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1.3 *Patients, doctors, information and the power of decision*

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Introduction

A central question, which is raised in the debates on the position of the patients in the health system and in doctor-patient relationships, relates to information about the illness and the treatments patients receive. The objective of providing such information would ostensibly be to give the patient some power vis-à-vis the doctor (LETOURMY A. - NAIDITCH M. 2000).

The contemporary Western patient is usually described as a person who is able to choose, to negotiate with the medical profession, to act as an informed patient, and to adopt the most reasonable health behaviours (MOUMJID-FERDJAOUI M. - CARRÈRE N.O. 2000; KHODOSS H. 2000). One speaks of the rise of an era of patients' autonomy. The studies on this topic make this claim based on the many texts promoting the right of the patient to information and the concept of informed consent. Such statements underlie the present concept of a "health democracy". This concept implies the redistribution of power in the field of health from professionals to nonprofessionals, and more particularly users of health care (RABEHARISOA V. - CALLON M. 1999, DODIER N. 2002, BARBOT J. 2002).

In the social sciences, the emergence and promotion of the concept of health democracy is explained by the disenchantment of many with the medical field (cf. AIACH P. - FASSIN D. 1994 (1)), and was brought to the forefront by the French conference – the "Etats Généraux de la Santé" in 1998 – where patient organisations reaffirmed their wish to receive complete and accurate information.

During this conference, the Prime Minister presented a declaration to take measures that would allow direct access of patients to their medical files. There were also many publications that asserted that the position of the patient has known a true revolution in doctor-patient relationships. For example, Gillot writes that today «being sick doesn't mean any longer to give up its rights and its prerogatives, it is on the contrary to affirm its quality of user of the system of health and to take advantage of the rights which are related to it», and considers that «it is an important change in the social relations» (GILLOT D. 2000: 5) [my translation] (2). According to Brocas & Coz, «the paternalism characterizing a certain form of relationship between doctor and patient is called into question by patients who are more highly educated, better informed and less submissive» (BROCAS A. - M. - COZ G. 2000: 10) [my translation] (3). Today, public institutions and many observers in the field of health praise themselves for the situation of the contemporary patient, saying that he/she has now more power and that he/she can take his/her health in hand, because he/she is educated and informed.

However, we may wonder to what extent this change can be observed. Can we consider that the contemporary patient is truly given this decision-making power, which some authors credit him with? These questions are at the core of my paper because I will put some interrogation marks behind the concept of patient power. My first question is: Is information really shared within the doctor-patient relationship? This question undoubtedly has a Foucauldian accent because the power of medical doctors tries to affirm itself and to fight nozzles and nails against the supposed growing power of patients. Yet, I will show that the responsibility for this unequal sharing of power is not always due to the doctors alone and that it is, in reality, well shared. My second related question is if patients really claim their power in this relation. The analysis will lead us to conclude that doctors and patients have practices enchased in strong compelling cultural patterns, and lead us also to call in question the quasi consensual postulate in social sciences of the patient as an actor.

The texts and the law

The principle of information availability is posed in many legislative texts and many charters, such as the Code of public health, the medical Code of ethics, and the recommendations of the ANAES. For example, the L.1111-2 article of the Code of public health of March 2002 lays out that each person has the right to be informed on his/her health. In fact, it was not necessary to wait until the holding of the Etats Généraux de la Santé to find legislative texts that guarantee the patient's rights and in particular their right to information: there are many texts and professional codes on the rights of patients, whether on the national level (Law Huriet 88, bioethic laws 94, the New medical code of ethics 95, the charter of the in-patient renovated 95) or on the international level (declaration on the patient's rights in Europe of WHO, etc.) (cf. KHODOSS H. 2000).

Article 35 of the medical code of ethics (of September 6, 1995) states that: «the medical doctor owes to the person whom he examines, whom he cares or whom he advises, honest, clear and adapted information on his state, and on the investigations and the cares he proposes to him» [my translation](4). Yet, if this text guarantees information, it allows for one exception; it stipulates indeed that: «However, in the interest of the patient and for legitimate reasons that the expert appreciates in conscience, a patient can be held in the ignorance of a serious diagnosis or prognosis (except whenever his illness exposes others to a risk of contamination)»(5). The principle of information suffers then some transgressions, provided by the law itself.

