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Once Upon a Time. . . At The Tenth SOBRAMFA International and Academic Meeting - S. Paulo - Brazil

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Abstract

In Brazil, medical practice and the predominant medical education model are based on specialization. Methodologies such as patient-centered medicine and narrative medicine are either unknown or not applied in a systematic way. In order to draw students' and doctors' attention to these approaches during the TENTH SOBRAMFA INTERNATIONAL AND ACADEMIC MEETING, an informal event called "Narrative Session" was presented. The meeting's attendees were asked to send patients' stories in advance. The stories submitted were selected and classified according to medical sociologist Arthur Frank's description of three structures or skeletons of narrative – restitution stories, chaos stories, and quest stories. A special ambiance – a setting evoking The Tales of 1001 Nights– was created for the presentation. The narratives performed showed the narratives' healing and didactic potential for patients, doctors, and students.

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1. Stories in Medicine: searching for humanistic roots

Medicine is a profession that involves relationship between at least two individuals – physician and patient. Telling stories is a natural tendency deep-rooted in the core of human beings. Ill people also need to tell the story of their illnesses and the stories they think are related to their sufferings. In the old days, resources for diagnosis and therapy were much more limited, and listening to patients with empathy was the only tool applicable in some medical situations. Even in the modern era, when physicians have much greater technical knowledge, patients don't trust doctors who do not pay attention to their stories and consider their feelings. The patient-doctor relationship always was, and will be, the foundation of a good medical practice. The core of good medicine remains the same: awareness of a powerful and important bond between doctor and patient. Although the science of medicine now is vastly different from that in previous centuries, the connection between physician and patient is still based on the same principles of human nature. (1)

Nowadays, medicine is a world dominated by technological advances, in which priority is given to increasing reductiveness and specialization. Physicians know a great deal about every segment of the human body and mind; sometimes this preoccupation with the technical details of disease hampers the perception of the wholeness represented by the human being. Although the dominant medical model offers innumerable advantages for patients' care, something is missing. Patients and doctors aren't totally satisfied, perhaps because the fragmentation of the human being and the highlighting of technology have obscured the importance of a good patient-doctor relationship. (2)

Most current clinical activity is driven by the principles of evidence-based medicine. “Using this model, clinicians try to turn patients’ stories into clinical questions and then search for the best relevant evidence to get the right answer.” (3) Scientific evidence comes from randomized trials or cohort studies applied to populations according to mathematical models. The results obtained through these studies concern populations or groups of patients similar to those studied.

The challenge is the real and unique patient doctors have in front of them. All the texts written about physiopathology of diabetes mellitus are similar, but each individual who is experiencing the illness has a distinctive and irreplaceable story. It is also necessary for the physicians to be able to read and understand this text. Good medical practice requires a proper application of evidence-based medicine concepts to the individual context. It is useless to know the best management for a particular disease, if the patient does not take the medicines, because he or she is depressed or has a system of belief that impedes his or her adherence to the treatment.

The development of a good patient-doctor relationship is a crucial resource for translating generalized scientific evidence into the particular human situation. This use of the doctor-patient relationship is a cornerstone of family medicine, which routinely filters science through the lived experience of the patient. Patient-centered medicine and narrative medicine are usual methodologies for this purpose.

For improving the clinical method, different approaches of patient-doctor communication has been developed during the last decades. “Clinical method is an interpretative act which draws on narrative skills to integrate the overlapping stories told by patients, clinicians, and test results.” (4) In 1957, the physician, Michael Balint,

introduced the term “person-centered medicine” to refer to a clinical method that has psychotherapeutic connotations and is based on physician self-awareness. Patient-centered medicine became one of the most important pillars of the specialty of family medicine. Ian McWhinney, a founding father of family medicine, and his disciples have guided family physicians around the world in developing a methodology composed of six basic components, whose function is to strengthen and expand the patient-doctor relationship. (5) Practicing patient-centered medicine implies the primacy of listening to the patient.

When patients meet doctors or healthcare professionals who are willing to listen to them with empathy, they easily start telling stories – stories of their lives and sufferings, and stories related to their beliefs and life philosophy. The point now is what to do and how to deal with patients’ stories, even those that apparently have nothing to do with their diseases’ clinical stories.

