Mateus Menezes dos Santos

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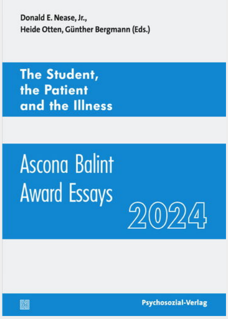

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All the Good Things, but Solitude

Mateus Menezes dos Santos

At the beginning of my second year of medical school, my desire for more opportunities for practical activities and the improvement of human skills led me to co-found an Academic League of Narrative Medicine, based on the principles of Rita Charon. The aim was clear: to establish a space for sincere dialog between students and patients. The conversation takes place at the university's pediatric infectious diseases clinic. Even before the patients were seen by the doctors, our meetings provided a unique opportunity to connect, far from the formality of a medical history. The professors in charge asked for the patients' permission beforehand, respecting their privacy and autonomy. In a private room, we students gave ourselves over to the art of empathetic listening, hoping to understand not only the clinical manifestations of diseases, but the human stories that surrounded them. After these conversations, we wrote chronicles or any other type of literary production about this meeting and then met as a group to discuss and share our experiences.

Longitudinal follow-up of children and adolescents who have contracted HIV through vertical transmission is very common in this clinic. One day, at one of these meetings organized by the Narrative Medicine Academic League, I was introduced to a mother who accompanied her son to all his appointments. I'll call them Eliza and Ruan, who was not in the room at the time of the conversation because only his mother agreed to take part. Eliza, a 55-year-old brown woman, wore a sad, worried expression, with a penetrating, frightened look that revealed the complexities of her journey as a caregiver for a son with HIV. Upon entering the room, the first observation that caught my attention was the fact that Eliza was wearing two N95 masks, even during a period of low COVID-19 contagion and with the boiling heat outside. This behavior clearly reveals her extreme concern not only for her own protection, but above all for the safety of her son.

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As students in the first few years, we have more openness and time for more subjective and in-depth conversations about the non-physiological aspects that permeate patients' lives. However, when I observe older doctors and professors, I realize that this possibility disappears over time as we progress through the course. Medical practice, often shaped by logistical issues and high demand in the single health system, especially in a country of continental dimensions like Brazil, becomes marked by quick consultations focused exclusively on the pathophysiology of the disease. The need to attend to a large volume of patients often limits the depth of interactions, directing the focus towards adjusting drug doses and requesting complementary tests to ensure disease control.

This transition throughout the course highlights the challenges faced in managing the gap between paying attention to the patient's subjectivity and ensuring the efficiency needed to meet the demands of the health system. It is a reflection on how, as we move forward, medical practice can move away from the richness of narratives to the detriment of the flow of care.

There in the room, alone with the patient, I felt enormously responsible. It seemed that the environment transcended the physical space of a few square meters. Although I was aware that my role did not involve prescribing medication or making clinical decisions, the feeling of responsibility was gigantic. It was clear to me that, at that moment, I wasn't just a medical student; to her, I represented the institution and, in a way, a medical professional, albeit one in training. The loneliness shared in that space resonated with the patient's vulnerability. I was alone for the first time with a mother, a guardian who was deeply concerned about the health of the human being she loved most in the world: her son. Even though it was a follow-up appointment, I realized the immense emotional charge that permeated that encounter. At that moment, I viscerally understood the magnitude of the trust that patients place in their doctors.

The patient's vulnerability in front of us, students and health professionals, is a fine thread that connects medicine to the most human essence of existence. In these initial moments, the mother exposed her greatest fears and worries, confiding not only her clinical concerns, but also the emotions echoing in her chest because of her son's medical condition. This experience highlighted the delicacy of this relationship of trust between doctor and patient, showing that, in addition to technical knowledge, the ability to be compassionate and receptive to vulnerabilities is fundamental to truly humanized medical practice. After all, being vulnerable in front of another person is one of the most intrinsically human expressions and, at the same time, one of the most precious gifts that a patient can offer to those who are attending to them.

