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Medical Care – A Discontinued Model in the Age of Autonomous Patients ?

I would like to start my presentation with a case vignette. A colleague of mine, a nurse and an ethicist herself, a mother of three young adults and the wife of an established internist told me about her experience with disease. Shortly after her 50th birthday she was diagnosed with breast cancer. A breast conserving surgery that removed the tumor was performed. A subsequent chemotherapy and radiation therapy were planned to which the patient gave her consent. As an alleviation for the chemotherapy, a permanent vein catheter was inserted. Several days after the insertion, the patient suffered a stroke causing a left hemiplegia. A clot that had formed around the catheter was the cause. It had found a way into the cerebral circulation through a not yet known persistent foramen ovale, a connection between both heart atriums. The decision, whether a lysis therapy had to be performed within the next few hours, had to be made under time pressure, as this was the best chance of dissolving the clot and thereby cause the paralysis to regress. The attending physicians explained the possible risks to my colleague and her husband. Their manner was very superficial and they stressed the fact that my colleague and her husband were experts themselves. My colleague, however, was not primarily a specialist in this situation but a patient in need of help. Her husband, likewise, was not the doctor in this situation, but a husband suffering with his wife. Both felt left alone in their decision making. In this example typical questions arise in regard to the physician-patient-relationship: How thoroughly should a patient be informed? How can one be sure that the patient has really understood the information? Is it still possible for the patient to make voluntary decisions, considering the diverse influences he is subjected to? When have the boundaries of the justified exertion of influence, by means of argumentative conviction, been overstepped? Which conditions are the patient's ability to reason and his discretionary competence bound to?

I assume you would like to know how my colleague's story continued. She and her husband decided upon a lysis therapy, which was successful. All neurological symptoms disappeared completely. What was the ultimate factor that caused them to opt in favor of the lysis therapy? The husband sought talks????? with the responsible chief resident and asked “What would you decide on, if this concerned your wife?” He replied, that he would decide on a lysis therapy. It was this personal opinion of the attending chief resident, when he was addressed as a person not a physician, that helped my colleague and her husband reach a decision.

To date, the physician-patient-relationship is the central element of medical interventions. This relationship has been subjected to a strong change in the last decades. The traditional physician-patient relationship, shaped by the paternalistic care of the physician, increasingly came under fire. The causes of this change are diverse. Surely the growing plurality of values in modern societies played a part as well. The economization of all areas of life, from which medicine was not spared either, has made it's contribution to this change.
For this reason the classic ethical questions concerning the physician-patient-relationship have arisen with a new actuality and might have lead to the choice of this conferences topic: “Who decides upon the treatment? Physician, patient or...?” These questions become especially significant if that which promotes the well-being of a patient the most, from a medical point of view, is not in concord with the intention of the patient.

Man as a Sovereign Client

The cause for such disagreements are often not the different assessments of single actions but rather more the different understanding of being human, of the conception of man. Recently, in wide areas of medicine, the image of the trusting patient seeking help has changed to the role model of the patient as a client. This corresponds to a sovereign human-being who is able to buy services ad libitum. In light of such a conception of man, physicians experience themselves decreasingly to be someone who primarily alleviates pain. They are increasingly forced into the role of a service provider. In this position, it is only his knowledge, as well as his skills that is on demand in order to fulfill the wishes of his patients. His attitude towards his patient's wishes is not asked for. It is but a pure contractual relationship, in which the personal side of the physician is left out. The physician is no longer expected to offer an unique service to an individual but rather to deliver a product which is primarily flawless and guaranteed to function smoothly. Such a service consciousness does not care if the sought after goals are good and supportable goals. Only the sovereign client decides on the integrity of the goals. Hereby medicine increasingly becomes a wish-fulfilling activity, which for example especially becomes manifest in aesthetic surgery. Medicine, which fulfills wishes without thinking, offers patients only very restricted help. It only serves to strengthen man in his shortsighted current desires. In this customer model of medicine time is usually the first to be sacrificed in a quest for efficiency and profits: Time to patiently wait for and permit a maturing process in which man is not regarded as a client but as a patient, as a sufferer who is seeking help.

Are we even able to, however, isolate ourselves from such developments?

