Discourse and Rare Diseases: Proposals for a Critical Analysis in the Spanish Context

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Abstract

This paper puts forward proposals for the critical study of discourses pertaining mainly to rare diseases in Spain. It takes as a starting point the characteristics of the hypergenre referred to as *social debate*, together with *legitimation* and *delegitimation* as fundamental ideological functions that help in the examination of the relationship between society and communication. Based on data obtained from leaflets and other (periodic) publications produced by patients' groups, together with journalistic texts taken from the Spanish media, it aims to explore, not only the discursive manipulation of *responsibility* of patients' groups, but also the manipulation of some basic characteristics of the illnesses in question (*identity* and *prevalence*).

Key words: critical discourse analysis, health communication, rare diseases, mass media, social debate, legitimation, delegitimation

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Introduction

Disease is a very complex reality not only from a medical and scientific point of view, but also from the point of view of discourse. For this reason, the impact of certain diseases on linguistic behaviour has been a frequent subject of analysis in a wide range of disciplines including psycholinguistics, biolinguistics, speech therapy, phonetics, and discourse analysis. From our reading of such studies we find that it is easy to identify at least three levels of use of the notion of discourse:

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- *discourse as a demonstration of health or disease,*
- *discourse as a tool able to promote health or disease,*
- *discourse as a proof of a specific social construction of health and disease.*

In each of these levels it is necessary to take into account the following factors, and note their impact on discourse: Firstly the way in which physical or mental disfunctions may be reflected in the linguistic and communicative end product. Indeed, we sometimes speak about a pathological discourse (Bartke & Siegmüller, 2004). Secondly, the fact that language is, by definition, fundamental in therapeutic discourse (cf. Labov & Fanshel, 1977; Morris & Chenail, 1995; Wodak, 1996). Thirdly, that analysis and discussion about health and disease through discourse implies an inevitable social representation that will depend on diverse contextual factors, often characterised by vested interests, poor communicative habits, unfounded distrust, and disconcerting ambiguities (Lachmund & Stollberg, 1992; Sharf & Vanderford, 2003; Bañón, 2004a). In the case of rare diseases [RDs], that is, diseases with a prevalence lower than five per ten thousand, and whose suffering involves serious physical or psychological consequences, the following contextual factors need to be taken into account:

- RDs are not normally known by health professionals,
- they are generally neglected by the relevant health authorities,
- they scarcely count for the pharmaceutical companies, and
- they too often inspire prejudice on the part of the broader population.

These contextual factors have created a situation which has persisted for decades and the immediate communicative consequence has been the exclusion from the social debate on health and disease of both those who have undergone this type of pathologies and their relatives. The World Health Organization (WHO) states that there could be around five thousand of this sort of pathologies, some of them due to genetic disorders.

In the first part of this paper, we shall establish our general theoretical basis concerning both discourse and disease. In so doing, we shall also include some observations regarding its applicability to the special case of RDs. In the second part, we shall analyse certain discursive strategies used by actors who, affected or not affected, speak publicly about these kinds of diseases with the intention of legitimizing or delegitimizing patients and patients' associations. So far, communication scholars have scarcely paid attention to this particular subject.

Since 1999, we have been developing a corpus of both writen and spoken discourses regarding RDs in Spain (see Communication and Rare Diseases Project (CER), Bañón Hernández, 2004, 2007a, 2007b). The examples

included in this article have been selected from: 1) *Papeles de FEDER* (*PF*),[1] 2) the information leaflets of six associations of patients who suffer RDs,[2] and 3) certain documents concerning RDs published in the Spanish mass media.

The Social Debate Concerning Disease

As we have stated above, disease is a very complex discursive subject; therefore, we need an extensive framework that includes a variety of actors, types of texts, attitudes, etc. This framework is the hypergenre referred to as *social debate*, a denomination that, even intuitively, is usually identified with rhetorical collective activity. In any social debate, we note a diversity of opinions concerning different topics, which owing to their importance generate, for a(n) (un)limited period of time, the interest of broad sectors of society. Frequently, the topics that form a social debate establish connections with other topics; in this respect, health and disease are sometimes linked to the arguments about inmortality or the essence of life. Furthermore, debates tend not to be exposed in all of their complexity. Instead, we usually observe sectorial debates as in the case of, the therapeutic use of embryonic stem cells, the consequences derived from the deciphering of the human genome or the transplant of organs. RDs would be another example of these sectorial debates. Naturally, the nuclear subjects of these debates may generate strong bonds; for example, people affected by infrequent diseases allocate a great deal of time to the discussion of the therapeutic use of stem cells.

