

## **“Between ethnology and the public sphere: a *pas de deux*”**

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In the debate which is currently raging about the links between science and society, any analysis of the links between public space and the ethnographic approach involves thinking (before and after the research) about the place occupied by society's own questions regarding those raised by research. However "social" the questioning at the root of ethnographic research might be, it does not necessarily correspond to a social requirement. Whilst the ethnographic approach can be rooted in the existence of a social question (whether it is explicitly formulated by the media, public institutions, associations, or any other expression of public opinion), the examination of a social issue does not necessarily, for anthropology, involve formulating it in the terms defined by the public sphere. Indeed, the role of the ethnologist is to construct an ethnographic approach and thus to stand back from public debate by either giving him/herself a new object, or by changing the existing one. This not only supposes a critical stance with regard to the categories of the ethnologist's own discipline, and constantly refreshing them by listening to the public sphere; it also supposes distancing oneself from questions from the public sphere, by processing them - by reformulating the problem.

In this article I intend to present the framework for the public debate that is currently taking place in the field of health with regard to the patient's role in the healthcare system, and to examine how this debate affected the development of the ethnological research which I recently carried out on information and lies in the doctor-patient relationship (cf. *La relation médecins-malades : information et mensonge*, S. Fainzang, Presses universitaires de France, 2006). By putting this into perspective, I will be able to highlight the dynamic proper to ethnographic questioning, i.e. to show how the problem specific to the research was constructed (by both *similarity* and *difference* to questions on this matter found in public space) and, in return, to show what this construction and the ethnographic approach it involved were able to bring to the debate. I will use this example to explain what the ethnographic approach owes to public debate, but also how it has contributed to later development, and the conditions under which this latter role was made possible.

## **The nature of the debate**

French society is currently seeing a major debate on the role of patients in the healthcare system. Many segments of the social sphere emphasize the new role of the patient, and make themselves heard in varied contexts (forums, associations, publications, etc.). Among the strong points of this debate are issues as diverse and complex as patient information, informed consent, the exercise of a more human medicine, and the participation of patients in their own treatment. To a large extent the impetus for this debate came from patient associations, and from the area of AIDS in particular.

One concrete example of the new role of patients being put into practice within the social arena, was the meeting of the *Etats Généraux des malades atteints du cancer* in 1999, following an initiative by the Ligue Nationale Contre le Cancer<sup>1</sup>. Like other public events, this meeting confirmed the need to take patients into consideration, to treat them more humanely and more especially to rethink how the illness should be announced, and the ways in which patients and doctors might communicate. Behind these demands lay that of allowing patients to stop being objects and start being individuals. The debate thus turned towards the recognition of patient as an actor, properly armed to be able to take decisions, whom both carers and society as a whole should allow to exist as such and towards whom they should demonstrate greater humanity. This debate essentially revolved around issues of competency and ethics. Some sociologists were party to this debate, basing their works on a stance that involved shouting the patient's role as an actor loud and strong, and arguing for this role to be recognised – although without it being clear whether said role was observed or demanded, in other words whether patient autonomy was a proven and observed social phenomenon, or whether it was a hobby-horse, one stake among many in a debate on patient status in the world today.

In this context, other voices made themselves heard, those of a certain number of health professionals expressing (in the worst cases) their scepticism with regard to patient competency, or else (in the best cases) their inability to properly manage the human dimension of a patient's treatment. In the latter case, they offered both technical reasons (the lack of time) and psychological reasons (patients' inability to hear diagnoses of their illness). It is indeed noteworthy that literature on this issue (be it written by doctors, patient associations, or

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<sup>1</sup> French national league against cancer.

sometimes even sociologists or philosophers) generally aims to defend a particular position – that of the doctors or that of the patients. Such literature has trouble getting away from the heartfelt debate on the question of information. The acuity of the public debate on this matter gave rise to the law of the 4<sup>th</sup> March 2002, known as the “law on patient rights”, which guarantees a person’s access to “all information relating to his or her health” and which marks a victory for patients.

It is no coincidence that the term public “arena” is often used to designate the public sphere. The former has a connotation of combat (which sphere and space do not) and is especially interesting in this respect, given the relatively polemical nature of the debates that take place therein.

This does not mean that ethnology has to come down in favour of one side or the other. Ethnologists must first of all decide how to approach the problem from a distance, even if they are then obliged to declare their choices and options (social, political, philosophical). It is only when the analysis is finished that they can choose to take part (not as citizens but as researchers) in the combat raging in the public sphere.

