

The change of paradigm in perinatal sciences: the role of Narrative Medicine and Medical Humanities

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The last ten years, the next ten years in Neonatology

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Abstract

Many healthcare and academic institutions are now recognizing Narrative Medicine and Medical Humanities as a means to developing holistic, individualized patient care, even though they are applied in professional development settings and less overtly employed with patient populations. In this article, we provide a general description of the impact of Narrative Medicine and Medical Humanities on perinatal care and educational programs. Above all, the need is stressed for an approach to these issues with innovative mental categories capable of overcoming pre-constructed and dogmatically-constructed patterns. The combination of medical science with humanistic science and the centrality of the value of narration are the cornerstones of a holistic perinatal culture.

Keywords

Narrative Medicine, Medical Humanities, narration, individualized medicine, individualized perinatology, holistic care.

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Introduction

In the medical world, every scientific practice is under the threat of refutation which gives rise to its evolutional dimensions. Therefore, change is one of the basic principles of the methodological and organizational healthcare sciences. However, change is difficult as it gives rise to the questioning of certainties and habits, activating feelings and actions that are often antagonistic, which is why everything becomes exasperatingly long. At times, perhaps even unwittingly, the resistance to change is directly proportional to the marginal value of a certain action or deed. And the less important it is, the harder it is to eradicate. This occurs in the case of individuals and organizations, meaning the place where people work together with different roles in order to achieve the same explicit goal.

Perinatal examples

Take, for example, the case of a high-risk pregnancy department or a neonatal intensive care unit (NICU), where the care of the pregnancy and the newborn, modulated by the delicate aspects of the tasks assigned, should naturally provide opportunities for being open and flexible. Nevertheless, among all roles involved, the work of the physician is that which is most inspired by tradition and tends to be reproduced and passed down without any appreciable changes, since each transformative mechanism requires a consolidated corpus of knowledge and expertise to refer to. It is not advisable for gynecologists or neonatologists to stray too far from the consolidated procedures or the methods established by protocols and guidelines. Even though these may not be infallible, they do offer comfort in the “certainty” of procedures, which are at times complex and difficult – ranging from diagnosis to treatment – and which in their clinical practice consist of four fragile aspects. Firstly, they crystallize decisions so that they are not always able to adhere to the specific case; secondly, by acting as guidelines, they tend to take the responsibility away from the professional; thirdly, they cloud over the physician-patient relationship, responding to needs

that are often unrelated to the latter, but for the most part ascribable to defensive medicine. Last but not least, their high rate of “old age” which means that, after the elapsing of the time necessary for them to be adopted and disseminated, they already seem to be outdated by the advances made in the technical/scientific fields. In short, they have a brief “half-life”. So decisions are made on the basis of indications that are out of context with the situations of each individual patient and no heed is given to the change even when solicited by innovative references based on evident scientific findings. The question that arises at this point is the following: is it possible to overcome the aforementioned criticalities, adopting alternative procedures and methods capable of moving outside the consolidated practices (based on standardized and collectivized medical lack of accountability), and accepting the challenge of *bedside medicine*? The latter is a faded memory, overwhelmed by technological, defensive, mechanistic medicine, just like the undergraduate courses at the faculties of medicine. Moreover, the social awareness of disease and the “rules for living it” always win over individual awareness: disease has been collectivized and the “medical protocol” is its most organic, inflexible and strictest expression. At this stage, could a dialectic responsibility come into play in which, without prejudice to the reciprocal roles between physician and patients, a healthcare agreement could be developed (not entrusted to pre-established protocols or collective procedures often based on professional qualms and potentially avoidable risk profiles)? New healthcare scenarios could open up for the individual sensitivities of patients, by doing away with the practice of stratifying patients according to the classification criteria of “sick organs and systems” with all the serious limits they impose, and replacing it with individualized medicine which is implemented in a substantial manner. The change in perinatal care passes through freedom with respect to the biological paradigm, that is, through a way of acting and thinking no longer of a Cartesian nature, but rather, with a holistic vision of the patient. Reference to successful good practice, which is fostered and updated at the same time as the experiences become significant and extensible, could support and justify the healthcare, as the result of personalized decisions guaranteeing respect for the patient’s individuality and, in the case of newborns, for the dignity of his/her parents. This might merely seem a difference in terminology, of little import, however it is not like that.

