

The doctor-patient relationship in selected literary works

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“Through the creative words of George Eliot, Tolstoy, Chekhov, Camus, or Thomas Mann, the experience of being ill, being a doctor, or dying can be powerfully evoked and vicariously felt. Literature also teaches the nuances of language, the way its structure and form communicate the inner experience of another person”¹. (Edmund D. Pellegrino)

Language is a key element of the assistance relationship between doctor and patient. In order to prepare this article, we followed the challenge of Edmund D. Pellegrino¹, one of the innovators of bioethics, to think about this unique meeting based on some works of several recognized authors. We will begin with the book *The death of Ivan Ilych*, by Lev Tolstoy, deemed a Russian fiction masterpiece and a classic of world literature, which analyzes in details the main aspects involved in the doctor-patient relationship². In this regard, we will use this narrative as a paradigm for a reflection on bioethics, although also making some references to other literary works that address this subject. Thus, we intend to refute some arguments of those who criticize the inclusion of literature and the humanities in medicine courses, as only an obsolete entertainment of clinical activity or intended for an elite of scholars.

Lev Tolstoy, also known as Leo Tolstoy or Lev Nikolayevich Tolstoy (1828-1910), was a Russian writer very influential in the literature and politics of his country. He is considered, along with Fyodor Dostoyevsky (1821-1881), one of the best novelists of Russian literature of the 19th century. Linked to the realist school, his most famous works are *War and peace*, in which Tolstoy represents, through the life of five families, the Russian society at the beginning of the 19th century, during the Napoleonic invasion in 1812, and *Anna Karenina*, which reflects the moral and social values of Russia in this period.

The death of Ivan Ilych has few pages, especially if compared to the aforementioned works, and it is written in a simple and direct style about a subject that is always not only difficult and complex, but timeless. The senselessness of suffering and death, the desire of immortality, and the (apparent) absence of God are universal

human feelings expressed in this novel in a sublime manner. In the preface of the edition we used, António Lobo Antunes cites that “there is no feeling not included in it, there is no emotion that is absent. Everything that we are can be found in a few pages, written in a masterful way”³.

The description of the meeting of the judge Ivan Ilych, the main character of this work, with a famous doctor, who Ilych visits by insistence of his wife, when the first symptoms of his deathly disease arise, reveals the doctor’s excessive paternalism, surely common in the Russia of the 19th century, as well as a total insensitivity regarding the patient’s concerns, because he is probably more interested in his brilliant diagnosis than in the patient’s well-being and health recovery. This attitude of unbearable superiority was not uncommon to Ilych, because it was the attitude he himself assumed before the accused persons in his work as a judge:

“Everything took place as he had expected and as it always does. There was the usual waiting and the important air assumed by the doctor, with which he was so familiar (resembling that which he himself assumed in court), and the sounding and listening, and the questions which called for answers that were foregone conclusions and were evidently unnecessary, and the look of importance which implied that ‘if only you put yourself in our hands we will arrange everything – we know indubitably how it has to be done, always in the same way for everybody alike.’ It was all just as it was in the law courts. The doctor put on just the same air towards him as he himself put on towards an accused person.

To Ivan Ilych only one question was important: was his case serious or not? But the doctor ignored that inappropriate question [...] From his point of view, it was not the one under consideration; the real question was to decide between a floating kidney, chronic catarrh, or appendicitis. It was a question the doctor solved brilliantly, as it seemed to Ivan Ilych, in favor of the appendix... All this was just what Ivan Ilych had himself brilliantly accomplished a thousand times in dealing with men on trial. The doctor summed up just as brilliantly, looking over his spectacles triumphantly and even gaily at the accused.

From the doctor's summing up Ivan Ilych concluded that things were bad, but that for the doctor, and perhaps for everybody else, it was a matter of indifference².