At the start of the conversation I wanted to understand everything from the beginning, so I asked Eliza how it all began, how she found out she was HIV positive and what it was like to deal with this reality. She shared an account full of emotions and marked by a series of impactful events. Eliza admitted that she wasn't sure how she contracted the virus, but suspected that it came from a blood transfusion she had to have around the age of 30.

Eliza shared with me her journey as a Jehovah's Witness, a faith that forbids blood transfusions. This restriction initially seemed to be an explanation for not revealing the real means by which she contracted the HIV virus. At a delicate moment in our conversation, I decided to ask her if the people in her religious community were aware of her transfusion, and Eliza, in a quick and visibly embarrassed gesture, confirmed it with her head. Later, when discussing it with my teachers, I realized that Eliza had mixed this transfusion narrative with the possibility of betrayal on the part of her partner at the time. The precise details of the infection remained unclear to us. I understood that my role at the time was not to uncover the intimate details of Eliza's life, especially when this information would not alter her condition that had already been established for years.

The complexity of Eliza's situation vividly illustrated the intersection between religious beliefs, personal relationships and health. As a medical student, I was confronted with the importance of understanding and respecting the diversity of patients' life experiences, recognizing that individual choices and beliefs can significantly influence health care decisions. The ethical dilemma that Eliza faced in relation to her faith and her health condition highlighted the complexities that healthcare professionals can encounter when dealing with religious issues. In a diverse society, where religious beliefs shape people's perspectives and decisions, it is crucial to approach these issues with sensitivity and respect. Throughout our conversation, I realized that Eliza was looking not just for a listener, but for someone who understood the multiplicity of challenges she faced. Her willingness to share her story indicated not only the need for medical support, but also for understanding and acceptance. Although the specific details of the infection remained inconclusive, the experience with Eliza highlighted the importance of a humanized approach in medical practice.

So I decided to continue the conversation respecting her space and prioritizing the information she felt comfortable sharing with me.

The starting point of this story, in her memory, was confused with the emotional news of the birth of her son and the simultaneous and overwhelming diagnosis that she was HIV positive. The moment she received the diagnosis was described by Eliza as a dry run. There was no preparation or any kind of welcome. The flood of information, added to the presence of her baby in her arms, left her dazed and with no prospects of seeking help immediately for her own treatment, she confesses. Apart from the fact that at the time, the therapeutic arsenal and prognosis were different, much more limited, the lack of support at this crucial moment deeply marked her initial experience with HIV. Eliza's story became even more distressing when, three and a half years into Ruan's life, she discovered that her son was also HIV positive. This revelation, according to her, is *"the greatest burden she will carry for as long as she lives."*

An overwhelming sense of guilt accompanies her, even though she knows that the bond between mother and child transcends any form of individual responsibility. This emotional weight has become a constant burden in her journey as a mother and caregiver.

Eliza became emotional as she told me this. This simple but deeply symbolic gesture encapsulated the pain and vulnerability that permeated her story. The tears, along with all the stigma presented by society, were silent expressions of a heavy emotional burden, a testimony to the strength and fragility present in Eliza and Ruan's lives. During our conversation, amid the sweltering 30°C heat in the stuffy room, the only thing that touched Eliza's mask were her tears. At that moment, I kept myself from bursting into tears with her.

The impactful story of how Eliza was diagnosed with a disease that would forever shape the course of her life led me to reflect deeply on the role we play as health professionals. It became clear to me the absurd influence we have on patients' lives. The way we handle the disclosure of sensitive information can cause significant consequences, leaving deep and lasting marks on their life experiences. That's why it was such a privilege just to be able to listen to what this woman had to say. At this point in our conversation, Eliza looked at me with eyes filled with feelings of guilt and anger at herself, but also with a certain relief at being able to share this very honest feeling with someone. It was at that moment that, for the first time during my medical course, I was able to internalize more deeply the meaning of Carl Jung's famous quote: *"Know all the theories, master all the techniques, but when you touch a human soul, be just another human soul."*

This maxim transcended mere academic learning and came to life in Eliza's emotionally charged, stuffy room. By recognizing her vulnerability and allowing myself to be vulnerable as a listener, I discovered that our shared humanity is a powerful bridge in the doctor-patient relationship.