Information is of increasing concern in our societies nowadays. The whole of the European health systems tends toward an increased respect of the individual patient's rights. It is well known that this situation was instigated by the questioning of the medical profession consecutive to the occurrence of medical scandals, which largely eroded the confidence patients placed in doctors and contributed to 'the crisis of legitimacy of medicine'.

The studies on doctor-patient relationships generally agree to recognize a radical change in the paradigm of this relation. Charles *& al.* (CHARLES C. - GAFNI A. - WHELAN T. 1999) identified three predominant models: paternalistic, shared and informed. The paternalist approach (that the author locates before the Eighties in the US) implies that the doctors assume the dominating role; the approach rests on the idea that they know what is best for their patients. This legitimation of medical control was buttressed by ethical codes, which urged medical doctors to act in the best interests of patients. In turn, this allowed both doctors and patients to expect that doctors (and not patients) should play the dominant role in the decision-making process. During the Eighties and afterwards, the credibility of this assertion was called into question. The informed model and the shared model of treatment decision-making were both developed in reaction to the paternalistic model. However, although Charles *& al.* (CHARLES C. - GAFNI A. - WHELAN T. 1999) assume that these two models (informed and shared) are distinct, they describe both of these new models of decision-making as resulting from the search for alternatives to the traditional paternalistic approach.

In a review of the scientific literature (mainly Anglo-Saxon) on the recent transformation of doctor-patient relationships made by Moumjid-Ferdjaoui and Carrère (MOUMJID-FERDJAOUI M. - CARRÈRE N.O. 2000), the authors present evidence for the transformation of this relationship in France through the use of legal and administrative texts, justifying this by the fact that scientific literature is not very developed on the subject. But can one adequately support such an argument using only legal texts? If these texts bear witness to an interesting change in the society, their use as an exclusive source to evaluate the reality of this transformation is not enough, though it is in itself an eloquent source. On close examination of the reality of the situation, one fails to establish such a modification in the doctor-patient relationship and above all to affirm that the patient is really informed.

This is the case within hospital-based medicine. The declarations on the necessary provision of information to the patient may rest on an ethical and political presupposition that information is an essential condition to the efficiency of a democracy. It indicates respect of the patient's autonomy and dignity. These declarations may also rest on a pragmatic point of view, since the provision of information to the patient contributes to the improvement of the quality of care (GHABI V. 2001). However, Ghabi notes that in a great number of cases, the written documents that the patient must sign aim more at protecting the doctor from the legal consequences of possible risks of treatment, than to inform the patient adequately. If the law relating to the hospital reform envisages the communication of all information contained within the medical file, there is no question in this law of actually giving the file to the patient. Rather it is the presentation of information by the practitioner, which is sought out (PONCHON F. 1998), based on the idea that the patient is unable to understand the contents of the file. If the claim of patient associations to view medical files without an intermediary led the minister to promise in 1998 a patient's direct access to his file, this is far from being realized. The provision of information to patients recommended by the texts is not so much an answer to ethical or therapeutic concerns as to a legal concern. It is very often because of the fear of prosecution that doctors inform their patients. If the goal of the legislative texts is to "cool down" associations of patients and their claims, they do not express a real will by the medical profession to make available, for the patients, information concerning their illness and their body, even though some of them agree it is better to pass information for therapeutic reasons. The model of shared decision itself seems to have been forged on the fear of lawsuits, more than based on the conviction of the doctors (6). It appears as if only legal reasons are at stake. The investigations on this topic show that doctors are often, insofar as it is not strictly required by the law, extremely reticent to give patients information on the state of their bodies and their care. If the declaration on the promotion of the patient's rights in Europe of 1994 would refer to the patient's right to be fully informed, on his health and on the risks and advantages that the medical acts entail (cf. PONCHON F. 1998), the communication of the patient's medical file is always done by the practitioner. My investigations reveal that many patients do not know their illness and their treatment, its risks and its consequences. In a way, the recommendations made by Hippocrates to hide things from the patient (7) seem to be still used. Broclain notes the absence of search for consent in the routine examinations in a service of cardiology, and considers that a long way remains to be made for the autonomist paradigm (8) to take shape in the practices of care (BROCLAIN D. 2001).

