

# Love and the Value of Life in Health Care: A Narrative Medicine Case Study in Medical Education

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## ABSTRACT

This case study is an example of narrative medicine applied to promote self-awareness and develop humanistic contents in medical education. The impact and the human appeal of the narrative lie in the maturity and empathy shown by a student when reporting his dramatic experience during the care given to a newborn (with Patau syndrome and multiple malformations diagnosed at birth) and to her mother. The narrative approach helped the student to be successful in bringing out the meaning behind the story and to position himself from the mother's and newborn's perspective. The student's introspection changed a seemingly scary interaction into a positive experience, overcoming many initial negative emotions, such as fear, disappointment, horror, hopelessness, and insecurity in the face of the unexpected. It is uplifting how the student was strengthened by the power of maternal love to the point of overcoming any remaining feelings of eugenics or rejection. Other important lessons emerging from the case study were the art of listening and the value of silence. This narrative shows how the development of narrative competence can help establish a good physician-patient relationship, because the physician or the student with such competence usually confirms the patient's value and demonstrates concern for them, focusing on what they say and allowing genuine contact to be established, which is necessary for effective therapeutic alliance. The student's interpretations of the meaning of love and value of life inspired him on his reframing process of a medical practice marked by vicarious suffering.

## CASE REPORT

It should have been a normal day—an interview with a patient at the hospital in my third-year neonatology elective module. However, before entering the ward, I was anxious because my teachers had alerted me that the case was complex and the patient's general condition was critical. Besides, I knew the first contact is always decisive in establishing a good physician-patient relationship. Inside the ward, I (JAMP) met

a shy and sad woman, Mrs F. I introduced myself and soon realized that she was very friendly and open to dialogue. She was 19 years old, married, and unemployed. She reported she had abandoned her studies after discovering she was pregnant. Now, she had just given birth to her first child, G.

Baby G was a 14-day-old newborn with an intrauterine diagnosis of holoprosencephaly (characterized by incomplete midline cleavage of the prosencephalon and associated with neurologic impairment and dysmorphism of the brain and face<sup>1</sup>), with multiple malformations diagnosed at birth. The diagnostic hypothesis was Patau syndrome, or trisomy 13. The prognosis of this syndrome is extremely poor: 55% to 65% of affected patients die in the first week after birth and 70% to 90% by the sixth month; only 5% to 10% survive beyond the first year of life.<sup>2-7</sup>

During the history taking, Mrs F told me very sadly that she wanted very much to have a child and that the baby had generated high expectations in her family. So I asked whether her expectations had been met. She answered, "No, they were not met. I had expectations of a beautiful and healthy baby, but my first contact was with an ugly and sick child."

I still had not looked upon baby G, and this statement by Mrs F reinforced my fears. When I turned my head, I saw a baby with multiple malformations on her face and an orogastric tube. She seemed to be looking at me too.

Frightened by the physical aspect of baby G (presenting multiple malformations in the face), I returned to the history taking with her mother. Then I asked Mrs F, "How was your first contact with your daughter soon after the birth?" She replied that she had been terrified because G was an ugly baby, contrary to all expectations that she had during pregnancy. Moreover, she reported that she did not have the courage to hold the baby in her arms during the first day of life. At that moment I put myself in the place of that mother, and then I realized that I would have had a similar reaction in this situation because I also would have had aspirations of having a beautiful and healthy child.

Continuing the history taking, I asked her about her relationship with baby G after the initial contact, and whether

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she knew about the severity of her daughter's illness. She said, "After my initial shock, I realized that G needed affection, more affection than a healthy child. She is my daughter and my responsibility. I love her." Again I stopped to reflect on that and asked myself: "Would I be able to have a similar reaction?"

When I finished the history taking, I started the physical examination. I soon confirmed that the child had skull alterations and multiple malformations in the face and other parts of the body. I then started the examination by palpating very carefully because I felt the child was very weak. I was afraid, all the while thinking she was really an ugly child. At this moment, a teacher came into the ward and said, "JAMP, do not be afraid to examine the child! She is not made of glass!" I waited for him to turn his back on us and completed the examination.