The Portuguese writer José Rodrigues Miguéis (1901-1980), exiled in the United States since 1935, had no better luck in his contact with some of the doctors that treated him during his internment in the Bellevue Hospital, in New York, during World War II. Here we present the testimony of one of these situations, described in his autopathography *A man smiles at death with half a face*: "I was now with strangers [doctors] that knew nothing about me, nor had with me any bond, and to whom I was only another hospital case, an object of clinical curiosity [...] I did not exist, I was a bunch of symptoms"³. In another excerpt from this work, Miguéis, however, makes the reservation:

"If, by citing some episodes, I was, at any time, ironic, it was always with a deep respect and touched gratitude that I mentioned the truey apostles of medicine I've been coming to know [...] By no means I tried to repeat the satire to which they have been exposed for thousands of years. It can be said of doctors the same we say of women and Jewish people: full of epigrams and attacks, humanity does not know how and cannot live without them"⁴.

One of the most important elements to the establishment of a relationship of trust between doctor and patient is an effective communication, which includes listening with empathy his/her history, let him/her express his/her worries and, whenever possible, transmit him/her the diagnosis and any treatment for his/her condition with words he can understand. None of this was present in the many meetings Ivan Ilych had with the different doctors he visited. After the first appointment,

"Ivan Ilych went out slowly, seated himself disconsolately in his sledge, and drove home. All the way home he was going over what the doctor had said, trying to translate those complicated, obscure, scientific phrases into plain language and find in them an answer to the question: 'Is my condition bad? Is it very bad? Or is there as yet nothing much wrong?'"⁴.

Many times, as Manuel Alegre mentions, "doctors speak another language, who can enter that code?"⁵.

However, it is the doctor's responsibility to decode the incomprehensible technical and scientific language into words the patient understands and may apply to his/her concrete clinical situation.

Joan Didion, author of the play *The year of magical thinking*, reveals her difficulty in understanding the language used by the doctors that assisted her daughter Quintana, when she was hospitalized in the Medical Center of the University of California, Los Angeles (UCLA), after a brain hemorrhage:

"I put something else in Quintana's bag this morning. The edition of Clinical Neuroanatomy that I bought at UCLA's bookstore when I did not understand anything the doctors said. This book has been at my bedside table in the Beverly Wilshire [Hotel] for five weeks, and I still do not understand anything the doctors say"⁶.

The Chilean writer Isabel Allende, in her work *Paula*, which tells of the hematological disease that killed her daughter, is even more blatantly critical of the specialist doctor who monitored her. In her imaginary dialogue with her comatose daughter, she reveals her anguish and the doctor's apparent indifference and emotional distance:

"Every morning I walk the halls of the sixth floor looking for the expert to ask for new details. This man has your life in his hands and I do not trust him; he passes like an air stream, distracted and hurried, giving me blurred explanations about enzymes and copies of articles about your disease, which I try to read but do not understand. He seems more interested in linking the statistics of his computer and the formulas from his lab than in your crucified body lying in this bed. This disease is like this, some recover from the crises in a short time and others take weeks on intensive care; in the past, patients purely and simply died, but now we can keep them alive until the metabolism works again, he tells me without looking me in the eyes"⁷.

The oncologist Dráuzio Varella, in his book: *The sick doctor: the experience of a doctor as a patient*, help us understand the feelings of a practitioner "from the other side" of the relationship. Varella describes with realism the attitude of a co-worker who revealed to him the etiology of his disease, similar to the triumphalist diagnosis of Ilych's first doctor: "The practice of medicine is populated by contradictions: in the doctor's voice there was a mix of lamentation for the seriousness of the diagnosis and a trace of pride for getting to it"⁸. While knowing the diagnosis of the disease usually has a calming effect on the patient, in the case of the fearsome yellow fever, the news could not be cheerful: "On one side, clarifying the diagnosis brought relief: nothing is worse than dealing with the unknown. On the other side, it was not pleasant to know that it was a virus to which there is no treatment and that it would progress to cure or death, and there was nothing I could do but to find strength to face it"⁸.

Miguel Torga (1907-1995) also reveals, in his last *Diary*, the way in which his experience as a doctor affected his condition as a cancer patient, namely with respect to the understanding of the seriousness of his clinical condition:

"I spent my life treating sick people, and I did it with all my soul. I did not owe humanity to any of them. But I still needed to go through the supreme test of suffering without hope in a bed by their side [...] undermined by

the same incurable illness. With the only difference being that ignorance allows them to keep an absurd glimmer of hope, which I, for professional wisdom, cannot share”⁹.