With regard to this debate, we first of all need to examine the reality of patient information and put the object to the test out in the field. But researchers must also consider the question from another angle; they must think about the problem in a different way, or else they would end up confirming or refuting a question which has been defined by the actors themselves. This may be achieved by ethnographic study and, above all, through the construction of the modalities of the study. It should be noted that, in our opinion, the construction of the object, included in the problematisation, is indissociable from the methodology. This is why I felt that it was necessary to do a dual study, from the patients’ point of view and from the doctors’ point of view.

### **The anthropological and ethnographical approach to the debate**

The founding principle of this study was that in order to make the most useful contribution to both public debate and theoretical debate, researchers must know how to free themselves from their assumptions and presuppositions. In other words they must not jump straight into the arena, must not take sides; instead they must create the conditions that allow them to understand both sides of the argument, both doctors and patients.

The aim of the research was to highlight the logics and mechanisms at the root of information exchange between doctors and patients. The surveys involved observing medical consultations and then separately meeting the doctors and patients with a view to examining the way in which the verbal exchange takes place and decoding the reasons and mechanisms behind acts and words. This approach inevitably led me to gather not only doctors' methods of informing their patients but also the ways in which patients pass information to their doctors and the lies that each tells to the other.

The study revealed numerous misunderstandings, for which I tried to reveal the causes, and which I used as a basis for once again addressing, in a critical manner, the question of doctor-patient communication, of the latter's decision-making power, and of the nature of the medical relationship of which lies appear to be an unavoidable part.

It should be said that with regard to ethnographic tradition, the fact of working on two groups at the same time does not mean working on two objects. Traditionally, anthropology tends to construct its object by identifying it with a group that it places at the heart of its research. Anthropological focus on a group is what usually leads it to only perceive its object through the eyes of the actors themselves. Anthropologists, if they wish to depart from this grid by creating conditions for self-distancing, generally base themselves on categories of thought, which can be identified with those of the group under study. Here on the other hand, the object of the research necessarily included two groups because it bore upon the *relationship* between them. The research was thus based upon two distinct lines of thought, produced respectively by possibly antagonistic patients and doctors, confrontation between whom was all the more complex as they sometimes echoed one another (after interiorisation of the medical discourse) and as they were also marked by a certain heterogeneousness. To achieve this, it was necessary not to favour one point of view over another. So it was not a question of doing an ethnographic study of patients or doctors, which would have led the ethnologist to develop empathy with one side *or* the other (in an exclusive manner), but of doing an ethnological study of a *relationship*, involving both sides, with regard to whom the ethnographic approach (with the immersion and observation that is implied), through the dual empathy that it helps develop, became the best tool for decentring. It was a case of not only creating a distance (a standard preliminary condition in anthropology) from the object under study, but of the researcher distancing himself/herself from the preconceived ideas that he/she inevitably holds as an ordinary citizen. This is a necessity which is hard to observe, because as private individuals, researchers are also involved in the debate. In this respect, to the need for *distancing* (which means not adopting the same way of thinking as the group under study) must be added the need

for *decentring* (which means gagging or changing one's own system of references and not becoming involved in the heart of the debate). Thus in addition to distancing from the object there is distancing from the social debate in which the object is included, through a *displacement* of the researcher who attempts, in turn, to put him/herself in the position of the various protagonists of the relationship being studied.

This necessity for decentring is even greater when the question asked by the status of the contemporary patient implies not that the patients be studied *as a group* but that they be studied *within the doctor-patient relationship*. Moreover, this relationship is socially defined as being potentially conflicting, due not only to the changing nature in contemporary society of patients' status *with regard to their doctors*, but also to the related stakes surrounding the issue of rights and powers (of which the satellite notions of "autonomy", "consent" and "negotiation" are very much carriers).

At a more strictly problematical level, to follow in the footsteps of the public debate on patient information (which mainly – particularly with regard to the stances taken by patient associations - revolved around the *manner in which* patients should be told the truth of their diagnoses) was to run the risk of either simply becoming the "spokesperson" for said associations (which is not the researcher's role) or of bringing the work into a biomedical domain by simply reducing the debate to the ethical or therapeutic stances of the healthcare providers. It was therefore a case of not only re-examining that which was considered as "obvious" by gathering ethnographic material out in the field, but also of accepting to come up with an analysis of "lying", at the risk of using a term deemed irreverent by the medical profession. Furthermore, by examining "lying" as a bilateral practice I was able to shift focus and look at therapeutic relationships as social relationships.