Moments later, when I reviewed the interview, I noticed that I had remained in silence during almost the entire physical examination. This silence was the expression of my ignorance about the child's disease and the fact that I was afraid to show my feelings about the situation. I went home thinking and asking myself: "How could I have had such a despicable reaction to the child? What about the mother? How could she have thought her daughter was ugly and terrifying?"

When I returned to the ward three days later, I was more confident because I had studied a lot about Patau syndrome. However, some doubts remained and that distressed me: "If the prognosis is poor and life expectancy is so low, why provide this baby with so much care, which will only postpone an inexorable process? Am I unconsciously wishing that child's death?"

Before I began the physical examination, Mrs F asked me whether she could feed baby G and I answered, "Yes." I was curious because I had never seen a child with cleft lip and palate being fed with a bottle. I was surprised. Despite all the difficulties and apparent fragility, the child struggled to suck and swallow milk that was given with a bottle inserted directly into the existing slot in her upper lip. Contrary to what I expected, it was one of the most beautiful scenes I had ever seen in medicine. Again I stopped to ponder: "Would that be the miracle of life? How could I have desired the death of this beautiful child?"

Now I understand how the mother went from an initial phase of fear and denial to a stage of acceptance, marked by warmth, love, and affection for baby G. At this moment, I noticed that I had the answer to one of my questions—that is, whether I was able to go through all those stages that Mrs F had gone through, with similar reactions.

After this second meeting, I found out that Mrs F was undergoing psychological treatment because she was suffering from depression. At the next two meetings, I tried to find out about the possible causes for her depression. Mrs F told me that she was anxious about baby G's prognosis, and the medical staff would be capable of giving her more accurate information only when the karyotype analysis was ready (which would take another three weeks). Furthermore, she was unhappy with the hospital environment because the other

mothers were asking questions about baby G's disease and she was afraid about whether she was prepared to devote the rest of her life exclusively to the care of her daughter.

In one of our meetings, an important fact reported by Mrs F was that she had the unconditional support of her entire family, especially baby G's father, who was very fond of his daughter and wife.

My encounters with Mrs F had been marked by several moments of silence, primarily because of my lack of knowledge about how to handle the situation. So I sought out the psychologist who gave support to the students. She suggested that we have a conversation with Mrs F away from other people in a quiet and private place. The psychologist was the one who conducted the interview and this was marked by long moments of silence interspersed with short dialogues and crying spells. Moreover, she performed the interview passively, by allowing Mrs F to reflect on her thoughts and sentences.

After this consultation I felt relieved because the moments of silence that marked my conversations with Mrs F were actually the best way to handle the situation, which was allowing the mother to express her feelings.

Two days later, when I came back to talk to Mrs F, she and baby G had received medical permission to stay home for a week. I remained with several questions and only one certainty: my encounter with baby G and her mother was essential for my professional growth, and even more for my personal growth, because I had the opportunity to learn a little more about the meaning of the word *life*.

## DISCUSSION

This case report is an example of how narrative medicine can be applied to promote self-awareness and develop humanistic content in medical education. JAMP wrote this narrative during the neonatology elective module in his third year at medical school. The reflective writing allowed the student's introspection to change a seemingly scary interaction into a positive experience, overcoming many negative initial emotions, such as fear, disappointment, horror, hopelessness, and insecurity in the face of the unexpected. This transformative experience led to increased sensitivity and empathy of the student to the conditions and feelings of the mother and the baby, promoting a humanizing effect especially in relation to baby G, who was seen initially as merely a passive and automatic object and was pathologized. The narrative approach helped the student to be successful in uncovering the meanings behind the story and to position himself from the perspective of the mother and the newborn. It is uplifting how JAMP was strengthened by the power of maternal love to the point of overcoming any remaining eugenics or rejection feelings. His interpretations of the meaning of love and value of life inspired him on his reframing process of a medical practice marked by vicarious suffering.