2. Turning stories into narratives: a healing methodology

During the last decades, a new methodology – narrative medicine, a term created by Rita Charon (6), or narrative-based medicine, as British authors prefer – has been constructed as a possible response to the above question. Such a methodology involves the use of patients’ stories as a therapeutic tool. Focusing on patient narratives, bringing them to light and considering alternative narratives, allows patients to participate in their own healing process. (7) Patients’ narratives are more than mere stories in which the facts are told one after another in a chronological and finite sequence. They also go beyond the familiar clinical stories physicians construct about their patients. In patient narratives, the feelings behind the events are often more important than the concrete events themselves.

Narratives always involve interpretation. (8) The same story can be told and listened to in many different ways. More and more health professionals agree about the healing power of the word and recommend that their patients express, through talking or writing in prose or poetry, feelings they have difficulty dealing with. (9) As patients have the chance to freely express their feelings, anxieties, fears, beliefs and the sad events of their life's story, they frequently leave the office better than they arrived. To fully appreciate patient stories, we need to have the narrative skills to apprehend various components of these chronicles, such as structure, plot, voice, and character. As the medical sociologist Arthur W. Frank asserts, "The subtle semantics of narrative suggest a structure underpinning the story, and narrative analysis locates structures that storytellers rely on but are not fully aware of". (10)

In order to practice patient-centered medicine in a proper manner, it is important to understand the human being in all dimensions – physical, emotional, cultural, social and spiritual. With the introduction of humanities departments in various medical schools around the world, medical students and doctors have been advised to improve their knowledge about inner human nature by studying the humanities – literature, philosophy and arts - and incorporating insights derived from these disciplines into their practice. Students and young doctors can, for example, be introduced to difficult themes related to life, death, pain, illness and suffering through literary, philosophical and cinematic works. In such a way, they can be prepared to deal with these difficult subjects before having to face them in real life.

But one may also enhance this literary apprenticeship in the daily practice of medicine by considering real patients' stories and how these stories intersect with and

relate to their own personal and professional stories. Such stories represent a source of teaching about the subtleties of human emotion and behavior. As listening to patient narratives stimulates reflection, doctors and students begin to learn about aspects of their patients' lives and their relationships with their patients that previously were inaccessible or only barely sensed. By sharing these narratives with colleagues and promoting reflection and debate, the knowledge obtained is expanded. It is possible that one patient's narrative will enlighten a similar situation lived by other patients. So, in many aspects, narratives acquire an important didactic role in the practice and teaching of medicine.

3. Stories in Medical Education: the SOBRAMFA experience

The Brazilian Society of Family Medicine (SOBRAMFA) is an academic society whose aim is to promote family medicine and to establish the proper basis and scientific methodology for family practice. SOBRAMFA runs a residency and other training programs for students and doctors, specialists and generalists. The principles of evidence-based medicine are applied to improve the technical performance of its trainees. Beyond that, humanistic resources are used to teach the philosophy and practice of the art of medicine.

Once upon a time, at the Tenth Annual SOBRAMFA International and Academic Meeting, a group of students and doctors from many Brazilian states assembled to tell and listen to stories in the opening session dedicated to narratives. Each year, this meeting opens with a session focusing on narrative, and this year was no exception. These sessions are an informal encounter whose aim is to draw the attention of students and doctors to the importance of narrative in medical practice. According to the

predominant Brazilian medical education model, students study a great deal about diseases, organs and systems and very little about the human beings they will have in front of them throughout their careers. Although the teaching of humanities has been introduced in some Brazilian medical schools, its study suffers a dichotomy in that it is rarely directly connected with clinical practice. And narrative methodology is practically unknown. Students and young doctors long for a way to acquire tools that allow them to deal appropriately with human beings in their completeness. We believe the narrative session is a stimulus to think about all these issues.

This year, in the “call for narratives”, the attendees at the meeting were asked to send in advance patients’ stories that had brought great learning or insights for them or showed a palliative or curative effect for patients. Eleven of all narratives submitted were selected, in a qualitative way, for having fulfilled the conditions required in the call. The final presenters were asked to either read or recite these stories from memory.