The issue of provision of information to the patient doesn't only amount to the issue of consent. It includes all that relates to the body and the health of the patient, the diagnosis and treatments, benefits and risks, and the action of prescribed medicines on their illness and their body. The gap between the texts of law and the reality of practices can be checked on various levels. For example, although the Code of Public health states that «any person has access to the whole of the information concerning his/her health held by professionals and establishments of health», information continues to be withheld from the patient. In the case of breast cancer screening as it is practised in screening centres the patient is forced to give the name of a doctor to whom the result will be communicated. The result of the screening is not communicated to the patient directly. This suggests that the patient is unable to deal with his life, his body, his health, and is incompetent to take the necessary measures. The refusal to recognize this capacity of the patient remains the strong marker of the paternalist model. It is a refusal orchestrated by the entire system of health and relayed or reinforced by health professionals.

Doctors and patients

The deficiency of information can also be observed within the framework of private consultation. In this respect, it is necessary to consider the real practices of the protagonists of this doctor-patient relationship. For example, a good part of what is called the misuses of pharmaceuticals is connected to ignorance of the patients, an ignorance that is maintained by the French system of health and, more broadly, by its social and cultural context: there is a tendency, on the part of doctors, not to inform the patient and even to lie to him about the illness, treatment, its reasons and its risks. These considerations are based on the observation that the practice of lying is a recurring practice in the behaviours of the medical profession with regard to the patients, as for example the fact of lying on the possible side effects of the drugs to incite the patients to comply with the prescription (FAINZANG S. 2002).

Many physicians to whom a general practitioner has sent a patient, rather than inform the patient of their impressions during the consultation, merely address a mail to their colleague without informing the patient about the diagnosis, or they will refuse to answer the patient's questions. Consequently, how can doctors claim that they guarantee the patient's autonomy when they refuse to disclose information relating to his own body and to his therapy? Therefore, if some social classes are denied the material conditions of the access to care, they are also denied a possibility of being in charge of their own health.

The fact that information is differently dealt with and communicated to patients (for ex., see GORDON D. 1991, for a comparison between Italy and the US) shows the social and cultural (and of course always historical) nature of information and of the reasons which underlie diffusion or retention. Today, in France, sharing of information continues to be perceived as of little importance considering the competence of the practitioner and the incompetence of the patient.

I do not mean that doctors and patients are necessarily antagonists, that is to say that they would be in a relationship where the first ones would always seek to keep information for themselves, and where the second ones would always seek to acquire it. Diverse studies on associations of ill persons have concluded that the patient is active, an actor dealing with his health problems and his therapy (LASCOUMES P. 1998, RABEHARISOA V. - CALLON M. 1999). However, this is not the most common behaviour in patients. This perception of the "contemporary patient" is extrapolated from the existence of relatively marginal associations. Of course, the associations bear witness to this will to react against this paternalist model. The federation of these associations into a "Collectif inter-associatif sur la santé" (which gathers associations of families, consumers, ill or handicapped persons) reveals their will to establish a counter-power vis-à-vis the medical power, by giving an institutional role, namely a direct participation, to the user. However, few people are in such associations. Thus, one can say that the associations are not representative for the majority of patients. Besides, the fact of belonging to an association of which the national office or the head department expresses some claims doesn't imply necessarily that the patient has, personally, the same attitudes. Though the associations of users clearly defend the right of patients to information (LASCOUMES P. 1998) and convey a model of a patient-actor (KHODOSS H. 2000) who benefits from his right to decision, the question is to know to what extent the majority of the patients really wish to exercise this right. (DEGNER L.F. - SLOAN J.A 1992). This question leads us to wonder whether the patient is really an actor, as is asserted by Rabeharisoa & Callon (RABEHARISOA V. - CALLON M. 1999) and Barbot (BARBOT J. 2002). To be an actor is to be active. It is interesting to note that according to Blanchard *& al.*, though 92% of the patients admitted to hospital with cancer would prefer that all the information is given to them, whether it is good or bad, their wish to have every piece of information doesn't necessarily result in active behaviour of seeking information when they meet the doctor (BLANCHARD C.G. - LABRECQUE M.S. - RUCKDESCHEL J.C. 1990) (cf. also BEISECKER A.E. - BEISECKER T.D. 1990). According to these authors, this discrepancy is related to the patients' vulnerable situation or fear that their request for information would be interpreted by the doctor as a lack of trust.

