Narrative Based Medicine and Neonatology: an interpretative approach

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Abstract

The use of Evidence Based Medicine (EBM) has progressively lead doctors to focus their practice on the disease and not on the patient anymore. They consider a sick body or a sick part rather than a sick person. Such an attitude results in a progressive process of alienation or “unauthentic experience”. On the contrary the Medical Humanities represents a strong reaction to this state of things, and for Medicine a chance to embrace again its humanistic “vocation”.

Narrative Based Medicine (NBM) places at the center of the clinical practice the communicative and relational dimension.

This study deepen the application of NBM to the scope of neonatal care.

As a result of our work, we have identified in the NBM applied to the neonatal area a fundamental characteristic, the Neonatal Triangle (doctors, patient, parents), and a triple functionality (diagnostic, ethical and educational) placed in three different ideal chronological moments (before, during and after). We explore the close connection between these functions and the clinical work and how the NBM model, through these same functions, enhance the opportunity of care and relationship.

The main assumption is obviously the Doctors ability to build a shared narrative relation with the Parents of the little Patients, that in the technical terms of the Narrative Based Medicine is called co-construction of the illness history.

We can remark that with the NBM we understand (the narrative frame), build (the therapeutic alliance) and share (decisions).

Keywords

Narrative Medicine, Clinical Ethics, patient education, communication.

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Introduction

In this work we try to outline an interpretative approach to the relation between Narrative Based Medicine (NBM) and the pediatric and neonatal areas, with their own peculiarity in comparison with other medical specialties, thanks to their relational and clinic characteristics.

Narrative Medicine and Neonatology

The Evidence Based Medicine (EBM) model is widely well known and used in contemporary medicine, with enormous and unquestionable merit, that lead to the huge development of the therapeutic potentialities of contemporary medicine. But each development, each evolution cannot be achieved without risks or eventually it doesn’t come without a cost to pay. In fact the use of EBM, detached from an in-depth analysis on the themes of relationship and communication, has progressively lead doctors to centre their practice on the disease and not on the patient anymore. They consider a sick body or a sick part rather than a sick person. Such an attitude results in a progressive process of alienation or “unauthentic experience”. This process has not only relational irrefutable consequences, but most of all lead sometimes to an inadequacy of the diagnosis process, merely reduced to an instrumental analysis. The Medical Humanities movement, by now wide and variegate, has represented a strong reaction to this state of things, and for Medicine a chance to embrace again its humanistic “vocation”.

NBM, within the sphere of Medical Humanities, has focused its attention on the communication and relational dimension. To apply NBM to the pediatric and neonatal area we must consider one of their distinguishing features. In fact, in the pediatric and neonatal area the communicative and relational process is never linear. By linear communication we hereby mean such a communication that happens between two groups of actors (doctors and patients) along imaginary parallel lines (Fig. 1).

In the neonatal area (similar considerations can be made for the whole pediatric) the relational dynamic is of a triangular type. In fact the doctors carry out their activity of curing the baby, while a significant part of their communicative and relational work is aimed towards the parents of the patient. In short, this two activities constantly interlace themselves conceiving what we can call the “Neonatal Triangle” (doctors, patient, parents) (Fig. 2).

Therefore the Neonatal Triangle is not an “additional” relation, of which we can do without, but the authentic narrative frame through which comes the clinic work. A peculiar relational dimension is then build between doctors and parents, the latter in the double role of stakeholders and caregivers. The relationship between doctors and parents must then become a

These elements as a whole enter in the narrative construction of meaning according to which the patient and the people related to him/her read and express themselves in the evolution of the illness. Similar narrative processes happen in parallel within the équipe environment, where different stories and different perspectives related to the community of the doctors interlace. We witness a continuous process that becomes warp of the therapeutic relation but where different elements, that at first we would have never considered central to the cure, come into play: esthetic, moral and existential factors. As a consequence, every clinical act has to assume this narrative frame.

NBM is not a simply approach that leads to equations or procedures, or at least they are not the central point of the proposal. It has to became a “mental dress”, a “forma mentis”, that comes along with the clinic practice.

NBM places at the center of the clinical practice the communicative and relational dimension. To apply NBM to the pediatric and neonatal area we must consider one of their distinguishing features. In fact, in the pediatric and neonatal area the communicative and relational process is never linear. By linear communication we hereby mean such a communication that happens between two groups of actors (doctors and patients) along imaginary parallel lines (Fig. 1).

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Figure 1. Linear communication.
“therapeutic alliance” that relies on the concept of “cooperative action”.