Help Based on Economical Standards

The cost-bearers, which are health insurances as well as governmental institutions, are counselled and influenced by health economists. They follow the trend of considering medicine as part of an industrial enterprise more and more, which is guided not by criteria of medicine but by the leading category of the industry. Infirmaries offer their services on high-gloss brochures and spend increasing financial resources on marketing and customer service. The question arises how much of the actual social concept of medicine can be preserved. In light of this, it is of central ethical significance to contemplate how medicine is changing through economical infiltration, not only from without but also from within. The procedures in medicine are increasingly understood as

production processes under the dictates of the market. Medical actions become a product that must be examined for it's quality criteria. Thereby, however, medical action loose it's uniqueness, they become exchangeable, something that is independent of the individual physician. It becomes something controllable and predictable.

The result, analogous to industry, is modularization and standardization. In the market system, the aspect of action is assigned a great value. The attitude with which the action is executed seems to be irrelevant. Indeed, certain medical activities can be validated, compared and sometimes even measured. Yet more and more, one loses sight of the fact, that the treatment of people is always carried out within an encounter and it cannot only be regarded as the product of an application of procedures. Furthermore, medical care does not only consist of what is done in practice. The quality of a medical action is rather more measured according to the personal approach and motivation, as well as the attitude it is executed with. In order for the social identity to become recognizable again as the basic element of medicine, modern medicine must invest not only in the optimization of the procedures in clinics and doctor's offices. It must especially invest in fundamental attitudes. We aren't dealing with a resource crisis, that is in the Western World, but rather with a crisis of fundamental attitudes. A crisis of fundamental attitudes of patients who regard health services as consumer goods. It is also a crisis of fundamental attitudes on the part of the physicians. They must learn to break away from the paradigm of the supplier and to come back to what actually represents the medical profession. What does this mean for the concrete embodiment of the physician-patient relationship?

The Physician-Patient Relationship as a Process of Collective Decision Making

In an article still worth reading today, Linda and Ezekiel Emanuel already wrote about various physician-patient-relationship models in 1992. The basis was the struggle for the role of the patient in medical decision making processes. This subject is not new to our conference. This struggle, that is often characterized as a conflict between the moral concepts of the patient and those of the physician, is about central ethical and legal aspects in relation to medical obligations. For this reason, it is of great importance for medicine to deal with the question what a preferably ideal physician-patient relationship should look like.

I want to present three ideal typical models of the physician-patient-relationship :

The ***informative model*** describes the situation of the sovereign client quite accurately. This is why it is also referred to as the contract model or the consumer model. In this model the patient's autonomy in decision making is emphasized. After the physician has informed the patient about the medical circumstances, the latter chooses the treatment option he prefers autonomously, according to his own moral concept. This model is also justified by the assumption that physician and patient disagree about fundamental moral concepts.

In comparison the ***paternalistic model***, that coined medical self-conception for centuries, emphasizes the duty of care. It is also called the parent model or priest model. The paternalistic model assumes that there are generally shared objective criteria that help determine what is best. As the specialist, the physician is therefore qualified to judge what is in the best interest of the patient. He decides which measures benefit the well-being of the patient most of all. The patient, for his part, trustingly takes on a subordinate role to the decision making authority of the physician. The physician rather acts as the guardian of the patient.

The ***deliberative model*** of the physician-patient-relationship stresses the mutual process of decision making. The physician informs the patient about the possible treatment goals in the current clinical situation. He and the patient mutually consider which health goals can be aimed for and by which means. According to the deliberative model, the physician acts rather as a teacher or a friend who conducts a conversation about the best opportunity for action. The patient is supposed to become competent to not just follow preexisting wishes without thinking. Rather more, he is to learn to consider alternative health goals and their value and consequences for the treatment. The medical care in this case entails helping the patient make an informed decision according to the patient's values. From an ethical point of view, one should give preference to the deliberative model nowadays. Both the physician and the patient invest an equal amount of effort to develop a mutual understanding of the current illness. If this process succeeds, it will lead to a treatment plan that can avoid conflicts between duty of care and patient self rule. It is self-evident that in this model of mutual decision making high standards are demanded of the patient's ability to consent.

But what makes the consent of a patient a truly autonomous action?

When is the Consent of a Patient also Autonomous ?

What are the preconditions of a medical consultation that enable the patient to decide and act autonomously as a consequence of this consultation? Based on the ideas of American ethicists Ruth Faden and Tom Beauchamp, there are at least four requirements that are to be considered: The power of judgment, understanding, voluntariness as well as authenticity.