It is naïve to speak of the "contemporary patient", without taking into account his social and cultural characteristics. It is clear that information is mainly given to the persons who are socially in the position not only to understand it, but also to ask for it, and who are the most inclined to confront the doctor and the authority he embodies. A recent study on the behaviours of patients towards their medicines, their prescriptions and their doctors, shows that even people from the same social milieu have different ways of behaving, which are related to their culture, namely religious family belonging or origin, and that these underlying influences are articulated in a certain relationship to power and authority (FAINZANG S. 2001). More concretely, it seems that many patients put themselves completely in the hands of their doctors and tend to deprive themselves of control over their body. This happens more in the milieus of catholic origin than of protestant origin, as members of the first do not grant the same value to autonomy and to dealing with their body and their illness. On the whole, and probably because the French population is much more marked by catholic culture than by protestant culture, a great number of patients do not read the leaflet of the medicines they take, do not draw their doctor's attention to their possible allergies if the latter doesn't ask, and, thinking that it is the role of the doctor to know what he has to do, delegate a great part of their possibilities of choice and decision to medical authority[9]. Therefore, one must not put all responsibility on the medical system nor on the medical professionals; the patients do play a part in this situation. There are contrasted observations on the percentages of patients who declare they want to participate in decisions or that they prefer leaving this responsibility to the doctor (ENDE J. 1989, BEISECKER A.E. - BEISECKER T.D. 1990). For Ende (1989) the seriousness of the illness, the age, the genre and education have a strong predictive value regarding the seeking for information; for Beisecker & Beisecker (1990), the socio-demographic characteristics and the state of health do not explain the differences among the patients. Other factors exist: Baider *& al.* insists on the ethical and cultural characteristics of the patients, especially as demonstrated by a study on the attitudes of Israeli versus Russian patients in cancerology (BAIDER L. - EVER HADANI P. - DE NOUR K. 1995)

If the paternalist model has not disappeared, it is also because patients have been taught, especially in the context of catholic culture, to conform to an authority, and namely to have a certain passivity and a certain submissiveness towards medical authority. It is interesting to note that many of those who resort to the Internet, do so because they do not dare to ask their doctor for the explanations they'd like to have. Many authors think that the Internet contributes to the emergence of a new patient role. Some go as far as speaking of an “expert-patient” (HARDEY M. 2004), insofar as, the patients use the Internet to gather information. To Hardey, this approach of the expert knowledge of citizens is inscribed in the vast movement of democratisation of science, connected to the loss of trust in the power of science and in the capacity of experts to save lives and bodies. Of course, a growing number of persons use the Internet as a source of information on health, expressing a real will to gather information, but this information is not often acquired in the framework of the relationship with the doctor. Patients confess that they often do not dare to ask for it. The Internet continues to be perceived in an ambivalent way by people who resort to it: some view it as a source of authority competing with that of their doctor in the same way as television (some spectators not knowing to distinguish what is information and what is advertisement), while others say that they consult the Internet out of curiosity but that they only believe what their doctor tells them (10). Here, the doctor remains the expert likely to confirm or to invalidate the information obtained elsewhere, as he sometimes does, with the content of the leaflets (FAINZANG S. 2002). Another issue is that of the reservations or even the reticence of some doctors towards the recourse and the use of the Internet by their patients. One may ask whether this reservation or reticence is due to the fear that this recourse makes the consultation less necessary because patients are able to obtain medicines without prescriptions. Or does the reluctance stem from a real concern of wrongly understood information: "*It's terrible! We have to repair the damages afterwards!*", some doctors lamented during my investigations.

