will transform the history of a disease into the history of a person who has an illness. So I teach my students of Paediatrics. Every clinical history they make should always start with “Once upon a time, there was a boy...”.

Physicians have one of the oldest professionals in our society and live with what is most human, with people's lives: their fears, sufferings, weaknesses, hope and many other feelings that arise when we are frail with an illness or in close contact with death. This, associated with the very nature of the profession, awakens in every doctor his or her side of a storyteller. Many doctors travel through the world of word and writing, and become storytellers, either orally or in writing. The first ones, when they come together, look a lot like a group of hunters or fishing men telling their adventures... With our medical colleagues, we have to describe in detail the case we saw, the factors that influenced that condition, the treatments we did and the results; with patients, we communicate telling and, while listening, we explain the possible causes of their complaints, making an effort to adapt our vocabulary, learning from experiences from many different lives... This listening and telling is very similar to the work of a writer, as both speculate or formulate hypotheses based on collected stories and finally write or speak for others to discuss...

At the very onset, almost every medical diagnosis was based on a good clinical history, the patient's narrative. With the advancement of technology, however, narrative

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has been progressively devalued, and sometimes it is possible to utter anecdotal phrases in emergency services such as: “Bummer, brain resonance is normal. We’re going to have to get a detailed story of the patient!”.

To narrate is to tell a story. Medicine is made of stories. We learned about the natural history of diseases through medical textbooks, narratives from our masters and the patients we met throughout our medical school. The problem is that the narratives of patients are always different and sometimes it is difficult to achieve a diagnosis. We often hear: “what a pity, patients do not read the medical books and each one explains the disease their own way...”. No two patients are ever the same. This is why Medicine is and will always be a non-exact science, something that requires both technical and human skills from those who practice it.

The first meeting between doctor and patient is something very important to both. A relationship of mutual trust may or may not be established. So, it is important to make patients feel we are there entirely for them. To hear with all our attention, with all our senses alert. And, we must have time. Time to listen to speaking and silences, which are sometimes more eloquent than words. Time to observe how they dress, how they speak with their mouths and their bodies, how they smell, what they believe in, which are their fears, conflicts, yearnings. On the other hand, we must subtly, from time to time and as little as possible, interrupt and ask questions to elucidate certain points. Or repeat something the patient said, putting a question mark before it. And always look at their hands, observe the gestures that accompany the words and so often contradict them, the legs that cross and uncross, hands that rub on the clothes to dry the sweat on their palms... And watch the chaperone, if there is one, how he or she reacts to what is being told to us, if with an eye roll, if with a half-smile of laughter, or a look of fear and compassion. Everything matters in the consultation. The place where we are sitting, the appearance of the room, the picture we hang on the wall, how we dress, how we talk. And, the more dramatic the diagnosis is, the better the patient will remember all the details. So, we must be very careful about the form and content of what we say. Over the last decades, handwriting has been replaced by computer writing, in Medicine. For some doctors, like me, it dehumanized my clinical descriptions and turned evident the need of a parallel chart. If we note in the clinical diary that the patient’s mother takes care of a family member with Alzheimer’s, in the next consultation we can ask her “How is your mother? Do you still have her at home?”. That little sentence will make a difference. It will make that lady feel treated as unique, as a single person within the context of her own life. This will make all the difference in the following encounters.

Medicine is learned by observing itself being done. For this reason, we always try to have, at our consultation, Paediatrics residents, fellows or medical students. They should never be more than two in the room; they should not be intrusive; and, sometimes, we have to ask them to leave for a while in order to ensure intimacy with the patient and family. At the end of that encounter we must know, in broad strokes, not only the history of the disease, but also the history of that person and his/her illness.

Being a physician gives us an authority that we are not ready to use when we are still very young. We can express opinions, make judgments that we are not yet prepared to make. When we are very young, it is also difficult for us to understand that being a doctor is not all about healing, but also, and above all, about caring. Literature can help identifying emotions, choosing the right words, knowing how to put oneself in the other’s shoes. It makes us reflect and solve not only the patients’ problems, but also our own. Being able to narrate a coherent story is a healing experience.^{1,2} Through the study of literary texts, we acquire interpretative tools of communication and empathy, and we learn about many lives and cultures, very different personalities, many situations and emotions exposed, that we would not have access otherwise in a single life. We learn that there are always multiple perspectives, we learn to tolerate ambiguity and become more prepared to deal with uncertainty. We also learn a great deal by reading the clinical histories our colleagues have taken: we learn about the disease, about the patient, and about the doctor who made that description.

Writing also solves many problems, many conflicts. The experience is better understood if well represented in a narrative and communicated to others. Writing materializes what we feel and was not obvious to us before. When we write the patient's story we reflect on it, choose words and learn something new that we will apply in a next consultation.

As Rita Charon, the mother of Narrative Medicine says, "teaching to read, to write well, to reflect on what we read or write improves the care we give to patients, giving us the ability to inspect what each one has perceived and share it with others, the ability to be aware that some aspects of a situation are above or below a palpable reality".³ It will focus the attention that the doctor will provide to the patient, help establishing empathy and improve the diagnosis. Narrative Medicine is not a substitute for Evidence Based Medicine, but a complementary tool to work towards the same end: the solution of a problem.

The study of humanities leads us to introspection and to define our values and to respect other cultures and ways of thinking. It allows us to recognize suffering and to care empathetically people who come to us.

In the USA, the study of literature has been part of medical school curricula since the early 1970s, and, in 1994, 30% of the medical schools taught literature as part of its curriculum. By 1998, 74% of medical schools taught courses in literature and medicine and, in 39% of them, it was a required course.⁴

In Portugal, to my knowledge, Narrative Medicine is taught as part of the medical school curricula as an optative course at Nova Medical school of Lisbon and at the Faculty of Medicine of Lisbon.⁵ I hope that in next years Narrative Medicine will become a required course in all Portuguese medical schools.

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