

Stories of the illness in a changing world of medicine

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Abstract

(OBJECTIVES) This study aims at evaluating the impact caused by the doctor's attitude before those patients who would be submitted to a surgical process and their outcome stories expressing their misfortunes and their evaluating the doctor's behavior facing this new situation. (METHODS) The data collection was done through interviews and a questionnaire applied by the psychological team while the patients had their hearts examined. For the process of codification and labeling the CAQDAS (Computer-Assisted Qualitative Data Analysis Software) was used. (RESULTS) Anxiety was almost a unanimous feeling in every story in which the patients had the opportunity to express their feelings arisen by the illness, as well as before a potential surgery. Also, a need of a more human contact with the doctor was told. (CONCLUSION) The patients who had any kind of faith surprisingly had a calmer recovery process. The absence of a more human relation with the doctor gave place to a deeper attachment to a divine figure in an attempt to overcome the fear of death.

Key words: Stories-Doctor's attitude-Humanization-Illness-Faith

Historias de la enfermedad en un mundo cambiante de la medicina

Resumen

(OBJETIVOS) Este estudio tiene por objetivo evaluar el impacto de la actitud médica frente a enfermos que serían sometidos a procedimientos quirúrgicos, como también sus narrativas, resultantes tanto de la expresión de sus infortunios como de la evaluación de la postura del médico y de su propio comportamiento frente a esa nueva situación que se configura. (MÉTODOS) Para la colección de datos fueron realizadas entrevistas narrativas en el instante en que se procedía a la evaluación del riesgo cardiovascular, siendo complementadas por un cuestionario investigativo aplicado por el profesional de apoyo psicológico. Para la etiquetación, codificación e indexación de los contenidos, fue utilizado el CAQDAS (Computer-Assisted Qualitative Data Analysis Software). (RESULTADOS) Una característica prácticamente unánime en todas las narrativas de los enfermos fue la ansiedad al relatar sus inquietudes ocasionadas por la enfermedad, como también sobre un posible procedimiento quirúrgico, además de la necesidad de un contacto más humano con el médico. (CONCLUSIÓN) Los enfermos que presentaron algún tipo de fe, sorprendentemente, obtuvieron una recuperación más tranquila, donde la inexistencia de una relación más humana con el médico dio lugar a un apego mayor a una figura divina, en el intento de vencer la ansiedad y el miedo de la muerte.

Palabras clave: Narrativas-Actitud médica-Humanización-Enfermedad-Fe

Introduction

In the present time, medicine is passing through a process of breaking its paradigms related to the reconstruction of the doctor-patient relationship (Frank, 1995; Hunter, 1991; Cardoso, Camargo Jr, Llerena Jr, 2002). This break is deeply related to the perceptions and interaction linked to time, history, and the experiences concerning the symptoms connected to the narratives of the patients' suffering; this has acquired different meanings right in the moment when the patients share their versions to the doctor. In this perspective, the doctor as the actor of the process of identification of the illness and active in the process of healing it, has in the relation with the patients' events, a decisive role in the translation of the stories that give shape to the illness itself, because for centuries, the act of telling stories about the reality of the experience caused by the suffering, has produced a dialectic knowledge on the human being and the health/illness issue (Lira,

Catrib, Nations, 2003 p.60). The concept of "narrative" in this article refers both to the patients' life stories and to localized talk during the interviews with their physicians.

In the process of humanization of medicine, restoring the narratives of the patients about their suffering, becomes in the present time, a condition *sine qua non* to the shared analysis about the events lived by them and the (re)created versions of them (Silva, Trentini, 2002, p.426), mainly because it can be seen that the doctor as (re)productive of pre-established truths is not motivated during his process of apprenticeship to perceive the real relevance of the patients' narratives for the construction of the diagnosis, specially because he is still too much linked to the paradigm of the hierarquical knowledge. However, it is through those narratives, which do not have their value appropriately inserted in the dialectic context, that the doctor takes

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his will to truth – but he lacks, in the perspective of humanization, the attitude of taking part in the patient's will to know.

Due to the presence of complementary technological exams, there has been formed a barrier in the communication process between the doctor and the patient. It is believed that that has happened during the process of telling the history about the pain and suffering lost its matrix of subjective sense because of the interest in the technological aspects in the moment of forming the diagnosis. That has silenced the particular aspects of those narratives. It is important to highlight the fact that in real life the technological process are not separated from the subjective ones (Merhy, 1997; 2002).

Due to the development of new aspects to identify the recognition of the diagnosis, the narratives provoke thematic, theoretical and methodological changes (Cardoso, Camargo JR, Llerena Jr, 2002) in the dialogical experience between the doctor and the patient in a subjective way (Minayo, 2004), so that a deductive and human meaning is added to the human suffering. Healing, therefore, it is not only about extinguishing pathology, it is about comforting in a moment of pain and suffering (Minayo, 2004). This way, the importance of narratives in medicine, considering its feature of "Science of the individuals" (Hunter, 1991), it is not only concerned with the ways of listening necessary to the process of healing or improvement of the patients' life conditions, but it is an epistemological part of the process of building a knowledge that comes from the practice and the scientific reasoning, which creates hypothesis – that connected to the deductive reasoning, necessary – determine what is supposed to be – moves towards the process of acquisition of knowledge (Cardoso, Camargo Jr, Llerena Jr, 2002).