The issue of information availability extends beyond the sole framework of the doctor-patient relationship. The problem of the access to information, a necessary condition of access to care and health, can be studied on other levels. For example, there is no other pharmaceutical information than that given by laboratories. The pharmaceutical industry is the main actor in the production and diffusion of medical information, and only some data resulting from clinical trials (achieved in order to obtain the authorization of commercialisation are used in the commercial promotion of these products to doctors and patients (cf. MINTZES B. 2001, LEJEUNE S. 2002, COLLIER J. - IHEANACHO I. 2002). An important part of the responsibility for this belongs to the State, which doesn't provide any neutral and independent information on pharmaceuticals [11]. The medical doctor is also, in part, a victim of this bad information ("Revue Prescrire", 1999). In this respect, the situation today is not exclusively that of an omnipotent doctor in front of a powerless patient, who would be a victim according to the "paternalist" model. It is rather that doctors and patients together are victims of pharmaceutical industry. Some doctors are aware of this power, as a recent Website called < Healthy Skepticism> proves. Doctors no longer have complete power, even though some fight to regain it, through adapted information (see http://www.healthyskepticism.org/index.htm). The desperate struggle for information is nowadays one of the major issues of our healthcare system.

Conclusion

It is obvious that information is an issue where shared power is at stake (DELCEY M. 2001). This issue is differently dealt with depending on the pragmatic (that is therapeutic) or on the ethical (that is political) level. However, if its legitimacy and usefulness is now recognised by the law, the reality of the doctor-patient relationship shows it is not recognised on a practical level. It is illusory to believe that contemporary patients enjoy all the conditions which would allow them to make choices, since, against current ideas of "enlightened patients", society doesn't give them the information that is the prerequisite.

The difficulties are many. For Lahoute, «If the rights of the users of the health system are well framed by legislation, the main problem is that of the application of these rules» (LAHOUTE C. 2000: 17) [my translation] (12). The author seems to see only a difficulty of application of the legislation in the civil society. Yet, the obstacles are not only in the juridical difficulties or delays. They are also cultural. There seems to be, among healthcare professionals, more professions of faith and declarations of intention on the necessity to inform patients than effective behaviours attesting this will to inform them. In spite of these declarations, one notices strong resistance from doctors as well as from patients, calling into question the postulate of a structural evolution in the doctor-patient relationship. Beyond the progress made possible by the action of patients' associations, the new practices of some medical professionals and the law on the necessity of information disclosure, it appears that doctors and patients have behaviours deeply rooted in strongly marked cultural patterns, and rest on values which are conflicting with the democratic carrying-out of information provision or seeking. There are social and cultural obstacles to health democracy.

I wish also to call into question the so-called ”working-out” of the logics which prevailed in the previous model of this relationship; not in order to argue that things have not changed, but to acknowledge that this model, resting on claims and rights to which the behaviours and practices do not echo; is desperately gasping for a new type of relationship. The issue of medical power must be raised in new terms (13). The point is to stress the new configuration in the doctor-patient relationship. If it is true that power is no longer exclusively in the hands of doctors and that it has become an object of covetousness between doctors and patients, it is also obvious that this power is unequally used, held or even claimed by patients. In this respect, the notion of "citizen" attached to that of "health democracy" is reducing insofar as it obliterates the social and cultural diversities on this matter, presenting patients as having a homogeneous statute in front of doctors.

These reflections lead me to question the conclusions of some studies in social sciences, which sometimes seem to convey more the phantasms of their authors than the description of reality. Declarations such as of Giddens' (GIDDENS A. 1994) on information, negotiation and decision seem to place us in front of the vision of a coming golden age for the patient, a patient who would be informed and reflexive. Is the patient really this active individual, knowing how to choose and negotiate? Observation of real situations reveals that information on health often remains in the hands of doctors. If the role of anthropology is to dismantle myths and to question "evidences", one should wonder if the idea of a "changing medical context" is not partly a myth (14), and ask more shrewdly what is really "changing". Maybe the nature of the change is not so much in the statute of patients as the discrepancy between the values conveyed by the notion of "health democracy" and the values that underlie the concrete behaviours of the protagonists in doctor-patient relationships.

Notes

(1) These authors evoke the shift of confidence to suspicion and doubt, and the crisis of legitimacy, which medicine has undergone

(2) «Etre malade, ce n'est plus abandonner ses droits et ses prérogatives dans l'urgence et la résignation; c'est au contraire affirmer sa qualité d'usager du système de santé et faire valoir les droits qui lui sont afférents. Il s'agit là d'une mutation importante des relations sociales».

