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A new instrument in the doctor’s toolbox

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Abstract

The doctor’s toolbox must contain a new instrument to be used in clinical examination. Thyroid cancer in progression and uncontrolled or partially controlled acromegaly are discussed as typical examples of disorders requiring a peculiar follow up approach. The relationship between the doctor and the patient, in fact, may became problematic, due to the necessity of sharing decisions and continually facing emerging health and compliance problems. Narrative medicine is the instrument that the doctors must possess in their toolbox in order to meet a patient’s hopes and expectations during the follow up of a disease which is eventually fatal or which may become chronically uncontrolled.

Key-Words: Narrative medicine, Thyroid cancer in progression, Acromegaly, Medical examination

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Introduction

A new instrument must be available nowadays into the doctor's toolbox. This instrument is not a product of advanced technology but an old one, which could be recovered from the days of philosophical medicine. We are referring to *narrative medicine* which is considered a revolutionary novelty in approaching the patient, but it was probably intrinsic in pre-technological medical practice. Indeed, narrative medicine is founded on theoretical bases that do not have their roots in biomedical science. Its roots can be identified in the work of Gérard Genette (1930-2018), who in his *Nouveau Discours de récit* - (*Narrative Discourse Revisited*) written in 1983 codified a system of analysis of literary text that examined both the actual narration and the act of narrating as they existed apart from the story or the content. It was Genette who defined the relationship between the doctor and the patient as asymmetric, since the patient, who is the first active component of the relationship, constantly expresses a request for help that it is often not explicit. The patient does not have the related knowledge and introduces himself to the doctor full of doubts and fears but also full of expectations and hopes, and ultimately, he hopes that the doctor will meet the former and realize the latter (1). Therefore, narrative medicine consists of the ability to know, to listen, and to interpret information while acquiring the most important part of the patient history.

Thanks to the narrative competence of the physician, the approach to the patient becomes holistic and global; besides looking for the clinical signs and symptoms, his approach also takes into account psychological, social, biographical and emotional aspects of the natural history of the disease. A patient-centered approach is the basis of humanizing care and implies the ability to penetrate the patient's life, to understand his state and to start a balanced, two way interview as defined by Rita Charon at the beginning of this millennium in her fundamental text "*Narrative Medicine- Honouring the stories of illness*", published in 2008 by Oxford University Press and in other related assays (2).

Patient and doctor. An evolutionary perspective

Until the end of the Second World War, the relationship between the patient and his physician was based on a paternalistic model. The doctor played a kind of shamanic role, while the patient confidently waited for his prescriptions and solutions to his health problems, totally uninformed of what was happening and supine in the face of every action or omission of the doctor. However, in the course of a few years, the situation is transformed by the implementation of the liberal model where the patient assumes a primary role as the holder of a right and a participant in the decision making process concerning his person, regardless of the necessary expense. The doctor, in his role, maintained the dyadic, beneficial and reciprocal role in the commitment to regain and maintain the patient's state of health. The liberal model appears as a natural extension of the *habeas corpus* principle enshrined in the fundamental law of the Italian Republic in Articles 2 and 32. Nevertheless, despite the claim of a complete respect for the Constitutional norms, a rapid Darwinian evolution took place. A newly evolved model affirmed its place: the model of Parsimony and of the Agencies. This model highlights the rationalization of scarce financial resources, according to rules set up by Agencies and Companies (*Aziende*) conceived as commercial enterprises. The rules, while recognizing the patient's right to health and to fully informed consent, impose, perhaps justifiably, the respect of resources. The patient should be adequately educated and the physician must follow, often without criticism, Evidence Based Medicine, guidelines, and consensuses, paying also attention to company productivity.Along with these seemingly reasonable rules, however, it is not uncommon for the doctor to be asked to meet a very large number of patients in one hour, thus, for only a few minutes each.

Two emblematic situations.