This episode reinforced the importance of cultivating empathy, recognizing the ethical responsibility we bear and understanding that behind every diagnosis there is a unique and delicate human story. I learned that medical practice goes beyond the application of technical knowledge; it's also about the art of caring, offering emotional support and recognizing the power of human connection in the healing journey.

The atmosphere in the room, now calmer, was charged with the words Eliza shared as her gaze wandered, fixed on a spot on the floor. Between sighs, she confessed to feeling like she was paying for sins, a weight she had carried from an early age as she witnessed her family face disagreements, drug use and financial difficulties. Eliza's anguish went beyond her own HIV status; it was a reflection on a vicious cycle of punishment that permeated her life and that of her loved ones. Eliza's narrative, permeated by a sense of fatality, brought back thoughts of the Buendía family from Gabriel García Márquez's *One Hundred Years of Solitude*. The writer concludes the work with the intriguing phrase, "because the strains condemned to a hundred years of solitude didn't have a second chance on earth". This association made me think about how many people and families, unfortunately, can feel trapped in a cycle of adversity that seems destined to last. I found myself thinking that, beyond magical realism, how many families, in fact, are sadly doomed? What is my role in the face of a tragedy that seems to have been announced and expected by so many families? But I'll tell you later why I disagree with Gabriel García Márquez.

* * *

In order to fulfill my role as a student and offer support to Eliza, I tried to better understand the dynamic between her and Ruan. Asking about their relationship, their aspirations, dreams and everyday aspects, Eliza revealed a close and affectionate bond with her son. She said that she is very close to Ruan and is actively involved in all aspects of his life. She said that Ruan has many friends, yet a shadow hangs over this apparent normality: none of his friends, and not all of his family, are aware of his HIV-positive status. Eliza's persistent fear is that disclosure will lead to some form of exclusion, even in contemporary times with wide access to information about HIV. In a moment of vulnerability, Eliza shared her deepest dream: she wants Ruan to achieve independence and follow his own path. However, even though she longs for him to walk life's journey alone, she confesses the difficulty in loosening this maternal bond. The sincere expression of her feelings reveals the complexity of motherhood in the face of adversity, suggesting a duality between the desire to allow her son autonomy and the fear of abandoning him after so many years of being an overprotective mother.

This revealing conversation highlights not only the practical challenges of Ruan's condition, but also the emotional struggles Eliza faces as a mother. In understanding the depth of these challenges, I realized the importance not only of the clinical aspect, but also of emotional support and building bridges to promote acceptance and inclusion, overcoming the stigma associated with HIV, often from the family itself.

But Ruan is not just a diagnosis: he is a boy immersed in the world of the arts. An active member of an artistic group, he has taken part in plays, attends drawing classes and has an affinity for dance and abstract drawings. Ruan is a young man from the world of ideas, as Plato would say. For Eliza, he represents not just a boy with a disease, but her most precious possession, coloring her world and giving a deep meaning to her existence. This portrait of Ruan highlights the richness of his personality and passions, making clear the importance of seeing the patient beyond medical conditions and valuing the uniqueness and potential of each individual.

I began to question her about emotional support over time, asking Eliza if she had ever considered seeking psychological assistance to deal with the complexity of her relationship and emotional dependence on Ruan. This turned out to be one of the most distressing moments of the conversation because, in my attempt to offer help, I noticed a possible momentary unease in Eliza. After I suggested therapy, she asked: "*No, why? Do I need it?*"

A question followed by a laugh shared between us. The lightness of Eliza's laughter dissipated some of the tension I felt at that moment. To soften the impact of the suggestion, I resorted to medical psychology concepts learned in my first year at university. I explained that it's not necessary for something to be wrong to seek the help of a psychologist. It can also be to maintain balance and preserve what is good. This preventative approach, focused on ongoing well-being, offered Eliza a new horizon. She expressed her willingness to see a psychologist as soon as possible, indicating an openness to considering the importance of mental health in her journey.

