

BEYOND DIAGNOSIS – THE THERAPEUTIC ALLIANCE AS A TOOL FOR CARE

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INTRODUCTION

There is an extensive body of literature on the doctor–patient relationship, consistently highlighting over the years the importance of deepening and strengthening not only technical-scientific knowledge but also relational skills to create a better therapeutic alliance. Evidence shows that a patient’s compliance, emotional experience of the illness, and, at times, even the therapeutic outcome depends on the quality of the relationship the healthcare professional establishes with the patient. Too often, however, academic training focuses on solid theoretical–scientific knowledge without giving sufficient importance to emotional competencies.

Care is not just medication but comprehensive availability and listening

Hungarian psychoanalyst Michael Balint, in his book *“Doctor, Patient, and Illness”*, emphasized how the doctor is, in fact, a “drug” capable of causing side effects, much like the active ingredients in chemical preparations¹. Balint asserted, “The most frequently used drug in medicine is the doctor, yet an adequate pharmacology of this drug does not yet exist”¹. Already in the 1960s, Balint began developing an awareness of medicine’s neglect of the person as a whole. Doctors tended to prioritize nosographic elements in the patient’s account, sidelining the individual’s story, as it was difficult to objectify with the available clinical tools².

Balint’s insights were pioneering: the relationship and listening become central. Increased emotional tension can trigger bodily sensations that exacerbate the patient’s physical condition. Balint’s work addresses doctors, nurses and healthcare professionals more broadly. Active listening requires time and dedication but forms the foundation for building a solid therapeutic alliance. When patients feel understood, they are more likely to trust the doctor, accept treatment, and process their illness more positively. As shown in the movie *Patch Adams*: “When you treat a disease, you may win or lose. When you treat a person, you always win”.

Doctor–patient relationship in rare diseases

When someone is diagnosed with a disease, they quickly find themselves in a vulnerable situation and expect, upon visiting the hospital, to encounter competent doctors capable of addressing not only the disease but also their personal suffering. For instance, in oncology, numerous studies explore how the doctor–patient relationship can reduce distress in people with the condition³. Unfortunately, the same cannot be said for the field of rare diseases, where more attention is still needed. In common diseases, the asymmetry in the doctor–patient relationship, with the doctor representing the holder of knowledge, is an advantage, as it, combined with relational skills, fosters trust, enhances adherence to therapy and encourages active participation in the care process⁴. It is well known that patients who feel less informed may be reluctant to express their concerns or discuss therapeutic alternatives, leading to poor communication, which can, in turn, compromise treatment efficacy.

In rare disease contexts, the dynamic changes because the doctor is no longer the absolute expert, as many rare conditions are not well understood even by professionals. Thus, the importance of the relationship and how the doctor–patient bond is co-constructed becomes even more central. Trust in the doctor cannot be based on presumed knowledge but rather on the doctor’s ability to acknowledge the emotions of both the patient and caregivers. Acknowledging emotions means recognizing, validating, and managing the emotions that patients and their families may experience when facing complex diagnoses and often challenging care paths⁵. This aspect is particularly crucial when the disease is characterized by uncertainties, where the complexity of the clinical picture requires greater attunement to the patient’s emotional experience⁶. Establishing trust in such contexts is also based on the doctor’s ability to manage both verbal and non-verbal communication with empathy and attention.

Doctor–patient communication in rare diseases

A longer, well-structured initial consultation can significantly reduce the number of follow-up visits caused by misunderstandings. When patients receive clear and understandable answers to their questions, they feel more confident in their treatment decisions. A study conducted by researchers at Harvard University demonstrated that effective communication reduces unscheduled visits by 30%⁷.

Specifically, communicating the diagnosis of a rare disease is a crucial moment. The way it is handled can shape the patient’s narrative of the disease. It is known that rare diseases often require complex investigations, and the diagnosis is reached only after a long process of excluding other conditions. Often, these diseases manifest in childhood, leaving parents with dramatic questions about their children’s futures.

In such a delicate context, it is evident that the communication style adopted by the doctor must differ from that used for common conditions. A study by Marvel et al⁸ showed that the average time a patient speaks without being interrupted is about 23 seconds. In the case of rare diseases, this approach is inadequate. The doctor must take the necessary time to put the patient and their caregivers at ease, ensuring an appropriate setting and providing space for clarification.

Contrary to common belief, investing time in good communication does not simply mean prolonging visits. While an effective conversation may indeed initially increase consultation time, there is significant long-term optimization. If patients and caregivers feel adequately supported, they are less likely to return with unresolved questions in the future.

A crucial step is focusing on caregivers’ concerns, centering the communication on emotions and coping strategies⁸. Additionally, doctors should avoid rushed communications or phrases that might induce nocebo effects, such as “We hope the treatment works” or “Can I be honest?”. These expressions can trigger negative thoughts in patients⁵.

Emotional competencies in doctor–caregiver communication

Emotional competencies are essential for doctors, especially in managing rare diseases. A study by Liberman et al⁸ showed that naming an expressed emotion reduces amygdala activity, providing a sense of relief to the patient. This suggests that doctors should help patients and caregivers name their emo-

tions, acting as an “auxiliary self”. Phrases, such as “You seem worried” or “How do you feel about this news?” can be tools to help verbalize internal experiences. A doctor who perceives and validates caregivers’ emotions creates a safe base to operate, a crucial aspect when navigating the uncertain territory of rare diseases. A study found that emotional support from professionals can significantly reduce the psychological and physical burden on caregivers, improving their psychological well-being and the quality of care they provide⁹.

One of the keys to effective doctor–patient communication is avoiding dissonance between verbal and non-verbal communication. As Paul Ekman demonstrated, facial expressions, tone of voice, and body language can convey more than words¹⁰. A doctor who verbalizes empathy but maintains a rigid posture or avoids eye contact may send a contradictory message, undermining efforts to build trust.

Practical advice for doctors

- 1. Allocate enough time:** Plan longer appointments for complex diagnoses and create a setting that puts the patient and caregivers at ease.
- 2. Practice active listening:** Avoid interrupting the patient, especially during the initial presentation of clinical history. Listening without interruption can strengthen the relationship and provide crucial information.
- 3. Acknowledge and name emotions:** Help patients identify their emotions, reducing anxiety and improving their treatment experience.
- 4. Attend to non-verbal communication:** Maintain eye contact and adopt an open and welcoming posture to avoid incongruities between verbal and non-verbal language.
- 5. Be transparent yet empathetic:** Balance honesty with sensitivity, avoiding uncertain or negative expressions that could induce nocebo effects.
- 6. Offer continuous support:** Keep an open and accessible communication channel, ensuring that patients and their caregivers feel supported throughout the treatment journey.

CONCLUSIONS

The doctor–patient relationship is central to any therapeutic pathway, but it becomes even more crucial in the context of rare diseases, where diagnostic and therapeutic uncertainties demand greater attention to emotions and communication. Investing in training doctors in emotional and relational competencies not only improves the quality of care but also enhances therapeutic outcomes by strengthening the patient’s perception of the doctor’s leadership.

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