(3) «Le paternalisme caractérisant une certaine forme de relation entre médecin et malade est remis en cause par les attentes de patients plus instruits, mieux informés et moins soumis».

(4) «Le médecin doit à la personne qu'il examine, qu'il soigne ou qu'il conseille, une information loyale, claire et appropriée sur son état, les investigations et les soins qu'il lui propose».

(5) «Toutefois, dans l'intérêt du malade et pour des raisons légitimes que le praticien apprécie en conscience, un malade peut être tenu dans l'ignorance d'un diagnostic ou d'un pronostic grave (sauf dans les cas où l'affection dont il est atteint expose les tiers à un risque de contamination)».

(6) It will be noted that concerning the "informed consent", the medical doctor must prove he gave to his patient a honest information, clear and adapted on the risks of investigation or the cares that he proposes to him, in order to enable him to give an informed consent or refusal to them (judgment of the supreme court of appeal of October 14, 1997).

(7) «We will make any thing with calm, address, hiding to the patient, while we act, the majority of things, giving him with gaiety and serenity the encouragements which are appropriate [...], not letting him foresee anything of what will happen nor of what threatens it: because more than one patient was put at any end by this cause, i.e. by a prognosis where he was told what was to happen or what was threatening» [my translation] («On fera toute chose avec calme, avec adresse, cachant au malade, pendant qu'on agit, la plupart des choses; lui donnant avec gaieté et sérénité les encouragements qui conviennent [...], ne lui laissant rien apercevoir de ce qui arrivera ni de ce qui le menace: car plus d'un malade a été mis à toute extrémité par cette cause, c'est-à-dire par un prognostic où on lui annonçait ce qui devait arriver ou ce qui menaçait») (HIPPOCRATES 2001).

(8) The autonomist model is supposed to have replaced the paternalist model; it is the model according to which the patient is in right, as an adult citizen, free and responsible, to refuse the decisions of his doctor and to assume, provided that he has an appropriate information, the role of final decision-maker of the cares which regard his case (BROCLAIN D. 2001).

(9) The use of the term "culture" doesn't imply that we must occult the social, economic and political realities which underlie the behaviours of patients towards their doctors. There are of course other determinants, such as gender, age, class, education, etc. which make the issue of agency a very complex one. But the issue of culture sometimes tends to be neglected on the motive that anthropological research has suffered from the fashion of culturalism and from its tendency to essentialise the realities that are observed. A right criticism has opposed omission to culturalism , on the grounds that it neglects the social realities and namely the social disparities and the historical context. However, rather than submit to this tendency to essentialize social phenomena and to consider them as founded on a reality given for ever, we can have a dynamic conception of culture and see the cultural context in which health behaviours develop as being in perpetual

construction, articulated to other dimensions no less dynamic such as the relationship to the body, to the Other, to knowledge or to power.

(10) Would the Internet be as the horoscope is for some people? Something they regularly consult while saying they don't believe what it says?

(11) Many works – for ex. VIAL A. 1999 – show that medical and pharmaceutical information is completely submitted to the requirements of marketing, a situation all the more harmful as they are substances, which are not deprived of iatrogenic risks.

(12) «Si les droits des usagers du système de santé sont bien encadrés par la législation, le problème essentiel est celui de l'application de cette réglementation».

(13) Things are complex: how to understand for example the discrepancy between the discourses of some patients (such as: "Doctors do not want to inform us"), and, as a counter-balance, the discourses of the doctors ("patients don't want to know"). In this respect, the position of the anthropologist is to take both discourses as valid and both parties as right. He must merely try to understand what is going on in this discrepancy and how concretely achieved are the use, the seeking for, the divulgation or retention of information. In this respect, social sciences and particularly anthropology should investigate the concrete context in which such notions as the "education of the patient" are used, when the social and cultural environment reveals that, in a complicity between professionals and patients, information and decision remain in the hands of the ones and are withdrawn from the others.

(14) In this respect, we can but agree with Christine Hogg when she stresses the myth of the patient as partner and as consumer: «There is a new myth, that patients can be partners with government, professionals and pharmaceutical companies» (HOGG C. 1999: 171).

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