Although the theoretical-descriptive aspects that could be approached in such an extensive framework would obviously be more numerous (Bañón, 2002, pp. 23-29), we shall, nevertheless, focus on just four fundamental components of the social debate on health and disease in the first part of this paper, namely: the communicative hyperstructures, the actors involved, the process of incorporation of associations to the debate, and finally the axiological representation of patients and diseases. We shall then analyse the strategies of (de)legitimation starting from the basic characteristics of both the actors and the discursive subject.

The Communicative Hyperstructures

All hypergenres have overall communicative hyperstructures which find their ultimate manifestation in what we could call *textual*, *discursive* or *interactive* types. Discursive types are marked by their possible identification as *communicative microprocesses* (i.e., communications that affect the health of a person or of a reduced group of people who, suffering a more or less serious pathology, go somewhere to receive medical advice or to carry out

tests), or as *communicative macroprocesses* (i.e., communications that have or aim to have a repercussion on collective health and illness or on the general conception that exists with respect to both). Examples of microprocess could be a clinical interview (Raffler-Engel, 1989) or a mutual help meeting (Arminen, 1998, 2001, 2004), whilst examples of communicative macroprocesses could be an institutional campaign against AIDS (Rinn, 2002; Miller & Williams, 1998) or against the addiction to tobacco, or a parliamentary session on the public health system. Persons affected by RDs have always had difficult access to these communicative macrocontexts.

Macroprocesses and microprocess originate from a hyperstructure generated through three ideal phases: a) *the presence of health and prevention of disease*, b) *the loss of health and regulation of disease*, and c) *the recovery of health and prevention of disease*. The importance of prevention (and consequently, of investigation) in this hyperstructure is clear. However, the nucleus of this process is constituted by the regulation-of-disease phase, which, of course, refers to political, economic, social, and medical matters. At the medical level, we could say that, in this nuclear phase, there are three basic structural stages as well: *towards the diagnosis*, *diagnosis* and *after the diagnosis*. Thus diagnosis is placed in the 'pivotal position' of the medical interaction (Barton, 1999).

The Actors Involved

All of us may be involved in a social health debate. Indeed, everybody (individuals or collective groups) may enjoy health or suffer from an infrequent disease. Even so, it is necessary to recognize that some protagonists may have more authority or capacity than others to draw the attention of society to their acts or their words. Nevertheless, we could firstly identify two major groups: on the one hand, people affected by a rare disease and those who support them; and, on the other hand, health professionals who take care of them. For the semiotic and discursive analysis of the first group we need to observe all the communicative behaviour in which they (i.e., patients, relatives, and associations) participate. In addition, we need to consider here the interactions or the texts whose nature is determined by the informal caretakers (voluntary or not), who are not necessarily family members. In the second group, the protagonists are researchers, doctors, pharmacists, and nurses. We also note a third group, much more heterogeneous, constituted by other actors with more or less direct responsibility in RD: pharmaceutical companies, politicians (mainly legislators), companies and health mediators. Finally, there is a fourth group constituted by those who not only participate in this social debate, but also,

and most interestingly, who represent it: journalists that deal with RDs health topics.

In this paper the four groups will be considered. However, before going any further, let us point out that whilst it is difficult to find doctors specialized in RDs, it is even more so to find mass media professionals interested in this field and with a suitable background (Otten, 1994, p. 114).