At this point we can proceed deeper in the analysis of the functions held by the NBM in the neonatal area. On the basis of what has been already outlined by the NBM, but relying also on the support given by other Medical Humanities disciplines, in particular Clinical Ethics and Patient Education, we can identify a tripartite structure of the NMB functions in Neonatology. Such structure not only outlines, as we will see, three different functions but it also characterizes three ideal chronological moments of the clinical relation (before, during, after). The main assumption is obviously the doctors ability to build a shared narrative relation with the parents of the little patients, that in the technical terms of the NBM is called co-construction of the illness history.

First function: diagnostic

The first function (chronologically before) is the one that in a more classical way seems to belong to the NBM, but that with just a little more difficulty can be applied also to the neonatal area: the diagnostic function. The narrative approach, while sharing the Illness with patients and parents, allows to retrieve important diagnostic elements: information, observational inputs, signs, insight. All these elements can be retrieved during the diagnostic process mainly by using the narrative approach. In fact, the narrative approach allows to acquire them avoiding the risk of loosing them, overwhelmed by the instrumental data. This knowledge, brought by means of the narration, is obviously not a scientific one. Often it represents information seen by the parents as of minor importance or even trivial, but doctors could turn it into clinically relevant information. The NBM gives the chance to all of this to happen.

Based on our direct experience, this function, classical in the NBM, is still effective when applied to the neonatal area. It enhances not only the anamnestic approach but also the enduring relation with the parents inside the NICU, where the stay can be very long. The mother presence near the incubator, if possible, offers also the extraordinary possibility of exploiting their constant attention towards the baby, in order to have a direct observation over a very long period of time.

Second function: ethics

The second function of NBM (during) is the ethics one. Contributions of Bioethics and Clinical Ethics showed that Medicine acts in a plural moral world, where the ethical-assiological horizons of the different moral actors are often far away one from each other. In this way the animated ethical-clinical dialectic found in the field of the neonatal intensive care shows how challenging and sometimes burdening can be taking part in these conflicts. Sometimes the different moral principles are so distant that a decision by common consent is almost impossible to take.

The NBM allows to understand each other. The co-construction of the Illness history creates a strong bond, that at least allows to acknowledgment of one another’s moral position legitimacy. Therefore it lays down the basis for an “ethical negotiation” aimed to agree upon a possible ethical choice, where each moral actor gives up something in order to achieve a possible decision. This scenario can be realized only in the presence of a very strong sharing experience and a solid narrative alliance. It’s advisable to outline that this NMB function can work not only in the relationship between doctors and parents but also, in a much more specific way, in the symmetric relationship between the doctors themselves, in the narrative frame of the team. Even in this frame, often, we need to find a mutual understanding based on the reciprocal acknowledgement of legitimacy of each others ethical position. The shared narration of a cure history and professional relationships makes it possible.

Third function: educational

Last but not least, comes the third function, the educational one, chronologically placed in the after, at the end of the therapeutic process. The NBM allows in fact to build up a solid cure path after the hospital stay. Several studies have underlined how a good communication is essential to the establishment of an appropriate “compliance” with the patient or, in our case, with the parents. There is, usually, a low adhesion to the therapeutic treatment in subjects that experienced an unsatisfying communicative relation. This aspect is further enhanced at the end of the stay in hospital, when the baby leaves the hospital and

Figure 2. Neonatal Triangle.
goes finally back home. In this situation we can detect the highest rate of resistance to the treatment or even withdrawal, recommendations regarding life style or particular attentions can also be neglected. All of them are signs of an incomplete and unbuilt narrative alliance.

Contributions coming from Patient Education studies show that, from a therapeutic point of view, the period following the hospital stay can be extremely important, especially for all the chronic pathologies, characterized by a long course that need particular lifestyle, treatments and attentions. From this point of view the Caregivers of a premature or syndromic baby have to provide him/her not only with a lifestyle and treatments essential to the growth and cure of the baby, but also with the expertise in the prompt identification of critical events. From this point of view the NBM, strengthening the therapeutic alliance can play a crucial role in the possibility to build up educative paths aimed to improve the ability to take and give care.

Conclusion

As a result of our work, we have identified in the NBM applied to the neonatal area a fundamental characteristic, the Neonatal Triangle, and a triple functionality (diagnostic, ethical and educational) placed in three different ideal chronological moments (before, during and after). Further contributions and studies aimed to get deeper in the analysis of what we have in this paper only outlined are recommended.

In conclusion, we can remark that with the NBM we understand (the narrative frame), build (the therapeutic alliance) and share (decisions).

Declaration of interest

No conflicts of interest exist.

References