Another point I was instructed to ask about was the family support network, which is also very important for adherence and staying with long-term treatments such as HIV. With this in mind, I tried to understand Eliza and Ruan's relationship with his father and brother. When I asked her about her relationship with Ruan's father, Eliza was incisive: "I don't know and I don't want to know. It's just me and my son". This statement, although direct, showed Eliza's decision to preserve her own peace, erasing from her memory any trace of a past that could be painful. Her firm response conveyed the message that certain wounds did not need to be revisited, as they had already healed. During the conversation, Eliza shared an old photo, a relic from when her two children were babies. The image, now recently scribbled on by Ruan and his older brother, revealed an affectionate bond between the two. This expression of mutual affection was a source of pride for Eliza, noticeable even behind the masks that covered her smile. As she complimented them, highlighting the beauty of the babies in the photograph, Eliza leaned her head on her shoulder, proud of herself.

The feeling of having contributed to a moment of lightness and wonder in her journey was priceless. Eliza's proud gaze at the photograph reflected not only the love between her children, but also the resilience and strength that permeated her own journey as a mother. This episode highlighted the importance of recognizing and celebrating moments of joy and connection, even in the face of challenges. Amidst the masks that hid part of their expressions, the exchange of smiles and shared complicity reinforced the beauty present in simple moments of recognition and appreciation in Eliza's complex life. It really was an incredible feeling.

Here, I found myself reflecting on one of the greatest pillars of medicine, which appears in the Hippocratic Oath, which I will take in front of my family, teachers and colleagues when I finish my degree.

"To heal when possible; to relieve when necessary; to console always."

I feel that, even with a few years to go before I graduate, I have managed to put into practice this maxim that is at the heart of medical practice.

Towards the end of our conversation, Eliza shared one of the most difficult moments of her life: when Ruan, due to the virus, spent months with severe communication and locomotion difficulties. Even years after that episode, he still carries a sequel that limits the movement of one of his legs, which becomes a challenge for someone who loves to dance and communicate through his body. That's when Eliza, her eyes welling up with tears again, said that:

"All I asked God for was to see him normal. If I had a study, I'd like to cure him."

It was at that moment that I held back my tears as I thought of all the effort a mother makes to see her son well and to make his dreams come true. I remembered my own mother who, from a distance in another city, makes a huge effort to make me realize my dream of becoming a doctor one day. I thought that at that moment, it was up to me to play the role of the person who recognizes all the work and concern that Eliza has had for her son.

With empathy, I explained to Eliza about the accessible and quality treatments offered by the Brazilian health system, pointing out that both of them, with undetectable viral loads, enjoy a practically normal life in control of the virus. Asking permission, I held her hand, fixed my gaze on hers and shared that I can only imagine how challenging it must be to live her reality. I reinforced the message that she is not alone, emphasizing that her and Ruan's follow-up is a joint effort between patient and doctors. I emphasized that neither she nor the health professionals are solely responsible, but rather partners in this process, cultivating a doctor-patient relationship based on transparency and collaboration. This approach sought to provide comfort and reinforce the importance of mutual support in Eliza and Ruan's journey.

After this moment of intense emotion with Eliza, I felt the need to take a short break for both of us, to get her a glass of water. As I walked down the corridor towards the water fountain, I saw my colleague engaged in a conversation with one of the children who would probably be seen soon. He looked at me like he was in a moment of mutual learning, a deep connection between student and patient. When I returned to the room with the glass of water, I realized that Eliza was already a little more emotionally stable. However, she chose to leave the glass on the table without touching it, perhaps reluctant to remove the mask to drink. This simple, seemingly insignificant gesture reflected the complexity of the emotions and situation we were facing. The constant presence of the masks during the conversation, as well as being a precautionary measure in the midst of the pandemic, became a symbol of the barrier between us and the vulnerability shared by Eliza. The glass of water, offered as a gesture of care, remained untouched, highlighting the delicacy needed when dealing with the emotions exposed during our conversation.