The other themes underlying this case report were the art of listening and the value of silence. This is especially evident after the interview conducted by the psychologist. Physicians and patients usually assume that they have a mutual

understanding although often there is a tension between the patients' and physicians' perspectives of illness. The patients have their worldviews in the context of their personal, family, and life experiences. Commonly, physicians impose their views on patients. When the patients' concerns, ideas, and expectations are perceived, this improves satisfaction, adherence, and disease outcomes. The patient's perspective may be elicited via active listening skills and asking open-ended questions that encourage them to share their feelings.<sup>8</sup> Aiming to avoid selective and partial listening, an inner silence and a pause in the conversation are often required to break the automatism and to not overrun the patient with the physician's worldview.<sup>9</sup> Whereas the common sense assumption is that silence is just the absence of speech, silence is a complex phenomenon.<sup>10</sup> Nonmessage is also a message, the silence tells us something, and this implies there is not an absolute distinction between language and silence. There is a dynamic connection and continuum between them.<sup>10,12</sup> Silence is just as important as speaking because it provides an opportunity to reflect on the value of what is happening, producing the emergence of meanings.<sup>10-12</sup> Moreover, under certain conditions, possible meanings can be found only in silence. In this case report, silence had a therapeutic function and might have been the most appropriate response.

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Medical schools have the mission to strengthen humanization principles in health care practices; the main objective of these principles is to instill professional attitudes, skills, and values in future physicians, aiming at developing a holistic approach to patient care and building new generations of clinicians who are capable of meeting the challenges of medical practice.<sup>13-19</sup> This mission contrasts with the biomedical model still considered to be the predominant model in medical education, which focuses on biological parameters, and in which the physician's task is limited to the diagnosis of the disease and its treatment, ignoring human aspects of illness on behalf of biomedical sciences.<sup>13,14,20,21</sup> This scenario has worsened with the great technologic advances in medicine in the past decades, as it promoted loss of individuality and increased the distance in the physician-patient relationship.<sup>15,20,22-24</sup> In recent years, changes in morbidity and mortality profiles and the large amounts of new information have led to profound reflections on medical education. Nowadays, the illness is seen not only as a pathophysiologic event but also as a personal, emotional, relational, and ontological consequence of lack of health.<sup>18,19,22,25</sup> In this way, medical schools that are traditionally influenced by the biomedical model are improving their curricula by integrating medical humanities (seen as the intersection of medicine and humanistic disciplines such as philosophy, anthropology, history, theology, and arts), integrating the psychological and social dimensions with the biological dimension. In the biopsychosocial model,

the physician must understand not only the disease but also the patient, and the physician-patient relationship gains therapeutic significance.<sup>13,14,16,17,20,22,23</sup> This model seeks a holistic view, in which psychological and social aspects are intrinsically linked to the biological ones, which requires the use of pedagogic strategies that promote the development and the preservation of the students' self-awareness and empathy.<sup>15,18,19,23,24,26</sup>

At the Medical and Nursing Schools of Escola Superior de Ciências da Saúde (ESCS), Brasília, Federal District, Brazil, the students complete six-year and four-year courses, respectively, that integrate basic science and clinical teaching from the first year of the medical and the nursing school. There is no separation into preclinical and clinical components. Students take part in small-group problem-solving sessions and clinical practical activities in the Universal Health System of the Federal District from primary to tertiary care in a Systems Based Curriculum.<sup>27</sup> The students are gradually exposed to practice and contact with many stressors, such as dealing with a congenitally deformed baby girl and a young mother, as in this case report. These stressors, which cause repulsion and suffering in most people, are sources for introspection and reflection in order to have a less traumatic and more productive habituation process.<sup>28</sup> To achieve this goal, many resources have been used in our medical school, such as psychodrama,<sup>29</sup> Balint groups,<sup>30</sup> and arts-related activities.<sup>31,32</sup> Before contact with real-world situations, simulation training is carried out.<sup>33</sup> For many of the difficulties faced by our students in these scenarios, our school also has the support of psychologist professors (as narrated in this case report) and a psychoeducational advice service.