Nevertheless, as Axel Munthe (1857-1949) observes in his remarkable work *The story of San Michele* “there is no medicine as powerful as hope, and that the slightest sign of pessimism in a doctor’s face may cost the life of the sick person”¹⁰.

Going back to Tolstoy’s book, João Lobo Antunes writes, on the first clinical meeting described on the novel:

“Obvious is the total absence of empathy, i.e., the doctor’s ability to understand everything that is transmitted to him, returning to the sick person the sign of this understanding [...] The doctor lacked warmth, compassion, and clarity of language; he abounded in authority and conducted the questioning in order to extract the answer that would only confirm the hypothesis previously built by him”¹¹.

Certainly there were good doctors, compassionate, helpful, and altruistic in the Russia of the 19th century, as there would be cold and impertinent practitioners, as the ones shown by Tolstoy, in the same time, in Portugal or in Brazil. In the classic of the Portuguese literature *The pupils of the Dean*, by Júlio Dinis (1839-1871), contemporary of Tolstoy, the notorious character João Semana is shown as an exemplary practitioner. His compassion, altruism, and generosity were recognized and admired by his countrymen:

“By official appointment, João Semana was also a surgeon of the poor, and he would always be by impulses of the heart, which did not allow him to witness any misfortune without sympathizing with those suffering and trying to relieve it by any means. Often, hidden in the hand extended to his patients, there went the alms, which he was clearly ashamed of giving, by that repugnance to ostentation of every kind, which was one of his character’s features”¹².

Júlio Dinis also reveals that João Semana, the village doctor, “was crazy for anecdotes, of which he was a living repository [...] A story told with time and grace is worth at least three prescriptions”¹⁷. The therapeutic value of humor is now recognized, even in cancer patients, as evidenced by the successful work of the “clown doctors” of the Red Nose Operation, in wards and pediatric hospitals.

João Semana has so many virtues that he may seem a utopian character. However, as João Lobo Antunes remembers, “it is comforting to know that João Semana did not represent an archetype idealized by Júlio Dinis, but he was modeled after a real doctor, namely Dr. Silveira, who had as a fundamental trait of character his profoundly human sensitivity”¹³.

Apparently, the most negative aspect of the life of João Semana was his reluctance, and even suspicion, to

keep up with the progress of medical science, which realistically depicts the attitude of many older physicians towards the latest innovations in medicine:

When Daniel quoted an author in vogue, or mentioned a remarkable discovery, or a new drug, João Semana used to shrug and smile:

“- It is all very beautiful, mate, – he used to say, with little contemplation toward the impatience of his young colleague – but for me it is worth nothing. Imagine if I, who barely have time to sleep, now, on top of everything else, had to read all this stuff”¹².

The writer Érico Veríssimo (1905-1975) also identifies the lack of time of the doctor Eugénio Fontes, main character of his work *Consider the lillies of the field* as one of the main obstacles to the update of his knowledge: “*The work was intense, the moments off were becoming more and more rare and short, and he barely had time to skim hastily through his medical books*”¹⁴.

In contrast to the indifference by Ilych’s doctor towards the patient’s anguish and concerns, we find, in *The pupils of the Dean*, the care of the young doctor in a visit to the Esquina family: “Daniel was miraculously patient in the attention given, and had a sublime seriousness and composure in his subsequent recommendations”¹². In Tolstoy’s book, however, the doctor character does not overlook a thorough and detailed physical examination, which included the traditional inspection, palpation, percussion, and auscultation, even when the fatal outcome of the disease was clear for all².