All the actors mentioned in the four groups do not always speak independently because certainly it is possible to identify hybrid categories or actors who act from more than one perspective (e.g. someone acting both as a doctor and a patient). Besides, it is evident that in addition to belonging to the group of patients, doctors, nurses, etc., there are other characteristics which can be of considerable interest in the analysis of a debate, which scholars should take into account. There will be differences, for example, between a discourse concerning an anonymous patient and, on the other hand, a discourse concerning a person who is very well-known due to say, his professional activities or public profile[?]y.

The Process of Incorporation to the Debate

The participation of an actor in a social debate cannot be simplified; it is, in fact, a slow and complex process in which persuasion and action are combined in different ways. In our opinion, there are five fundamental phases that make up the sequential structure of an ideal participation, and that are more or less explicitly present in communicational studies on patients' activism (cf. Brashers, Haas, Klingle & Neidig, 2000):

1. *Identification*: Society and the rest of the actors need to be aware of the existence of a disease or of a group of diseases and, therefore, of a patient or of a group of patients.

2. *Constitution*: The patients themselves have to be aware of the need to participate in the social debate on health and disease in a collective and unified way.

3. *Recognition*: The other social actors who take part in the social debate on health and disease need to be aware of patients' associations as valid and necessary interlocutors.

4. *Access*: It is necessary to persuade the relevant social actors to include the patients in the forums representing rare diseases. And

5. *Exposition*: It is also necessary to explain the specific demands of the patients to the other social actors in order to improve the patients' overall situation.

Indeed, it may be necessary to repeat certain phases of persuasion as a way to advance or to regress in the process of incorporation to the social debate. Whereas people affected by a certain pathology will try to simplify the process or, in any case, to complete it successfully, there will be other actors who will have the opposite intention: that is to say, the exclusion of the patients from the social debate, either by means of obstructing their identification, constitution, recognition and access, or by means of prevention and manipulation of the way they present their demands. It is easy to find, for example, doctors who refuse to offer their patients any information concerning associations of persons who suffer a RD, even if they have knowledge of the work carried out by these groups. This can limit the legitimate growth of the associations and in turn reduce their representativeness, both of which are essential for the successful completion of the constitution phase referred to above. Furthermore, those who wish to discriminate against such groups welcome the opportunity to block the participation of the patients in this process at the earliest possible stage.

The Axiological Representation

In a social debate, actors offer different opinions and therefore, inevitably, different evaluations that can affect both the topic and the actors involved. At the level of representation, we argue in favour of the identification of, at least, eight elementary discursive types, taking the following variables as a starting point: the represented topic (in this paper, patients who suffer a RD); the inclusion or non-inclusion of the speaker or actor in the patients group; and, finally, the expression of a desire to participate in the debate by means of positive or negative attitudes, or, rather, the expression of an intention to avoid the question by means of non-positive or non-negative attitudes towards the groups or individuals represented in discourse (Bañón, 2002).

Based on these variables, we propose the following discursive types:

1. Involvement. Non-affected speaker. Positive evaluation: *supportive discourse.*
2. Involvement. Non-affected speaker. Negative evaluation: *discriminatory discourse*.
3. Involvement. Affected speaker. Positive evaluation: *self-assertive discourse*.

4. Involvement. Affected speaker. Negative evaluation: *self-discriminatory discourse*.
5. Inhibition. Non-affected speaker. Non-positive evaluation: *preventive discourse*.
6. Inhibition. Non-affected speaker. Non-negative evaluation: *condescending discourse*.
7. Inhibition. Affected speaker. Non-positive evaluation: *self-segregating discourse*.
8. Inhibition. Affected speaker. Non-negative evaluation: *resigning discourse*.

These concepts have a direct repercussion on the two fundamental fields of human behaviour: *doing* and *saying*. Besides, the eight identified textual types may be produced *directly* or *indirectly*. In this sense, sometimes the superficial and direct expression of certain discursive evaluations may in fact be hiding other intentions towards the subject in question (van Dijk, 1998, pp. 216-217). Indeed, speakers normally prefer to express themselves in more positive terms and to minimize their true opinion thereby protecting their social image. Thus, what may sometimes seem to be a compassionate representation of sufferers from RDs should instead be interpreted, in certain contexts, as a preventive representation. Similarly we should note that a preventive representation can sometimes be interpreted in discriminatory frames. Conversely, speakers may give an inadequate representation of others suggesting that they express themselves in terms of resignation, thereby minimizing their capacity to both react against the disease and assert themselves with the aim of improving their situation from a personal and social point of view.

