

## **WP 4: A survey on the state of public debate on immunosuppression and tolerance induction in the context of human transplantation.**

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As part of the Riset project on transplantation tolerance, an analysis of the state of the public debate on immunosuppression and tolerance induction was performed, in order to explore questions emerging or circulating in the public space. The studied areas were media, institutions, associations and personal exchanges. A corpus of texts and other resources was assembled: articles (daily press, medical press), TV, internet sources (national transplant agencies, patient associations, forums/lists of discussion of patients). The social needs for information were addressed by analyzing the information delivered through various canals, the exchanges between patients or their families and the needs they expressed. The countries involved were France, Netherlands, Belgium, Germany and Italy. In the field of health, information is potentially the condition for debate to be possible in society. It is considered that the analysis of the data collected will provide an indication of what it is desirable to know or what is perhaps taboo.

### **Analysing the media to observe and understand the debate**

The media are considered to be a public area in as much as they symbolically reproduce an area, a place where points of view are exchanged and compared, enabling each person to develop his/her own opinions. A newspaper is an area open to a great diversity of discussion, knowledge and opinion. In this study, the area of the media (daily newspaper, specialized press, television) presents a real interest for grasping, through the various viewpoints expressed, the issues of transplantation and the research pertaining to it, in particular with regard to tolerance induction. The diachrony (period of time) defined for this study extends from 1990 to 2006, which should enable observation of the emergence and evolution of relevant questions.

### **The notion of "public": a methodological difficulty**

It is important, in an analysis of public or social debate to find out what the true public for debate is. But the notion of "public" and its definition is not simple when the resources are electronic. Apart from menus clearly identified as being aimed at "professionals," "doctors," or with access controlled by codes, the architecture of the sites, the type of information, and the way it is stated, define actually the public. It is then possible to look for links established with the various publics (proximity/distance, expert language/ popular or everyday language). When everyone has access to the information there is then the question of understanding more or less specialized language.

### **Results: The information paradox**

Analysis of the various resources revealed a paradox between the diversity of information concerning immunosuppressive drugs and the feeling of a lack of information on the part of transplant patients.

#### **1. Diversity of debate and feeling of "lack" of information**

The expectation of information appears clearly, on the part of transplant patients, through the search that shows up in their exchanges (mention of articles, audiovisual programmes, conferences or specialist Web sites), or by their complaints. This observation is in agreement with other surveys. This feeling of lack of information can be interpreted as translating the anxiety induced by having to take medication for life, the uncertainty of the future (permanent risk of graft *versus* host reaction or rejection). There thus appears a relative inadequacy between the responsibility of providing information and the real need for information on the part of transplant patients. This characteristic perpetuates the already well-studied problems of scientific information. Information considered being a need for knowledge does not answer the needs of the public, more oriented towards practical aspects (which come through quite clearly from the exchanges on the forums).

## **2. Immunosuppressive drugs: a major concern of transplant patients**

For institutions or associations, information concerning immunosuppressive drugs is mainly descriptive (list of drugs, side effects, sometimes dosage) and is based on the requirement for “anti-rejection” prescriptions or presented as a guarantee of quality of life for patients.

Patients use a considerable part of their on-line exchanges for dealing with immunosuppressive drugs (acceptance, adjustment of dosage, changing of drugs, side effects) which preoccupy transplant patients and feed their anxiety. These characteristics are also to be found in the few articles in the French daily press that we analyzed. In the forums, sharing experiences also contributes to balance out the negative side of the treatment. Some Internet users thus put the side effects into perspective by emphasizing that they do not systematically appear, or by mentioning the quality of life regained.

This preoccupation with immunosuppressive drugs and their effects – which appears here in a predominant way – does not surface much in the social arena. In the television programmes (on a reduced corpus), mention of treatment disappears in favour of a very positive debate on the quality of life recovered and/or ideological debate with regard to organ donation. In the FAQ’s of institutions, the usual questions, in France as well as in Germany, United Kingdom and Italy, the issues are mostly technical (transplantation surgery) or procedural (consent procedures).

Paradoxically, immunosuppressive drugs raise few ethical questions and few questions with regard to research in the field of immunosuppression and tolerance induction. Indeed, the side effects, even the most detrimental ones (loss of graft, appearance of certain disorders), produce no questions as to the limits of the feasible. The transplant induces that sort of inescapable state of pharmacological dependence practically undisputed.