Every year, a special ambiance is prepared for the narrative presentations, a setting inspired by a literary or cinematic work in which a storyteller played a significant role. In 2006, a setting evoking *The Tales of 1001 Nights* was created, and, on the “stage,” a SOBRAMFA second year trainee incarnated the character Scheherazade to conduct the session. After an explanation about narrative methodology by one of the event coordinators, SOBRAMFA’s Scheherazade opened the performance with the following story:

“Once upon a time a cruel sultan lived in a very, very distant realm. Because he had been betrayed by one of his wives, he became convinced that no woman was trustworthy. So, he made a promise to himself – he would never be betrayed again. In order to keep his promise, each time he took a new wife, he killed her on their wedding night. That was the way he found to avoid potential betrayal. Then, he chose Scheherazade, a princess of a neighboring kingdom, as his wife.”

Scheherazade had a gift – she knew how to tell stories in a way that made people fascinated. And each night the sultan kept her alive because he wanted to listen to a new wonderful story or to know the end of an earlier one. The stories told by Scheherazade originated The Tales of 1001 Nights.”

Then, the trainee explained that the choice of scenario was based on the following idea: knowing how to tell stories made the difference between life and death for Scheherazade. Similarly, in medicine, a profession that deals with human relations, knowing how to listen to and tell stories also can make the difference between death and life, disease and health, sadness and joy, suffering and transcendence.

Next, Scheherazade called on the participants in a predetermined sequence resulting from a previous categorization of their stories. The stories selected were classified according to Frank’s description of three structures or skeletons of narratives – restitution stories, chaos stories and quest stories. This classification was chosen because it has shown a great applicability to the daily practice of family medicine, especially in didactic palliative care settings. The following text, in which Frank’s insights about narrative was presented and explicated, was intermingled between the narrative presentations. (11)

Frank considers the patient to be a storyteller and the telling and receiving of the story as a gift relation, not a professional exchange. Storytelling is a recursive elaboration of the relationship between those sharing the story. There is a storytelling relation, in which someone can be speaking, but stories are told with – not only to – listeners who are part of the story. Stories are not material to be analyzed, but relationships to be entered. Each one of the three narratives’ skeletons described by Frank may become a pathway, a way of entering relationships. The structures described by the author are not rigid, but

represent a predominant pattern in the story. Depending on the manner in which the story is told and listened to, one can change from one pattern to another in its development.

Stories allow for the emergence of meaning in relation to illness and suffering; and the identification of the meaning by itself can exert a therapeutic effect on the patient. And this is true not only for the patients, but for physicians and medical students as well. When these professionals tell their stories, they are not merely looking for clinical advice. Like their patients, they too are looking for meaning, a clarification of their relationship with patients; and they are trying to learn how to suffer with patients.

4. Illness and doctoring through stories: restitution, chaos and quest narratives

In the narrative session, restitution stories were the first presented. These stories concern a person who gets sick, receives care from a doctor or health professional, and, through treatment, his/her wellbeing is restored. During the evolution to healing, what was wrong becomes corrected, and the doctor sometimes emerges as a hero. In such narratives, the physician or health professional is the main actor or actress in the scene and the disease is an enemy to be conquered. The monological discourse of the ill person is to recount that the treatment was efficient and effective or at least is expected to lead to healing. Restitution stories are appropriate for those patients with great likelihood of cure and are often related when illness is in an initial phase. They are well illustrated by Frank as follows: "Restitution stories represent the triumphant optimism of medical science." Doctors who are searching for successful clinical outcome and efficiency are easily attracted to this kind of narrative. In these stories, the subjectivity of the patient, which should be an ill person's most significant characteristic, vanishes almost entirely in the healthcare professional's recounting of the patient's story. In our country, as a result of

fragmented training, most of doctors are not used to paying attention to patients' stories, and when eventually, they do so by some inner impulse, they tend to want to tell restitution stories. Certainly, ill people's family and friends also want to hear these kinds of narratives, where health and well-being are restored.

Here are some fragments of restitution stories:

I learned with my patients, for instance, that many of them keep inside seeds of healing and if someone put water on these seeds, they sprout in surprising ways.

She gazed at a point and tears poured from her eyes. Then, I did something I thought is forbidden for a doctor – I closed the door, took her hands, sat down on her bed and asked her to tell me what was disturbing her. And for the first time, as I could apprehend, she spoke about her feelings, suffering, and emotional pain to a doctor... No doctor had discussed her treatment and although she thought she could be healed, she had also many doubts. After the clarification, she got calmer. There was a nun accompanying another patient in a nearby bed. When I said good-bye, she whispered to me: 'You are young, but never forget to sit by the side of your patients when they are in need'. That patient adhered and responded very well to the treatment and went back home in a different mood, with her courage plucked up.