This brief episode in the corridor, marked by the shared glances between my colleague with the child and me, reinforced the idea that, even in busy clinical environments, there is room to learn from every interaction. Each patient, whether a mother like Eliza or a child waiting for care, has valuable lessons to offer, challenging us to cultivate a deeper understanding of the human experience. The experience reinforced the importance not only of addressing patients' medical needs, but also of recognizing the emotional and social complexities that permeate the clinical environment. The symbolic gesture of the glass of water, even though it wasn't consumed, represented an attempt to nourish not only the body, but also the soul.

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The experience with Eliza not only enriched the more human dimension of my student-patient relationship, but also allowed me to deeply re-evaluate concepts previously ingrained in me. In particular, it questioned a notion that I perceive still haunts many junior doctors, myself included, when they enter medical school: the ego. This quest for absolute control and aversion to death, especially when facing non-curable situations, are aspects that I have noticed shape the medical imagination. The experience with Eliza served as a catalyst for rethinking and challenging these conceptions, offering a more compassionate and realistic perspective on the complexity inherent in medical practice.

I notice that, in addition to preferences for more clinical or surgical approaches, the choice of a medical specialty to follow is often permeated by the desire to achieve curative results. There is an inclination to consider that only the complete cure of a disease is a satisfactory and worthy outcome. Although the desire to fix and solve problems is a characteristic shared by those who choose medicine, I realize that the perspective in relation to this can directly impact the doctor-patient dynamic.

It is crucial to recognize that medicine covers a wide range of challenges and situations, often going beyond the ability to provide a definitive cure. Developing a more holistic understanding, valuing effective management, quality of life and emotional support, can enrich medical practice. This perspective not only reflects the complexity of clinical reality, but also strengthens the connection and understanding between doctor and patient, especially in cases where a complete cure may not be a viable possibility.

As I've said before, I believe that the doctor's primary function, in line with the principles of Hippocrates, is, above all, to improve the patient's quality of life, not just to seek a cure. I recognize that dealing with the feeling of powerlessness in the face of a disease that is still incurable or an irreversible process is challenging. However, I see this situation as a unique opportunity for students and doctors to talk to their own ego. It is essential that we understand that, although we are often charged by society to act as omnipotent, medicine is not an exact science and we cannot always offer definitive solutions. Facing this aspect of medical practice not only demands humility, but also opens up space to explore other dimensions of care, regardless of whether a complete cure is a possibility. This approach reinforces the essence of medicine as a profession centered on caring for the person and humanization, transcending the mere search for curative results.

After experiencing the neurology rotation in the fourth year of college, combined with experiences with patients like Eliza, facing diseases that were not curable but were susceptible to dignified longitudinal therapies, I decided to pursue the specialty of neurology. This journey has reinforced my commitment to providing continuous support and compassionate care, recognizing that even in the face of therapeutic limitations, it is possible to contribute to a meaningful and quality life for those facing neurological challenges.

Having taken part in various conversations with patients with HIV, Multiple Sclerosis and other diseases that, as yet, have no cure, has made me realize that a person or their family is not destined for a solitary existence, reflecting the sad fate of the Buendías in Gabriel García Márquez's novel. I understand that our role as health professionals goes beyond the search for a cure; it is, above all, to offer warmth and comfort so that our patients can live as well as possible, considering their circumstances. I recognize the limitations of medicine in the face of certain conditions, such as in the case of neurological patients, where a definitive cure can be an unattainable goal. However, this awareness does not diminish my satisfaction in providing hope and contributing to the quality of life of these individuals. Knowing that I won't be able to cure all neurological cases doesn't discourage me, as my focus is on the possibility of witnessing meaningful moments in their lives.

