

IMMUNOSUPPRESSION AND TOLERANCE INDUCTION IN HUMAN TRANSPLANTATIONS

STATE OF THE PUBLIC DEBATE



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INTRODUCTION

In an EU project on transplantation tolerance, an analysis of the state of the public debate on immunosuppression and tolerance induction (TI) was performed, in order to explore questions emerging or circulating in the public space.

The studied arenas were media, institutions, associations of patients 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).

THEORETICAL BASIS AND METHODOLOGY OF THE SURVEY

THE NOTION OF « PUBLIC DEBATE »

Following the works of Jurgen Habermas, the public debate is considered as a set of locations where social actors express themselves.

These spaces determine particular forms of information (discourses) which are the expression of their positions : mediatic, institutional, associative discourses, and patients exchanges on forums and on lists of discussion.

THE AIM OF THE SURVEY

In the setting of the Riset project (WP4), it was planned to analyse the state of the public debate on immunosuppression and tolerance induction in the context of human transplantations.

The aim of this survey is to exhibit the social and ethical questions which emerge in the public space. It also aims to better understand the various modalities of expression and of knowledge circulation.

These questions were explored within a defined time period : 1990 - 2006.

THE SETTING OF THE SURVEY

Social and ethical questions rise from the following spaces:

- Media space (press and TV),
- Institutional space (national transplant agencies),
- Associative space (associations of patients (recipients or patients on waiting list),
- Internet public space (forums, lists of discussion between patients concerned by or interested in organ transplantation).

THE COUNTRIES INVOLVED



FRANCE



BELGIUM



THE NETHERLANDS



GERMANY



UNITED KINGDOM



ITALY



SPAIN

RESULTS : STATE OF THE PUBLIC DEBATE

➤ ABOUT TOLERANCE INDUCTION

TOLERANCE INDUCTION APPEARS AS A VERY MARGINAL TOPIC OF THE PUBLIC DEBATE

In medical discourses :

T.I. is presented as a promising field of biomedical research, but still problematic for human application. For transplantation actors, T.I. would allow to avoid side effects of immunosuppressive drugs, to resolve the problem of the survival of organs and would also result in increasing the number of available organs. However, it remains an experimental model.

Associative discourses and exchanges between patients are characterized by caution, as shown by the following extracts : « if they acquire it » ; « that encounters very large difficulties » ; « it is probable that the situations of microchimerism are rare and it is necessary to remain careful ».

It is thus evoked as a benefit (economy, disappearance of the side effects), a recovered autonomy, an ideal state and a hope for the recipients. T.I. represents an answer to the ethical questions raised by the long-term administration of anti-rejection treatments.

SPACES AND COUNTRIES

- European transplant organisation (Eurotransplant) and Medical press (*The Lancet*);
- Associations of patients (EuroLiver Foundation, Belgium),
- Internet forum (« Transforme », French association of patients).

➤ ABOUT IMMUNOSUPPRESSION

IMMUNOSUPPRESSIVE DRUGS APPEARS AS A MAJOR TOPIC OF THE PUBLIC DEBATE IN EUROPE.

Medical discourses are characterized by discussions about the risks/benefit ratio about the side effects of anti-rejection drugs and by caution.

Institutional and associative information are descriptive (list of the anti-rejection drugs, side effects, posologies).

Immunosuppressive therapy is presented as a need. Extracts : « it's necessary to... » ; « It prevents the rejection of the graft ». The aim of information is to reassure : « The post-graft drugs are well controlled today ».

The patients exchange many questions about the side effects of anti-rejection drugs, the re-adjustment of posologies and the change of drugs (discussions « on line »). For the associations as well as for the national transplantation agencies, the social representations of the public needs (institutional or associative FAQ and TV programs) are firstly technical (transplantation surgery) then procedural (legal model of the consent).

The ethical questions (restricted to the acceptability of the side effects) are not explicit, neither are the questions about the state of research in this field. Many of the questions asked by the patients represent an implicit form of the ethical discourse.

SOCIAL NEEDS : A LACK OF INFORMATION !

We observe a paradox between the heterogeneous mass of information about immunosuppressive drugs and the feeling of a lack of information expressed by recipients. Social needs appear in the « on line » exchanges between patients : quotation of articles, TV programs, conferences or specialized websites.

Lack of correlation between the information produced (mainly descriptive) and the social needs (pragmatic aspects): this shows different social representations of required knowledge.

It is necessary to reconsider information packages and their format using these results.

SOME PROPOSALS

- Creation of specialized open areas for dialogue (information, exchanges, help groups...) in transplantation centers ;
- Creation of Internet forums, specialized lists of discussion, and websites for recipients (for all grafts) where transplant agencies and associations of patients would jointly assure promotion ;
- Creation of a newspaper which would be a link between grafted patients (national level and in each country).