But the future of transplantation – in terms of research – is marginal, both for institutions and for associations. The latter hardly mention life after transplantation other than as entering into a new community of sharing in which the social aspects are predominant (encounters, recreational manifestations, sports or cultural events).

And yet, research on tolerance induction, if it evolves favourably, could, according to Professor Pierre Gianello *“change the face of modern transplantation and solve the problem of the long-term survival of organs.”* (article online on the Web site of the Belgian association EuroLiver Foundation).

## **3. Future therapies and tolerance induction: subjects which are taboo?**

Over the entire corpus, a sort of silence on the future of immunosuppressive therapies can be observed. There is an almost total absence of information relating to research on immunosuppression –

and tolerance induction – whereas a perception of anxiety linked to “anti-rejection” treatment on the part of transplant patients has just been demonstrated.

As far as the transplant institutions are concerned, Eurotransplant is the only one to mention the subject. Tolerance induction is presented as a panacea.”).

As far as the associations are concerned, only the EuroLiver Foundation, in Belgium, has a medical article online, under a menu “Medical News.” The tone of the article is similar to the Eurotransplant information.

As far as the public is concerned, one of the Internet users, in an on-line exchange with another transplant patient, mentions and summarizes an article in *Le Monde* on the microchimerism and expresses great caution with regard to this type of information.

Tolerance induction is part of the pulling force between fascination and caution which characterizes scientific progress, particularly since the 1990's. It is perhaps the reason why publicizing this topic is so marginal. It only seems to be the subject of debate in the scientific world.

## **Discussion: The emerging social and ethical questions**

### **1. Side effects of treatment: an implicit ethical question**

The recurring theme, in institutional information or exchanges between transplant patients, of side effects related to immunosuppressive drugs postulates the implicit question of the limits of what is acceptable. For instance, the description, by patients of the disorders or illnesses induced by these drugs and the anxiety that their questions manifest is, without doubt, one way of touching on the questions of acceptability by society of modern therapeutic methods. This debates starts in the press.

### **2. Finding back one's place in the community**

The commitment of patient associations in assisting transplant patients to reintegrate society (legal, financial, logistic aspects), as well as the exchanges in the discussions, point this as a major post-transplant concern. The idyllic description of life regained (“a rebirth” for some, “a new life” for others) is jeopardized by the weight of medical follow-up and its relatively disabling effects (fatigue, various disorders), depending on the type of transplant. The discussions between transplant patients show a great disparity of situations, often related to the effect of treatment and to the patients' entourage. Some go back to work quickly, others don't. But most of them need to change jobs and work out specific arrangements. At present, associations seem to be the only place in society which offers the transplant patient a new identity and a new community.

### **3. Cost of treatment: the unmentionable part of the debate?**

Suppressing the economic aspects of transplantation and in particular the cost of immunosuppressive drugs in the discussion leads to/infers that the subject is unmentionable today. However, this question is raised by one Internet user in one of the discussion groups” And yet this is an ethical question which is worth thinking about.

## **Conclusion**

In some respects, our analysis corroborates studies carried out in the humanities and social sciences with regard to scientific information. We did indeed observe a deviation between the information emanating from *ad hoc* structures and the expectations of a public, which actually differs from the public to whom this information is generally aimed to. This deviation reveals the different, or even conflicting representations of "knowledge", between the protagonists involved (care-givers and transplant patients). The results of the analysis show that transplant patients have a common interest in their treatment, not met by the information from institutions or associations as it appears in the material analyzed. Thought needs to be given as to the type of information that might reduce the anxiety of patients for whom a transplant means dependence on drugs for life.

The demand to rationalize practices with regard to information, although marginal, could win the support of all those who are "standing by" for information. This is the case in the transplant centres, and could be developed from an already existing model (associations): exchanges between future transplant patients and those already transplanted, discussion groups, documentation, and information briefing sessions. The desire for standardizing information emphasizes the anxiety caused when there is diversity in communication practices, given the psychological and emotional context specific to transplantation.

Based on this work and on other researches, the Riset consortium is now working on specific recommendations for improving the dialogue and better meeting the needs of patients for information.