Among the numerous disorders that may complicate the meeting between the patient and the doctor, two may be chosen: thyroid cancer in progression and acromegaly. Thyroid cancer in progression may become fatal sooner or later. During this period, the doctor must cope with a person’s hopes and expectations along with pain, health loss and suffering, caused also by the side effects of drugs. Acromegaly is characterized by a long period where it is not recognized.Once recognized, the first-line treatment is surgery, followed by variable uncertainties of its course. In this light, acromegaly resembles any other chronic disorder which can be treated and controlled but not cured, such as chronic kidney failure without being immediately fatal. Both thyroid cancer and non-cured acromegaly, albeit in their specificity, have a strong influence on the nature of the relationship between the patient and the physician.

Nevertheless, each one has specific characteristics and raises specific problems. It should not be taken for granted that, in the first case, the most important problem is survival and in the second, the quality of life.

Thyroid cancer in progression

Based on a valuable analysis of the biological behavior of human cancer and of its progression (3), a category was applied to thyroid cancer (4) by identifying three different types. The first is an unidentified cancer, which is generally clinically unapparent (pre-clinical stage). The second is diagnosed and intrathyroidal or diffused to loco-regional lymph nodes and is easily managed and cured by means of conventional and standardized procedures and drugs. The third one is symptomatic, systemic, poorly differentiated or dedifferentiated and refractory to any conventional treatment. In some cases, the second type of cancer may evolve into the third type and become fatal. During the third type, the progression is rapid, and the disease quickly becomes symptomatic or is already symptomatic at the onset. The response to treatment is sometimes ineffective, or has limited efficacy and, in any case, the patient is burdened by numerous, unwelcome side effects that have a profound influence on the quality of life and on the duration of survival. Although rare, patients with these characteristics exist and require that the doctorapplies a dedicated communication model.

Narrative competence must be considered as one of the most important medical skills, consisting in the ability to know, to listen, to interpret and in the ability to acquire an active part in the history of patients. Thanks to the narrative competence, the approach with the patient becomes holistic, global: alongside the clinical data, psychological, social, biographical and emotional elements are also taken into account.

A patient-centered approach underlies the concept of humanization of care. The doctor must possess or, if he does not possess it, must acquire the specific competence, not only to improve the relationship with the patient, but also that with himself, with other doctors, and with the rest of society and to protect himself from the objective risk of burn out.

Elisei and Trimarchi (4) propose and describe the motivational interview techniques that facilitate the communication with the patient regarding symptoms. This technique promotes the mutual exchange of information and emotion on the progression of the disease and on the transition to a plan of advanced therapy. At the first moment of communication, the interlocutor is immediately involved with a personalized dialogue and listening skills.

The second moment consists in establishing, together, the agenda of interventions: this enhances the autonomy and decision-making process of the person (self-determination) and confers to the patient an active role during the visit and the future procedures.

During the third moment of communication, all of the necessary information together with advice and suggestions related to therapy including its positive and negative effects are provided. The doctor must know how to offer information, solicit and offer again, after having acquired the willingness of the person to have the maximum of awareness. The final phase of the consultation and of the interview is that of the open questions and of reflective listening; the doctor will have to determine that the patient has successfully understood the conversation, while respecting the patient’s autonomy and self-determination. (5).

Acromegaly

Prior to becoming a medical record, the acromegaly patient’s life runs as if it were a play or drama structured into a prologue and two, three or four acts. The 40 year old British journalist Jon Danzig described in an article appearing in BMJ (6) the dramatic and gradual changes which took place during almost 10 years. He noticed that his *“ shoe size grew from 9 to 11*” and mentions that his girlfriend that he was going to marry left “*after we stopped having sex*”(…) “ *I also dramatically changed, both personally and physically*”. His nose became bigger; his face and hands became puffy and coarse. He outlines that the aforementioned changes were gradual and that he realized them only in retrospect. His friends and relatives were aware of the changes, but Danzig had to wait almost 9 years for a diagnosis. Most patients who experience these changes do not attribute the changes to a disorder and probably consider them as a result of some psychosomatic disturbance, thus avoiding meeting a doctor or, frequently, the wrong one. After the first period (*Prologue*) during which there is the risk of minimizing the symptoms, the patients enter the labyrinth of medical examinations and laboratory tests and imaging (*First Act*). During the First Act, the patient experiences fear and expectations wondering, "*I need a diagnose. I do not recognize myself. I want my face back. Will I be healed?*" The First Act finally ends with the diagnosis, but immediately afterwards, the Second Act of the drama begins.