Thus, this study has the objective of evaluating the impact of the doctors' attitude in relation to the patients that suffer from different levels of pathologies and that were to be submitted to surgery, as well as their narratives, which were a result of the expression of their sufferings, of the evaluation of the doctors' behavior, and their own behavior concerning the surgery.

Methods

Seventy-six patients were analysed from January 2003 to November 2004; 49 (64,4%) men and 27 (35,6%) women. The patients observed were those that had surgeries previously scheduled; none of them in risky conditions. The age ranged from 22 to 69 years; all those patients were submitted to surgeries in the same hospital. The data consist of narrative interviews with patients who had their hearts checked; it was also used a questionnaire applied by the psychological support professional.

The researchers were introduced into the public hospital and selected patients 24 hours before their surgery in order to have time to register the information about their heart condition and other important data that could help the understanding of their emotional state. The analysis of content (Krippendorff, 1980;

Bauer, 2002) was used in the evaluation process of the discourses, considering the discursive corpus elaborated by the patients on their fears, doubts and insecurities related to the surgery. For the process of tagging, coding and indexing the contents, it was used the CAQDAS - Computer-Assited Qualitative Data Analysis Software (Fielding, 1998; Kelle, 1995), in order to make the link, order and (re)order, segmentation, structuring and search, of the discourse (Bauer, 2002). The procedures started after the research being approved by the Ethics Bureau, and they were: patient's authorization for the research; individual interviews; transcription of the interviews and explanation of verbal expressions.

Results

It was noticed a common feature in almost all narratives of the patients: the issue of anxiety while telling the disturbances caused by the illness, as well as about the surgery. This feeling of disturbance, in some cases, caused changes in the patients' clinic state, provoking changes in the blood pressure, breath difficulties and agitation. These information was observed in 26 (34,2%) patients, only 21 (27,6%) had previously been submitted to surgery, but did not show lack of anxiety, in fact, there was an increase in their level of anxiety.

While analysing the length of time that took from the diagnosis, the suggestion of surgery and the patient's decision to submit himself to it, it was observed that this period varied from "short" (02 to 06 days) in 11 patients, which represents 14,5%; "medium" (01 to 04 weeks) in 39 patients or 51,3%; and "long" (more than 04 weeks) in 26 patients or 34,2%. This data show several factors of social, emotional and cultural nature, since the narratives related to this decision showed, among other points, lack of trust in the doctor figure due to the few contacts between them, fact that aggravated the illness and made the patients feel more vulnerable to take the decision.

It was observed that 29 (38, 2%) patients out of a total of 70 had looked for a second opinion on their pathology. That represents insecurity in the doctor figure and a search for different opinions concerning the data previously presented in their narratives or by the doctor. This data also reveal that 41 (61,8%) patients did not look for a second opinion either for lack of other professional options, or lack of financial resources to support a travel to a bigger city that could offer better technology to help in the diagnosis.

It was also analysed the patients' reaction to the information on the need for a surgery; 13 or 17,15% told had got the news about it from the doctor in an impersonal way – that can be understood as a lack of a more human relation between them. 32 patients or 42,1% told that the news were informed in a quick and indifferent way ; 21 of them or 27,7% told the doctor's account of the diagnosis in a sudden way and only 10 or 13,1% mentioned the existence of a more dialogical attitude. So, it can be seen that the services are organized from the perspective of the professionals and that of the

institution, and are not focused on the patients' needs (Boaretto, 2003; 2004).

These informations bring to the center of the debate the issue of diversity in the separateness of the details of each case, where the subjective load present in the narratives of the patients during their contact with the doctor is not appropriately considered, since the doctors have to fulfill a specific deadline and a number of consultations per day. From the other hand, the narrative of the professional is central to the epistemology and practice of medicine, it is this epistemology necessary to the rational investigation where the subjective experience and accounts of that experience done by another person which constitutes the basic and original data of the clinical assistency (Hunter, 1991).

An interesting point is that the majority of the surgeries did not involve any risk; the patients observed were not in serious condition, however, 82,2% (61 patients) revealed in their discourse fear of death concerning the surgery itself: "I am going to die...I have so much doubts and fears. How long is it going to take? Am I supposed to get any anesthesia? Will I survive?" "Is it going to hurt? I haven't seen the doctor today. I'm waiting for him. They say he's good, but he doesn't talk to me." "The doctors only care for the boxes of medicine and we just move from one place to another." These narratives reveal a will to know (Mairesse, Fonseca, 2002, p.112) that rises from the needs related to the experience of translation of their narratives in their contact with the doctor, which produces and reinforces the patients vulnerability and anxiety linked to the surgery, that is, it is an effect caused by the offer and demand produced by the discourse (Mairesse, Fonseca, 2002) in the doctor-patient relationship. From this effect of offer and demand, rises fear of death, since there is a lack of dialogue and negotiation.

