

February, 29th: the commonplace, the interesting and the rare

29 de fevereiro: o banal, o interessante e o raro

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TO MY FELLOW PHYSICIANS AND COLLEAGUES,

Have you ever been on the other side of the equation? Have you felt firsthand how despairing it is to be the patient? Have you felt the tight embrace of uncertainty and wanted to escape? Have you been visited by the purest feeling of helplessness and couldn't deny it? Have you felt the loneliness, fear, and pain, even from minor interventions, that only you were capable of recognizing? If you haven't experienced this and have no idea what place I'm referring to, have you ever had a loved one on the other side of the equation? Have you felt the anguish of not knowing the next step? Have you relied on your technical knowledge to conceal your most carnal fears and apprehensions? Have you drowned in reality and realized how powerless we become in the face of certain situations life puts us through?

It is in based on this feeling and reflection that I write to you. For you, who have studied so much to be where you are, who have dreams and plans to soar higher, or for you who have already found professional fulfillment and wish only to maintain it: I hope you don't have to go through any of these situations in a turbulent manner, neither in

your practice nor in your finitude. But there are three words from our daily lives that we urgently need to talk about: the interesting, the commonplace, and the rare.

The “interesting”: an adjective commonly used to classify some medical cases.

I understand medical curiosity and how this term automatically triggers the infamous thirst for knowledge that inundates us and is instilled in us during our training so it does not get satiated. But I wonder how many colleagues and mentors remind us to look at that human being, that frighteningly similar being to us, without nullifying them and without reducing them to their ICD code? If you, like me, lack these reminders at some point, I hope to remind you of all the plurality and history that exists in your patient and that goes far beyond that pathology.

For those whose cases are considered and labeled “interesting”, we provide the broad advantage of generating extra interest even in the most seasoned caregivers. We get excited about the different and are driven by the thirst for knowledge. This thirst can come so overwhelmingly that we forget how uninteresting it must be for our patient to have that pathology. A life reduced, in seconds, to an ICD code.

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Conversely, there's the "commonplace": classification given to routine cases, without great mysteries, the famous "more of the same." A urinary focus sepsis without signs of antimicrobial resistance, a streptococcus bronchopneumonia with no alarm signs, an ischemic stroke without indications of reperfusion, a hemorrhagic stroke due to a hypertensive peak: the range of these cases is extensive, but the truth is that, if we stop to think about what's behind this commonplace, we can also come across a individuality that is not at all banal.

In the banality and recurrence, we forget about Joana who, despite an uncomplicated UTI, will experience very uncomfortable days during the treatment, or about Roberto who from then on will have a motor deficit in his right hemibody and about Maria who, despite having a full recovery after days of intensive care and months of rehabilitation, will face challenging and exhausting days and experience the end of life as she knew it. These people have in common the obligation that arises to face their pathology, which, just a few seconds ago, was unknown to them and now is established by the force of chance and/or destiny - call it what you will.

On the other hand, there's the "commonplace": classification given to routine cases, without great mysteries, the famous "more of the same." A urinary tract infection without complications, but with days of intense discomfort during treatment, from Joana, days carrying a motor deficit in her right half, from Roberto, days challenging and exhausting, and living the end of the life she led, from Maria. These people have in common the obligation that arises to face their pathology, which, a few seconds ago, was just an unknown to them, and now forces the emergence of a relationship established by the force of chance and/or destiny - call it what you will.

Walking to the other extreme of the commonplace, we come across the "rare": pathologies categorised based on a numerical classification relative to their low occurrence, in terms of the world population.

It is acceptable, extremely understandable, and even expected that, in the midst of a range

of so much knowledge, the rare is not within the technical domain of many of us. It seems that, with walking, we forget to talk about the importance of recognizing limitations and having transparent communication with our patient that we lack more information, but we are committed to seeking them in the best possible way. And I believe that this is one of the best conducts in these cases.

On the other hand, what should not happen is cling to this rare title in the hope of exempting ourselves from the obligation to at least provide support and comfort to that patient who comes to us for help. This attitude of ours, often motivated by the fear of the unknown, nullifies the center of our care and distances us from something that also competes with us: the mission to offer ways to alleviate suffering.

In the midst of medical education, with an avalanche of content, I understand how circumstantial the act of devaluing the footnotes of books or the extra information that presents itself as theoretical curiosities throughout teaching can be, and thus, information about rare pathologies ends up being neglected. However, I believe that the true mistake arises when, even in the face of the rare and the new, we retreat and take refuge in our fears and technical insecurities, forgetting the individual in front of us. They certainly did not want to be in this place of rarity. They and their families probably already live and will continue to go through struggles that we cannot dimension, just for being rare.

In the midst of such a plural society and even in the face of so many advances in medicine, this patient will face difficulties in dealing with that condition that will accompany their life, just for being born or becoming different among so many others. Often, they will hear that their case is "interesting" and that it arouses curiosity and motivation in some professionals; they will hear that there is nothing to be done because, at the same time it is interesting, it is rare and, there, or at that time, there is still no knowledge about it; they will hear these and many other things when, in fact, much

of what they would like to hear from their doctor is that they are not alone, that they can count on them for whatever comes, and that they will not lack support to resolve interurrences along the journey.

On this February 29, World Rare Disease Day, it is worth remembering that, currently, there are more than 10 million Brazilians who fall into the group of carriers of diagnoses considered rare, traversing different spectrums of history, severity, comorbidities, and trajectories.

This text comes as an ode to the valorization of the individuality and history of each of our patients. May you not be naive, as I once was, to think that my professional path would not intersect with that of some of the more than 10 million brazilians living with a rare pathology.

May our busy routine and our fears of daily contact with finitude not nullify trajectories, not demean pathologies, not reduce lives to adjectives and qualitative attributions, and above all, may we not forget our care goals. May we not forget the importance of recognizing technical limitations; may we not reduce our patients to commonplaces, to the interesting without identity or to the rarity out of reach. May we recognize our fears of finitude and not project them onto our care. May we remember the positive impact of a welcoming environment, the power of sincere eye contact, active listening, complicity, and understand that our primary function can be well executed when we make ourselves available to promote comfort.

May we, daily or whenever necessary, remember what truly is “being a doctor”.