I believe that every hug, every piece of abstract art and every scribble on a photo are valuable expressions of affection and vitality. They are gestures that transcend physical limitations and reinforce the humanity of each patient. Maintaining this perspective is fundamental to preserving dignity and hope, not just during medical appointments, but throughout the course of these people's lives. Our mission, then, is to provide support, understanding and an environment that allows patients to embrace life with meaning, even in the face of adversity.

When I chose medicine, my central desire was to cultivate a deep doctor-patient relationship. However, when I started the course, I was confronted with the scarcity of opportunities to improve or even minimally practice this aspect. As we progressed through the course, this finding was corroborated, echoing the findings of the well-known study "The Devil is in the Third Year: A Longitudinal Study of Erosion of Empathy in Medical Study". The academic path often leads us to a gradual loss of empathy, prioritizing quick, objective care over a deeper connection with the patient. This contrast between the initial aspiration and the reality of the course led me to reflect on how we can reintegrate empathy more meaningfully into medical teaching and practice.

I believe that it is vitally important for the training of every doctor and health professional to have opportunities, throughout their academic journey, to conduct more subjective anamneses, centered on the patient and not just on the disease. The practice of writing about subjective experiences should be commonplace in medical courses, since the profession is, above all, centered on human relationships. This more global approach allows students to deepen their understanding of the patient as a unique being, involving not only physical symptoms, but also emotional, social and cultural aspects that impact on their health. Cultivating this skill from the early years of training not only nurtures empathy and understanding, but also contributes to building more complete professionals, capable of offering more comprehensive and humane care to patients.

As for human relations in medicine, I believe that developing soft skills is the most valuable skill to exercise and polish. This competence encompasses empathy, effective communication and an understanding of patients' emotional needs, essential elements for shaping a medical practice centered on human care. In contrast, even with significant advances in artificial intelligence, there are intrinsic aspects of the doctor-patient relationship that cannot be authentically replicated by machines.

The complexity of human emotions, the nuances of interpersonal interactions and the ability to interpret not only physical symptoms, but also emotional and social contexts, are elements that defy complete replacement by artificial intelligence. Empathy, in particular, is a profoundly human quality, based on experiences, understanding and emotional connections that transcend the capacity of machines. The trust, comfort and security that a patient gains from interacting with a human doctor are products of genuine communication and holistic understanding, crucial elements that highlight the irreplaceability of the human touch in medical practice.

After our conversation, Ruan expressed his desire to continue dancing and began a professional journey creating graphic designs on the computer. Eliza, for her part, decided to take up the hobby of practicing street dance. The end of the conversation was marked by a warm hug from Eliza, who expressed her gratitude for the opportunity to share thoughts she had never revealed before, not even to herself. From that day on, I realized that I had made the right choice for my life. Watching Ruan and Eliza's horizons change, unfolding into new aspirations and activities, reinforced the importance of medical care that transcends the limits of physiology. For me, medicine is not just about diagnosing and treating illnesses, but about promoting quality of life and the emotional well-being of patients.

The positive impact on Ruan and Eliza's choices highlighted how narrative medicine can be a powerful tool for reconnecting patients with themselves and their passions, contributing to a more holistic approach to health. Eliza's heartfelt hug and expression of gratitude were a vivid testimony to the importance of listening to, understanding and sharing patients' stories. This experience solidified my conviction that choosing narrative medicine as an integral part of my medical journey was indeed the right choice. By providing a space for personal narratives to emerge, we can positively influence not only patients' physical condition, but also their emotional journey and the way they perceive life itself.

Finally, I'm curious to know which roles Ruan most enjoyed playing, or which artists were his favorites. I hope the next hundred years of his and his mother's lives are filled with all good things, except solitude.

The Author

Mateus Menezes dos Santos, Brazil
Federal University of São Paulo, Paulista School of Medicine