Unfortunately, it is not unusual for health professionals to face circumstances of profound suffering and pain that have no possibility of remission or solution. Incurable diseases or the imminent death of a family member are situations that generate chaos stories, in which there is no apparent order in the sequence of events. Chaos stories are characterized by incomplete sentences, periods of silence and questions with no answers. Sometimes, doctors become emotionally immobilized in these situations with the subsequent reaction to run away or to ignore the conditions that make them feel impotent. Chaos stories are the ones we don't want to hear, because students in medical school are not taught to deal with feelings of powerlessness, and doctors usually seek solutions, even in situations where there is no solution, except listening. It is difficult to teach medical students to have that attitude, because they are taught to give answers all the

time, as if they lived in a multiple choice world. But life is not a multiple choice test.

When deeply ill people do not realize they have a story to tell, or do not meet a healthcare professional interested in their story, they will keep themselves isolated in their suffering. Thus, they cannot find a way to transcend their pain in order to achieve a more balanced emotional state. Without help, they probably will stay indefinitely immersed in their chaos story.

Here is a chaos story:

It is finished – That’s what I thought when her sister-in-law called to say she had been taken to the hospital by her husband, because she had started exhibiting periods of sleepiness alternating with periods of extreme agitation. Before that, she had nausea and vomiting and could not tolerate food. A CT showed brain metastases.

Suddenly, the eight month period I cared for AGS came to my mind. AGS was a thin and determined woman who came several times to our palliative care clinic.

She arrived for the first consultation ignoring her actual situation. She had an advanced biliary tract cancer with no possibility of surgery, and was very icteric, but she thought she had pancreatitis. When she left with her daughter, her husband stayed a little more asking for help in telling her the truth. The surgeon had suggested the diagnosis of advanced cancer, but it seemed she had not understood. Her husband believed that AGS should know the truth in order to prepare herself for death. She had always been a religious woman and took part in a spiritualist group. Certainly she could benefit from the support of the members of her faith group.

I was already prepared to broach the subject in the next visit to the office when I learned that AGS’s son had become drunk and crudely blurted out the reality of her situation to her. My patient’s reaction was unexpected – she simply ignored her son’s words and persisted in pretending to have pancreatitis.

Her attitude never changed. During the visits to the office it was always the same. When I tried to broach topics like her disease, beliefs or questions about death, life, suffering or solitude, she quickly changed the subject. I persistently showed a disposition to listen to her, and explained she could tell me anything. But it was in vain. At home, AGS also ignored her illness. She did the housework as a healthy person, worked as hard as possible to be a good patient and tried to eat as much she could. She accepted, without discussion, all steps I recommended to improve her life quality and took the medicines, always asserting she would be well.

When, finally, I knew about her death two days after the hospital admission, I realized I lived a story that had finished abruptly, without a satisfactory conclusion. Then, I was overcome by a feeling of emptiness...

Perhaps we can consider chaos stories as stories without an end, or, at least, a satisfactory end. But such chaos stories can be transformed into quest stories for both patient and physician. Depending on the interaction between doctor and patient, the sufferings and diseases become a teaching opportunity. Although healing and restitution are impossible or improbable, the illness can be lived as a quest, in which the learning points and deep transcendence are the final result of the journey that doctor and patient can share. As Frank states, “quest stories are being told when the teller claims new qualities of self,” and illness is no longer chaos when meaning or even value emerges. By listening, one allows the storyteller to find meaning for his or her suffering and to awaken unimaginable inner resources. Quest stories provide lessons of life in which the patient evolves into a higher level of consciousness and becomes a person who learns and teaches through the illness. Quest stories show the patients’ and doctors’ trajectory from chaos and uneasiness to an attitude of gratitude in which there is no need for fantasy or pretense. During their journey, patients become grateful, not for the disease, but for the life that includes being an ill person. Patients who live a quest story accept their life in an unconditional way.

Here are fragments of quest stories told by students in palliative care settings:

I attended some terminal patients for about six months and interacted with their family members. With them I lived the anguish of dealing with terminal illness and learned to value the importance of relieving the pain and physical symptoms in order to secure the best life quality possible. I understood that I had to stimulate everyone involved in terminal patient care to live intensely each moment. Being willing to approach emotional and spiritual questions can also provide a great help.