It was also evaluated the patients' opinion concerning the length of time of their conversation with the doctor; the majority of them 68, 4% (52 men and women) revealed that they had had only one consultation and one return to show the exams and to be informed that they were supposed to be submitted to a surgery, and would meet the doctor again only on the moment of the surgery. The patients complaint in their narratives that "The doctor doesn't have time for me. I'm not important. Only my illness matters, but I'm healthy. I think he listens to me only because I'm paying." "I wish I had the opportunity to talk more, but he didn't give me any more time. Time is complicated for him." "I don't understand why the doctor's car are always full of books; they do not care for us." These data point to a common link of insecurity, mainly because 31 (41,9%) patients said they did not have any information about the process of the surgery and 24 (31,5%) told they got information about it from other non-medical sources on their health state.

The procedures to which those patients had to submit themselves were: hysterectomy 21 or (27, 6%); Prostatectomy in 15 (19, 7); abdominal herniorrhaphy in 11 (14, 5%); Hemorrhoidectomy in 09 (11, 9%); cholecystectomy in 08 (10, 5%); partial and total

thyroidectomy in 03 (3, 9%); splenectomy in 01 (1,4%) and orthopedic surgeries in 06 (7,9%).

It was also analysed if the patients had any kind of faith or hope; 67 revealed having faith and hope (88, 1%) and 09 denied having these feelings (11, 9%). The habit of praying and devotion to a Mighty God was present in 32 (41,1%), but 09 denied this habit (11,9%), and 47 told that just rarely they used to pray (61,8%). It was noticed that the praying group had a better and faster period of recovery and had less complications. A 52-year old patient account shows that: "If I did not have any kind of faith I would be dead already. It's too lonely, Mister, in this hospital." Faith appears as a decisive factor in the narratives and not only in the process of healing, but also it influenced the patients' life quality (Koenig, Larson, McCullough, 2000; Koenig, Cohen, 2002). For example, a 69-year old patient states that "I would be lost without God. He listened to me, gave me comfort, and stayed with me in my silence."

So, science is led to reflect on the relation between faith and its positive effects on the patients health conditions, because it was noticed that a patient who has hope and trust can live more and have less complications or not, but at least his mood allows him to live better with himself and his pathology. At the moment, it can be seen that there are several studies concerning the healing power of faith (Koenig, Larson, McCullough, 2000; Koenig, Matthews, 1999), as attempts to demonstrate the positive relation between the medical treatment and the fact that the patient has a hope (Groopman, 1998; 2000; 2003).

Conclusion

It can be seen that there is a barrier between the doctor and the patient, so that there is not enough time for basic information to be discussed; some patients did not know even the name of the procedures they would have to be submitted to. Apparently, this behavior is linked to the fact that the procedure and the hospitalization take place in a public hospital. Recent studies show that the social and cultural distances bring a gap in their relation. In this asymmetry and facing the medical routine, the population that depends on the public service normally is not informed enough about their rights, and thus, loses its autonomy and have difficulty in negotiating their rights to information and active participation in the process (Boaretto, 2003).

That's why the medical encounters must be seen also in terms of an asymmetrical relationship. In the literature on the medical praxis, researchers call the attention to the need of observing the balance of power between patient and physician. The lack of symmetry can even be seen in local terms, i.e., even at the level of the individual interactions: doctors and patients may each have their agendas to develop regarding to who will speak, when, how and about what and usually their agendas differ.

It is important to analyse the patients' narratives and give them a more human treatment, since they are not responsible for the expression of subjectivity and

polissemia of voices that ask for a more attentive listening concerning their real experiences concerning the surgery. It is in this context that strategies are created by the patients in order to deal with the process they will have to face, for example, faith and attachment to a subjective figure that represent security and calm in their universe recently thrown into the chaos, anxiety, uncertainty and insecurity.

A medical encounter has been the topic of much discussion but still lacks to be subjected to scientific scrutiny. Whereas several aspects of medical practice are included in the physician's training, the approach to the patient is expected to be on the basis of intuition, to be learned by experience. In the past, continuous

relationship between patient and physician was the rule rather than the exception. As a result, warmth and mutual understanding could develop. As patterns of medical care have changed, the serial encounters between physicians and patients are being replaced by patients' short-term encounters with numerous specialists and other health specialists. As a consequence and as some studies about the medical praxis show, there is a crescent criticism aimed at the lack of warmth and humanity in the community medical care. Researchers (Shuy, 1983) suggest that patients feel more comfortable with medical encounters that are more conversational rather than like interviews.

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Fecha de recepción: 12-04-11

Fecha de aceptación: 12-08-11