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Invisible diseases and the doctor-patient relationship

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Abstract Headaches can be considered as a paradigm for the so-called “invisible” diseases; difficulties that headache patients encounter and complain from often relate more to the lack of understanding and communication than to lack of a cure by their doctors. Even when treatment is available, although symptoms are relieved, this might not cure the suffering and the burden caused by headache. This paper will present the difference between disease and illness, will highlight difficulties encountered by patients with “invisible” diseases and will underline how these difficulties might be reduced by a better doctor–patient relation-

ship. The physician who acknowledges and considers the subjective aspects of the *illness*, has important elements both for a personalised diagnosis and for a therapy that the patient will be able and willing to follow. The physician has to improve and to train his/her human capabilities in order to have a good relationship with the ill person, and not only to use his/her technical skills for individualising and curing the *disease* in the patient’s body.

Key words Illness • Disease • Invisible disease • Physician-patient relationship • Care • Cure • Suffering • Pain • Ill person

Contemporary medicine has made huge progress in understanding and treating specific *diseases*. The diagnostic and therapeutic possibilities of medicine have increased, and technology has taken one step further in providing highly scientific tools and procedures. *Diseases’* classification nowadays is mostly based on pathological lesions and on processes enlightened by medical technologies. Such progress has enabled medicine to *understand the disease*, without referring to subjective symptoms strictly connected to the patient, considered often only as the “carrier” of disease. As for evaluation of an efficient therapeutic approach, pharmacology and surgery offer criteria that are valid for all patients in the same clinical conditions. Biomedicine has therefore greatly advanced through focusing on *diseases*;

this, unfortunately, might have contributed to a lack of attention towards patients’ experiences.

This is particularly evident in the ‘*invisible diseases*’. The clinical eye that tries to individualise the physiological and organic causes only of the *disease* does not see them. Subjective symptoms, related to the psychological and social experience of the patient, are not considered as something the physician has to be interested in. These *diseases* are not acknowledged as real diseases even by society. The risk is that nobody takes care of the patient. Moreover he/she feels ill while nobody thinks that he/she is ill. Headaches can be considered as a paradigm for all invisible diseases; difficulties that headache patients encounter and complain from often relate more to the lack

of understanding and communication than to the lack of a cure by their doctors.

The relationship with the patient is one of the deficiencies so characteristic of contemporary medicine, which emerges from its basis in a mechanistic worldview. In this view, *disease* can be understood according to the model of 'machine breakdown': doctors are scientist or technicians who fix or replace broken parts. This dualistic paradigm has generated the search for precision drugs and surgical procedures, with the emphasis on scientific rather than humanistic training for the physician. Much of the efficacy of modern medicine rests on its dualistic and mechanistic foundations. But extreme attention to the *disease* risks letting the patient face the most difficult aspects of his/her condition alone.

The physician in clinical practice is called to *take care of the ill person* and not only to *cure the diseases*. The problems, even the clinical ones, get bigger when the physician is not worried about *comprehending* the ill person, but focuses his attention only on *understanding* the *disease* with a scientific and technological approach. The physician must relate not only to the scientific and more objectively noticeable *disease*, but also to the more subjective and humanly detectable one, the *illness*.

In contrast to the medical characterisation of *disease*, the term *illness* refers to the experience of sickness. Any *illness* is inescapably individual. Even if one shares the same *disease* with another, the challenges, limitations and suffering involved can vary considerably from person to person. For each patient the *illness* is a unique, peculiar experience that varies not only in relationship to the patient's physical and psychological peculiarities, but also according to his/her social and cultural context. The *illness* becomes for each person a moral and existential issue, depending on its interpretation by the patient itself. The *illness* event may be experienced, for example, by some as guilt, by others as an obstacle to overcome or an occasion to focus on their existence again. Even the fact that a person might be surrounded by support of family/friends, or live in complete solitude, strongly influences the approach to the *illness* and the *suffering* to be faced.

Different people suffer differently even if affected by the identical *disease*. *Suffering* connected to the *illness* is to be distinguished by *pain* caused by the *disease*. They both involve the entire psychophysical person, and their intensity and way of expressing change in relation to each patient. *Pain* is located in a specific area of the body; it is usually possible to trace it and kill it. In the '*invisible diseases*', pain killing is not so simple, because the pain is peculiarly multi-factorial. *Suffering*, due to pain and to other elements, cannot be located in a specific point but can be faced by establishing a significant relationship with the suffering patient. The interpretation of the *illness's*

meaning is connected to several factors, among which are the patient's way of experiencing life, his/her emotional relationships, his/her religious beliefs, his/her culture and depth of thought. *Suffering* is the intimate way the person approaches the *illness's* various phases and the transformation he/she has to face.

The *illness* is a state of imbalance, in which the patient lives a temporary or definite situation of disintegration of his/her reference points: the relationship with his/her body, with the surrounding environment, with relatives and friends, undergoes strong loss of integrity and engenders a global disorder.

This condition of disorder may find an answer, also a clinical one, in the relationship with the physician. This relationship does not have to be purely formal and *depersonalised* (as the relationship between an object and its observer); instead the patient has to find in it dialogue, trust, attention to his/her experience and questions. Only in this way can the clinical relationship give the patient the possibility to face both *disease* and *illness*.

A relationship based only on the clinical analysis and on the objective individuation of *disease*, in fact, is a *depersonalised* form of relationship, in which the patient lives his/her condition of *illness* and of global disorder without any human help. This detached relationship with the physician can even cause the worsening of the illness, because of the bad feeling of the patient who feels even more frustrated, fragmented and puzzled. Besides, if the physician cannot find time and words to help him/her to understand what is going on, he is not really *taking care of the patient*. The patient will not be able to actively take part in a diagnostic and therapeutic process without being involved in it as a person.

Conclusions

The physician who acknowledges and considers the subjective aspects of the *illness*, has important elements both for a personalised diagnosis and for a therapy that the patient will be able and willing to follow. The physician has to improve his human capabilities in order to have a good relationship with the ill person, and not only use his/her technical skills for individualising and curing the *disease* in the patient's body.

Dialogue through a comprehensible language, time devoted to examining and reciprocal acquaintance, empathic understanding and personal care are not elements that are optional in medical practice. They are necessary for acknowledging and practicing what is peculiar to medicine, that is *curing and healing* but also *taking deep care* of the ill person.

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