In palliative care, it's essential to provide support to patients' relatives. Certainly, they are having difficulty facing the profound suffering of living with a terminally ill patient. I learned to try to transmit that each act of affection, even the simplest, makes a great difference for patients and family members.

5. A poem from the heart: A spontaneous epilogue

At last, all the narratives had been presented. The meeting was nearing its conclusion, when a fourth year medical student, moved by the presentations, explained that in medical school she had no opportunity to talk about her feelings and no training to deal with incurable patients. To cope with her emotions, she wrote poems, practicing intuitively the concept of reflective writing (12), in order to heal herself and, then, improve her practice. Her offer to present some of her poems was immediately accepted. The student took out her guitar and, with a beautiful and deep voice, chanted three poems. Here is one of them:

Medicina Contemporânea

*“Doutor, por que razão me dói o peito?
Será que adoceceu meu coração?
Exausto estou, mas sem ter nada feito
Sou forte, nunca tive disfunção.”*

*Estresse altera tudo e eu suspeito
Que, contido na reclamação,
Exista um ser humano insatisfeito
Sintoma mais comum da depressão.”*

*“Aqui está a droga que receito
Retorne em caso de inquietação
Mantenha a porta aberta e passe bem.”*

*“Prozac eu já tomei, não surte efeito
O mal de que padeço é a emoção
E ser poeta é a dor que me sustém.”*

Contemporary Medicine

*“Doctor, why my chest is aching?
Could it be my heart doesn't work well?”*

*I'm exhausted without have done anything
I'm strong; I've never got a disability*

*The stress affects everything and I suspect
The stress affects everything and I suspect
My complain actually is hidden something else
An unsatisfied human being may be
The best common symptom in depression”*

*“Here is the medicine I recommend
Come back If you have some anxiety
Keep the door opened
And be well.”*

*“Prozac I've already taken and it didn't work
I think the illness I suffer has something to do with emotion
And to be a poet is really the pain that sustains me.”*

By Rebeca Jesumary Gonçalves – fourth Year Medical Student – UNESP- Brazil.

6. Conclusion

Once upon a time, in an almost unknown country, a group of doctors and medical students assembled to share stories. During the final discussion, they became conscious that chaos stories were very, very common in medical practice, for both patients and their physicians. Then, they realized that chaos stories could be transformed into quest stories and started searching for ways for help them in such a task. They concluded that, by listening emphatically to their patients and sharing stories they had lived together, they could acquire greater intimacy with profound aspects of life and death, an essential point in a profession that deals with the subtleties of human nature as medicine and, particularly, in the specialty of family medicine, which follows patients across a lifetime.

(13)

In the end, these doctors and students found that, beyond listening and sharing stories, the arts in general – literature, poetry, and music – could also be valuable tools to help them in their journey of transcendence. So, we believe the narrative session of the

Tenth SOBRAMFA Meeting fulfilled an extremely important role – to awaken students and young doctors to a larger vision about the practice of medicine.

In the call for narratives, we had asked attendees to send patients' stories. In fact, patients stories were sent and told, but they were enriched by professionals' and students' own feelings, memories and stories, at such a level that, sometimes, we could not recognize which was the predominant voice. There was an unexpected *mélange*, and it was evident that much suffering and pain had been shared between healthcare professionals or students and patients. Most of the participants had never heard about Frank's works, but they demonstrated that listening empathically to ill people means to be compassionate and that it was possible to move naturally from one kind of story to another. Frank presented the practice of healing, especially for those living in "deep illness," as entering relationships based on storytelling. The way events occurred in the narratives session confirmed an awareness that we had already recognized in our palliative care ambulatory training – that the application of narrative methodology according to Frank's approach is a tool capable of providing cure to students and healthcare professionals as well as to patients, especially when they are wounded by the sad circumstances that commonly make up a significant part of their daily practice.

The most gratifying surprise was that during the narratives session, first-time storytellers could act through methodologies they had not yet formally learned – narrative medicine, reflective writing and narrative methodology, according to Frank's analytic categories. This intuitive capacity was aroused by an unpretentious stimulus – in the phrase of Robert Coles, the progenitor of narrative medicine--the call for stories. Today we still continue to receive new stories conference participants have written

spontaneously and wish to share, stories of patients that brought great learning or insights or showed a palliative or curative effect not only for patients, but also for their doctors.

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