1. The Power of Judgment (Competence)

The first question that must be answered concerns the question of the power of judgment of the patient. Is the patient capable to absorb and process the relevant information of the conversation? The power of judgment only exists in actual fact when the patient is able to oversee the consequences of his decision. In doing so it must be taken into account that the power of judgment is not a categorical factor that does or does not exist. Rather, the ability must be regarded as a gradual one, one can have or loose again in different degrees. Thus a patient with Alzheimer's Disease is completely judicious at the beginning of his illness. This ability is slowly lost step by step. On the other hand one must consider that the power of judgment is only valid with regard to certain decisions. Therefore a patient with Alzheimer's Disease, who may not be able to judge the purpose of the medicine he takes, is still able to judge well enough if he would rather take liquids or tablets. The question of the power of judgment must always be asked in reference to a specific action.

2. Understanding (Information)

Understanding belongs to the most important requirements of an autonomous action. But what does “understanding” mean? The criterion that understanding is measured by, is not the completeness of information. Understanding rather depends on how the information is suitable and, above all, relevant. While many physicians tend to restrict themselves to purely medical information, many patients regard their illness in connection to the consequences that these have on their circumstances. These aspects, and not only the technical details, must be essential contents of conversation in the decision making process.

3. Voluntariness

The decision for a treatment plan must not be controlled by exterior influences only. These can be diverse and reach from tangible economical influences to psychological influences. A critical limit has been reached when the conversation is based on persuasion. To persuade someone means that the willingness to be open to refutation is missing, meaning that the concern of the patients are not longer listened to. The act of persuading must therefore be seen as manipulative. If we are, however, able to convince someone in a conversation, then this means that my counterpart is voluntarily willing to adopt my opinion. Therefore, to persuade someone with good arguments does not endanger the autonomy of the patient in any way. One must consider that one can only speak of voluntariness if a sufficient knowledge of alternative opportunities for action is given. Voluntariness therefore is closely linked to informing the patient.

4. Authenticity (Good Consideration)

Within the context of mutual decision making, the physician must also affirm if the consent of the patient is in accord with his values, goals and attitudes, thus authentic and in this sense well considered. In doing so, special care is required as one runs the risk of patronizing the patient, even patronizing him. On the other hand, only by regard of good consideration can one prevent a patient from making decisions that are clearly contrary to his subjective standard of value. An example is the irrational overestimation of acute burdens, like pain, that blur, at least for a short time, the vision of the patient with regard to his values and attitudes.

Respecting the autonomy of a patient as a basic maxim of medical action, is undisputed not only from a legal point of view, but even more so from a ethical one nowadays. The previous statements, however, illustrate that this is a challenging issue that can only be realized in an authentic relationship between physician and patient.

Attention Oriented Medicine

In modern medicine, one seems to increasingly forget that every action is ultimately fulfilled within an encounter of human-beings. This encounter is unique and evades standardization. Recovery is ethicist Giovanni Maio, I want to advocate for an attention oriented medicine. Attention means that one, as a person, faces another person, takes an interest in them and supports them. A big challenge here is the fact that the physician must fulfill a double role in his relationship to the patient. On one hand, he is by all means in demand as a professional helper and professional expert. On the other hand, he will not be able to fulfill this role if he does not also see himself as a human-being in this encounter. Technology is indispensable, but it requires relationship to really take effect. The relationship therefore does not stand for a replacement of technology but as a precondition for its success. The more reliable, the more understanding, the more empathetic a physician is perceived as, the more the technical application will develop its impact. Only via this attention that shows understanding, the person seeking help will sufficiently comprehend that he is important to us and that what he is feeling and thinking is acknowledged as something important. It is an attitude of succor that raises a feeling of salutary self esteem for the patient. And this is the actual agent of an attention oriented medicine.

Is medical care a discontinued model in the age of autonomous patients? I hope that my explanations have made clear, that this question is to be answered with a decisive “No”. Medical care has, however, changed significantly over time. It has become distinctly more complex in postmodernism, where man has the freedom to pursue any desired goal but is becoming more and more insecure about which goals are worth pursuing. As physicians we are further on called to care about the well-being of the patient. By the well-being of the patient, however, it is nowadays understood that the physician accompanies the patient on this path to a free, truly autonomous decision for or against certain medical actions. An attention oriented medicine, an attitude of succour is not imaginable without this aspect of care.

At the end of my presentation I have the misgiving that all of this is self-evident for you, that I have delivered the wrong speech to the right audience. Because the Médecine de la Personne, shaped by Paul Tournier, is an attention oriented medicine. Have both Giovanni Maio and I indirectly come to the conclusion of that which has always been a central concern for Paul Tournier?

Well, if this presentation only repeated nothing but self-evidences for you, I can at least comfort myself that it is repetition that supports us in becoming masters. And if I could contribute a little to your being encouraged to carry your mastership in medical care into modern medicine, then these repetitions have been worth it.