In the current practice of medicine, there is a tendency to prioritize complementary diagnostic exams, particularly imaging, rather than anamnesis and physical exams, despite the fact that these provide 70-80% of the necessary information to reach a diagnosis¹⁵. In the words of the Portuguese surgeon Jaime Celestino da Costa (1915-2010), this reality “is nothing more than a typical situation of a consumer society – a kind of supermarket of medicine”¹⁶, in which “the physician has more to do with exams than with patients: they undress themselves less and talk less with the doctor, who knows less about their illness, personality, and environment. There is less mutual knowledge”¹⁶. This point of view is shared by the doctor and writer José Pedro Lima-Reis:

“Formerly, the patients only brought with them the story of their pains, and on the table, where a device for measuring blood pressure, the stethoscope, and a reflex hammer rested side by side, they would put at most the hands that gave them form, driven by the conviction that we could help them overcome the pain. Today, they greet us with a hello, bringing with them collections of valuable letterheads with graphics neatly arranged and dressed in poorly written reports and dump them on the desk while waiting, silent, suspicious, and anxious, for us

to give them, on a silver platter, a bureaucratic diagnosis that does not need to trespass upon their intimacy¹⁷.

Another aspect emphasized by Tolstoy in *The death of Ivan Ilych* is the hypocrisy and the lie by everyone surrounding the patient, except for his servant Gerasim, the only one to talk to him honestly and compassionately:

“What tormented Ivan Ilych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and he only need keep quiet and undergo a treatment and then something very good would result. He however knew that do what they would nothing would come of it, only still more agonizing suffering and death. This deception tortured him – their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie².”

The resource of the white lie has been widespread by the doctors in their relationship with patients with serious, incurable, and fatal pathologies, as an attempt to minimize the suffering, as Érico Veríssimo portrays:

“Dr. Seixas scratched his beard, and standing over there beside the bed, looked at the old friend who was dying little by little. From time to time he grumbled in a rough voice: ‘It is nothing, Alzira, tomorrow you will be fine. It is nothing’. They had done everything they could. They had convoked the best doctors in the city in closed session. Now all that was left to them was to wait for death and make those last hours of life less painful to the moribund patient¹⁴.”

However, in the last years, we have seen a gradual change in this behavior, clearly paternalistic, into an attitude of sharing information with the patient, with sensitivity and good sense, about the diagnosis and prognosis of his/her illness.

It is also part of the human nature, especially in painful situations, the wish to be authentically comforted by those who provide care and by relatives and close friends. Sometimes such wish is hidden under a cloak of social conventions and the common attitude of “not acting weak”, which does not correspond to the true feeling of the patient, as we read in Tolstoy’s work:

“Apart from this lying, or because of it, what most tormented Ivan Ilych was that no one pitied him as he wished to be pitied. At certain moments after prolonged suffering he wished most of all (though he would have been ashamed to confess it) for someone to pity him as a sick child is pitied. He longed to be petted, kissed and comforted like a child. He knew he was an important employee, that he had a beard turning grey, and that therefore what he longed for was impossible, but still he longed for it².”

During his hospitalization in New York, José Rodrigues Miguéis met an exemplary nurse, Mrs. Abbey, who took care of him mercifully, after a post-transfusion reaction that caused him fever and intense shakes:

“Mrs. Abbey did not abandon me for a single moment. Inclined, she smiled at me, talked to me like one talks to a baby in the cradle, scrubbing me, snuggling me into a better position, telling me cheering words. How solicitous and tender this bossy and harsh woman was, and how hearty she was, after more than forty years of a hardening profession⁴.”

However, Dráuzio Varella recognizes that, as a patient, “the most humiliating thing is to obey with the docility of a lamb, because the disease has the talent of making us go backwards to the time when we used to surrender defenselessly to maternal care⁸.”

The compassion the healthcare professionals demonstrate can have an immediate therapeutic effect on patients. The travel journalist Ryszard Kapuscinski (1932-2007) in his book *The shadow of the Sun* reports an occasion he needed to see a doctor in Tanzania and the benefits of this meeting: “I broke through the crowd and asked for doctor Doyle. An exhausted and tired middle-aged man received me and was immediately friendly and warm. His presence, his smile and his friendliness were enough to produce in me a soothing effect¹⁸.” In this respect, Axel Munthe is decisive to affirm that “it is not possible to be a good doctor when you are not compassionate¹⁰.”

The reflection we presented through the reading of different literary works emphasizes the importance of the doctor’s virtues and character to the complex relationship between doctor and patient. That is why Edmund Pellegrino highlights the value of literature to the ethical and human education of doctors and everyone else that, in one way or another, deals with sick and suffering human beings.

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