Narrative Medicine and Medical Humanities

Narrative Medicine and Medical Humanities enter into this scenario, as a fresh perspective through which to better clinical practice, learn about and teach the study of perinatal care, as real protagonists of the change towards a new form of medicine [1]. It is necessary to get to know Narrative Medicine and Medical Humanities without any preconceived ideas and to grant them the same dignity as other clinical and educational skills of medicine, considering them instruments of professional emancipation for the whole realm of medicine, including perinatal medicine. Why do we have to use the word “emancipation”? The term “emancipation”, from the Latin *emancipatio*, now means to obtain freedom by side-stepping hierarchies and dominant behavior. Why to emancipate perinatal medicine? Neonatal medicine consists of scientific knowledge, data, technologies, logic, reasoning, troubleshooting, and decision-making. But it involves relations not only with a body but also with a psyche, not only with biological systems, but also with emotions and feelings. Neonatology must free itself from the subordination to the biological paradigm, that is, from considering the patient as merely the sum of circulatory, respiratory symptoms, a sort of brain-lung-heart preparation, and not a human being with all the desires and emotions, hopes and fears of humanity: in our specific discipline, we are dealing with a newborn in an extremely significant moment in his life. Moreover, like all medical sciences, neonatology must also ask the following question: has the art of “individualized medicine” been lost [2]? But does Narrative Medicine hold the answer to the current crisis in the physician-patient relationship? Does storytelling really work? What evidence, if any, supports the positive impact of Narrative Medicine on patient care, clinical practice? There is a growing body of literature, though mostly qualitative, suggesting that Narrative Medicine does affect patient care. Narrative Medicine is described as a model for empathy, reflection, profession, and trust in the patient-physician relationship, which requires careful listening to the patient’s story. In a certain sense, Narrative Medicine proposes a similarly fresh way of looking at patients. Instead of approaching each patient in the same manner and eliciting the information required to fill in the blanks, Narrative Medicine would have doctors take their lead from what patients want to tell them and the way in which

they want to tell it [3, 4]. We are trying to assess how Narrative Medicine can be used in perinatal care for making appropriate, personalized and shared decisions together with the parents, above all if ethically sensitive. The crushing effects of disease, especially when serious, create an emotional state of anxiety and distress in the parents. This psycho-emotional fragility is amplified and interacts with the process of therapeutic alliance, and with that, the sharing of critical decision-making [5]. Moreover, narrating and above all, re-narrating, makes it possible to customize healthcare, with all decisions and practices being tailored to fit the individual patient [6]. This method is in contrast with the current trend which stratifies and considers patients according to their gestational age and weight, and in part, also their prognostic probabilities, etc. We have demonstrated how Narrative Medicine could help parents to explore more effective strategies for coping and making informed choices for their infants in the NICU. In treatment, it antagonizes the validation of patients depending on their pathologies, encourages a holistic approach and integrates the analysis activity for making good decisions about difficult cases in the NICU [7].

In training, Narrative Medicine can develop students’ thinking skills, nurture their creativity, and prepare them for the complexities of clinical work (by perfecting empathy, and encouraging thought and reflection, they remain stamped in the mind). In research it strengthens the dimension of translational research. Narrative Medicine allows professionals from all fields of medical sciences to understand the patient’s total experience of illness, and meet his/her needs in an empathetic environment, helping to spread holistic knowledge of a multitude of complex clinical conditions. We have also investigated the role of Narrative Medicine in women who become pregnant after a liver transplant by using their narrations of this very special clinical and existential condition. In particular, we describe our study with narration and listening to the stories of three women expecting their first child after a liver transplant, by analyzing the structure and role of narration in the context of relationships between patients and caregivers. The women narrated this experience in three phases: transplantation, pregnancy and delivery, and post-partum. They described all phases of pregnancy as stressful but satisfying, whereas the fact of becoming a mother was perceived as a victory both as a woman and as a transplant patient. Our results suggest that Narrative Medicine represents

a significant professional tool for caring for transplant patients during pregnancy [8].

The Wonder of Birth

A cultural contribution to the field of Medical Humanities is a book of poems in which I've tried to express the emotional dimension of various aspects of my profession as a neonatologist. This book, entitled *The Wonder of Birth*, has been adopted for training programs in neonatal medicine [9]. The reading of poems to the students immediately allows them to enter in contact with the empathetic world of the issue I'm addressing at that time. A Harvard professor commented the book as follows, "This collection of poetry opens a window to the beauty and sorrow of the neonatal world. These poems offer a significant contribution to the best of literature in the Medical Humanities. They educate and delight the moral imagination. They should be read and savored not only by physicians, other pediatric caregivers, and medical students, but also by parents, family members, and anyone who seeks to comprehend difficult truths through poetry" [10].

Conclusion

Perinatal care has to deal with increasingly more complex situations, for which it must provide research capable of producing knowledge, the translational effectiveness of which is decided not merely *via* scientific production, but also from the impact it has on the health of the population. Finally, a translational action of Narrative Medicine in perinatal care provides answers to professional complexities, thus producing culture regarding the sensitive issues faced daily for promoting the health of mothers and newborns, creating perinatal thinking boxes, containers to be filled with the multiplicities of our knowledge. However if the centre of our interest should be focusing on the person or a sum of organs, the patient or the disease, and if the use of "serial medicine" and generalized technology should not have any limits – and which ones – in

order not to further compromise the physician's relationship with the patient, then we have not yet solved the paradigm. Physicians who lock the care experience into an often excessively "silent" form of resorting to instrumental investigations and laboratory tests are most likely suffering from the "Ulysses syndrome", due to the fact that just like the Homeric hero, they wander aimlessly amidst the islands of the Mediterranean before finally reaching Ithaca. But this is another story... and another long narration.

Declaration of interest

The Author certifies that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

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