In fact, the right diagnosis is not the end of the drama. The doctor proposes to the patient the first line treatment of a surgical intervention "*which touches the brain*". This step is generally accepted by almost all patients, but a new problem may raise: the incomplete solution of the health problem. Pituitary surgery can, in some cases, be followed by only a partial healing and control of the disease or by persistent activity of the disorder. During the Third and Fourth Acts, the dramatic action develops with the representation of various situations including the partial failure of treatment, the need for life-long treatment, and the establishment of alienating practices. Disillusionment and exhaustion take place over time, the patient pretends to be autonomous, and the risk of "burn out" becomes concrete and imminent, as illustrated by Cannavò et al. (1) Over the long term, a true alliance must be established between the patient, the doctor and the caregiver's team. Education and information should be reciprocally shared and, alongside the scientific information, the alliance must be based also on the narrative medicine approach (1).

Narrative medicine

The advancement of clinical medicine became unstoppable even thanks to the generalized use of advanced technology, which permits to investigate the post-molecular mechanisms of health and disease and the most hidden phenotype of any anatomical and functional disorder, due to the development of digital imaging. Narrative medicine must be included among the components of a medical examinations which cannot be based exclusively on "*printed signs and symptoms (sintomi e segni di carta)"* (7). According to Rita Charon (2), doctors must acquire narrative competence. They must have the ability to know, to listen, to interpret, and to acquire an active part in the history of patients. The clinical approach must be global and directed towards the evaluation of clinical data along with psychological, social, biographical, emotional elements. The result of such an approach is the humanization of care and the improvement of the relationship with the patient, but also with that of himself, with other doctors and with the rest of society. Regarding the enormous number of conditions that require medical assistance throughout life, as seen regarding acromegaly, a narrative medicine approach appears necessary. Based on a questionnaire administered to a cohort of persons suffering from acromegaly, Gurel et al (8) reported the hopes, requests and expectations of patients. First, the patient asks forgreater participation, empathy and understanding of their problems (initially patients choose their endocrinologist based on competence, but soon after, they count on their empathy and sensitivity); they want to be heard and understood as well and reassured.

They want to be considered "*a person and not just a patient*". The second request concerns a major involvement of the family doctor because patients frequently turn to them for minor health problems (and they inevitably find them to be insufficiently competent) and with the hopes of acquiring better knowledge of the disease and gain assistance with the maze of doctors and lab tests that they must face. Finally, adequate emotional and psychological support is expected, while also offered by patients' communities (1).

A conclusion

More than 10 years ago on March 20, 2008 *(personal communication*), when not all doctors were paying attention to this basic aspect of medical ethics, Massimo Mannelli, professor of Endocrinology at Florence University and one the most distinguished experts in studies on paraganglioma , wrote, in Italian, this almost poetic text:

> *"When you welcome a patient, look him into the eyes, and you will have already begun to ask questions before speaking.*
> *Let her or him talk and listen to her or him; the person will communicate to you much more than he tells you.*
> *Remember that if the person has looked for you, it is because she or he has a small or great suffering from which she or he seeks relief.*
> *Do not believe that you have understood everything immediately and do not expect to possess the truth.*
> *You are not different from the patient.*
> *You must consider that sometimes it is not possible to diagnose a disease.*
> *But you never deceive the patient about his healing if you are not more than convinced.*
> *Render the patient an active participant of your reasoning and explain to him the reason for your choices.*
> *Be sure that you will not spare yourself trying to help her or him and that you will take care of the situation until you have no more doubts left.*
> *Let your patients know that you will walk together, wherever you take the road*
> *and that anyone willing to share it is welcome.*
> *If you stay close to the patient, you will have much to learn to better help others in the future"*

Today the patient has the right to conscious information and has the right to understand what is happening and what could happen. However, even in the case of highly educated patients, they may have the cognitive tools to understand complex information, but it is up to the doctor to use the correct tools and ascertain if the patient has correctly understood the information.

The signing of an informed consent is legally important. However, the fact that the patient properly understands what the doctor is explaining and what awaits him in the future is essential to create the right human relationship between the patient and the doctor who share the management and possibly healing of thedisease.

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