Among the major arts-related activities, the narrative medicine exercise plays an important role in enhancing empathy and clinical skills in the curriculum of the Medical School of ESCS. In a broader view, literature plays a critical role in sensitizing writers and readers. We make sense of the world and things that happen to us by constructing narratives to explain and to interpret events, both to ourselves and to other people.<sup>19,34</sup> In this sense, Rita Charon, MD, coined the term *narrative medicine* to describe medicine practiced with narrative skills and marked by an understanding of complex narrative situations among physicians, patients, colleagues, and the public.<sup>18,19,22</sup> Physicians are in a privileged position to become writers. Conceptually, medicine and storytelling go together because multiple narrative possibilities are generated by illness and healing: autobiographic descriptions of the patients, the physicians' reports, and the course of the illness, exposing associations between language, subjects, and time.<sup>20,22,26,35-37</sup> Physicians are in constant contact with the frailty and strength of life. They have the opportunity to observe an extremely fragile side of life: parents with malformed children, children with cancer, infertile women, young individuals deformed by burns, and all types of human misfortune. On the other hand, they can witness the miracle of life when a child is born, during the successful resuscitation of a patient with cardiac arrest, and in the happiness of surviving a malignant disease. These

situations allow a unique learning opportunity concerning the nature of human relationships.<sup>20,37</sup>

There is strong academic support regarding the importance of the study of narratives in medical education.<sup>21,24,26,38-41</sup> Every patient has a personal story and wishes more than the treatment of his/her symptoms.<sup>20,25,42</sup> The education focused only on the interpretation of increasingly complex diagnostic examinations and the prescription of drugs does not meet the desires of patients, who want to understand and give meaning to their own expectations at levels beyond the biological one.<sup>13,16,19,24,25</sup>

In narrative medicine, the student is invited to produce a narrative marked by the interaction with illness and healing from a self-reflective practice, in an integrated way, providing to the students not only a descriptive skill but also the ability to perceive the humanity of patients, individuals who have a history, values, knowledge, and feelings, and who developed their illness in the context of their lives.<sup>18,19,21,22,24-26,37,43</sup> This ability to understand the meaning and significance of stories, considering the patients' perspectives and desires, becomes a key component of clinical practice in narrative medicine. It is an invitation to the development of empathic skills, such as insight, listening, analysis, and interpretation of subjective experiences with humanization and professionalism.<sup>18,19,21,22,24-26,37,41</sup> This practice opens up new possibilities for clinical experiences and relationships that bring the benefit of pursuing a more humanistic medical approach, by which it strengthens the therapeutic relationship.<sup>18,22,24-26,37,42-44</sup>

Narratives provide access to knowledge not just about patients and their conditions but also about the students themselves, as narratives allow the free expression of students' subjectivity. This expression can speed up the maturing process of their personal and professional identities, providing not only a better understanding of the patient and his/her illness but also a chance to dive into the students' experiences, generating greater confidence, the development of values and virtues, and the capacity to recognize and prevent errors.<sup>18,21,24-26,38</sup> On the other hand, if the student has an impersonal or cold demeanor, without qualified listening skills, his/her narrative ends up reflecting emotional impoverishment or directly expressing natural difficulties. Then, the teacher is more likely to perceive this trivialization and the disappearance of the human dimension by reading the student's narratives.<sup>44</sup>

## CONCLUSION

Narrative medicine is a model of humanized and effective medical practice, consistent with a formation that aims to enrich medical practice, favoring the exercise of qualified and humanized medicine. This case report shows how narrative medicine can be applied to promote self-awareness and develop humanistic content in medical education. The impact and the human appeal of the narrative lie in the maturity and empathy shown by a student when reporting his dramatic experience during the care given to Mrs F and baby G, in which JAMP successfully reached the depth of his being and positioned himself from the perspective of the mother and the newborn. Reflective writing allowed the student's

introspection to change a seemingly scary interaction into a positive experience. This successful case illustrates how important narrative medicine is for building new generations of clinicians who are capable of meeting the challenges of medical practice and pursuing a more humanistic medical approach. ❖

## Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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### Something More

Medicine alone takes as its province the whole man. ... With man in all the complexity of his body and mind from his conception to his last breath; and its concern extends increasingly beyond his sicknesses, to the conditions which make it possible for him to lead a healthy and a happy life. We speak of medicine as both a science and an art, and surely these two aspects are complementary. Science is analytic, ... art is intuitive, and sees in the whole something more than can be explained as the sum of its parts.

— Russell Brain, DM, FRCP, FRS, 1st Baron Brain 1895-1966, British neurologist