My decision was thus to also break away from the stance taken in most works on the question of truth in medicine. Unlike works done within the framework of these debates, and which generally tend to lead to writings in the form of justifications for what is known as "therapeutic privilege", or else to pleas for patient participation, it became vital to change the perspective from which these issues are generally approached.

The heuristic dimension of the approach is closely linked to its richness in relation to society's stakes, because by constructing a new stance, borrowed from the axiomatic foundations of the discipline, it rebuilds the object, leaving the road open to new observations, on the fringe of those made by other disciplines such as medicine and psychology. Indeed, as a counterpoint to the psychological perspective from which existing literature examines the issue

of patient information, considering that the truth is told to those who are psychologically apt to hear it, it was necessary to “depsychologise” the approach to this phenomenon and to look at its social mechanisms.

By breaking away from the usual explanations of a psychological type, so widely distributed throughout the public sphere, the ethnographic study made it possible to highlight the anthropological and sociological mechanisms, giving the debate a new direction. The study has made it possible to reveal the existence of sociological mechanisms at the root of patient information. Unlike a debate between those who believe that patient information is no longer a problem, because it is provided in full, and those who say that it is not being provided (the latter being in turn divided into those who deplore it and those who defend it), this study revealed the *conditions* for this information. It highlighted the fact that information is not given in an identical manner to all patients, thus reproducing or even strengthening social inequality regarding access to information.

### **A contribution to social debate**

Of course, in the aftermath of research one cannot avoid the question of what the ethnographic approach brings in its turn to the public space, through the recentring that took place during the study : so, by contrast with the contours of the social debate sketched above, particularly with regard to whether or not giving complete information to patients is well-founded, as we have seen, the ethnographic approach revealed the mechanisms of this information and the social inequalities it creates. Henceforth the contribution which the ethnographic approach makes to the public debate offers a reversal in perspective. It is not simply a case of knowing the effect of medical practice (by choosing whether or not to inform patients) at a therapeutic level (to the benefit or detriment of the latter), but also its effect at a social level. The deconstruction of the issue and the decentring of the researcher allow him/her to rephrase the question asked in the public sphere, in a different form. This change is made possible both by consideration of the public debate and by the reproblematisation that the ethnological approach achieves, in keeping with the observations of the ethnologist. It is thus at the end of an almost circular path that scientific production comes into effect and contributes towards the questions that society is asking.

The ethnographic approach thus affects public debate through the objectivation that it creates. For it does not produce one point of view among many, as they are expressed in civic

debate, but facts which are proven by the study, with its specific analyses strengthening or reorienting the debate.

Moreover, although deeply rooted in social debate, the ethnographic approach allows one to re-examine works carried out in the academic field. In the case in hand, the ethnological study of information and lies between doctors and patients reveals that lying is not a weapon used solely by those in power. Despite the standard anthropological analyses done on this practice, it is also a weapon used by others (those who are dominated, the weak, patients – however one might wish to label them, depending on the context). Whilst the ethnographic study allowed me to rethink the doctor-patient relationship, it also enabled me to rethink lying as a social practice, the meaning and function of which here reside in the tension between the choice of conforming to or resisting the social roles allocated or defined by society. The contribution to this theoretical debate is made possible by the new perspective used, which is itself conditioned by the ethnographic approach chosen.

## **Conclusion**

The tendency of social science disciplines is often to espouse or to repudiate public debates. Some embrace the ideas of social combat, going so far as to formulate their research in the exact line of the questions raised by the media or by the actors present in the arenas. Others look at public debate with contempt, and consider that it should in no way interfere with fundamental research, relegating any works which might serve its cause to the level of research-action. Another avenue is that which consists in stepping back from the presupposed aspects of public debate, in order to affirm a specific and original disciplinary approach through which to re-examine social issues through one's own eyes – perhaps the most beneficial way to make them progress. Ethnology can seize a social issue and reformulate it in its own terms, with its own tools and its own particular epistemological stance, and it is this decentring which allows it to produce new results that it can then restore to the public sphere and which are of a type to help or reorient the debate. Ethnology and public sphere thus dance a *pas de deux*, in an enterprise of jointly constructing knowledge, albeit on the condition that the former is able to free itself from the forms given to the questions that the latter is asking. The effectiveness of its work and of its role in society depends on it. But so does its autonomy which is its prerequisite. In this sense, the condition of the researcher's contribution is

sometimes to remove him/herself from the framework of the problem, inside which others want to enclose him/her.