(De)Legitimation and Basic Characteristics of Patients and Diseases

As van Dijk states (1998, p. 255), legitimation is one of the main social functions of ideologies which allows the elites to maintain political and economic power. At the same time, legitimation implies delegitimation with respect to those who do not belong to the elites and want to change what they consider to be injust. Both legitimation and delegitimation have obviously an effect in text and talk, and their objective is to evaluate the group or the individual as representative of a set of people.

There always exists a set of reasons for delegitimizing a non-dominant group with a non-official discourse. In the specific case of associations of patients who suffer RDs, the fundamental reasons to prevent the development of solid organizations are the following: 1) In addition to the natural distrust of political and economic elites towards social movements in general (Bañón, 2003) and likewise, in addition to the traditional oscillations in discourse

about informal carers (Heaton, 1999), scientists and medical structures are not ready to accept the claims of associations representing sufferers of RDs. 2) Deficits in public health departments is one of the most important financial problems for western states. Once the real situation of patients affected by a RD has been recognized, regional and central governments need to give additional resources for a small group of people, whose influence on electoral results is insignificant. Besides, treatments for these diseases are usually relatively expensive.

The written and spoken discursive strategies that are used to support strategies of legitimation or delegitimation may focus, for example, on the production level, or on the local meaning level. Thus, newspapers frequently ignore representatives or leaders of some social groups as relevant sources, or at least restrict their access to communicative macroprocesses. Furthermore, the four moves included in the "ideological square" (van Dijk, 1998, p. 267) offer an excellent framework for describing procedures of legitimation and delegitimation: 1) They express / emphazise information that is positive about Us. 2) They express / emphazise information that is negative about Them. 3) They suppress / de-emphazise information that is positive about Them. 4) They suppress / de-emphazise information that is negative about Us. These moves are performed by means of specific discursive mechanisms, such as lexical selection. Just as in the use of *illegal* to speak about immigration, the adjectives *unreal*, *unnecessary* or *not solid* carry out the same function regarding patients' groups. We shall look into the use of these strategies, moves or mechanisms in the section on the textual (de)legitimation of associations of patients who suffer from RDs. We shall see how (de)legitimation can be achieved by manipulating the basic characteristics of not only sufferers groups, but also of the diseases themselves.

In the specific case of groups of affected people, we shall observe the discursive manipulation of *responsibility*. Responsibility is a concept by means of which the analyst can observe the activities which the patients groups may or may not be supposed to carry out. In the case of RDs, we shall analyse two fundamental characteristics: *identity* and *prevalence*. Identity alludes mainly to the different techniques of identification and labelling of diseases. Prevalence captures the percentage of people affected by a particular disease of a certain social or political community.

The Responsibility of Patients' Associations and Discursive Legitimation

As a general rule, owing to a lack of funding, associations of patients with RDs are unable to influence society through the media by means of advertising, for example. In a sense, however, the appearance, on the one hand, of new electronic media, and, on the other hand, the intelligent use of

traditional communicative tools, have partly replaced the existing difficulties (Patsos, 2001, p. 285). Brashers, Goldsmith and Hsieh (2002, p. 260) have stressed the relevant function of online support groups to provide information regarding stigmatized illnesses and rare diseases, but Henwood, Wyatt, Hart and Smith (2003, p. 590) state that the more traditional sources and media still have a relevant role in informing patients of health matters. For Selander Troein, Finnegan & Råstam (1997, p. 182), for example, printed health information "can be analysed as an educational text with the purpose to convey information and to convince the reader that the information given is accurate and reliable". Here we refer to *leaflets*, in particular, which are one of those traditional tools whose legitimizing and counter-delegitimizing importance, it would seem, has not been adequately valued. This is especially so with regard to its discursive functions in the process of incorporation of the patients into the social debate.

Dixon-Woods (2001) has analysed patient information leaflets from a social-discursive angle. She proposes two different discourses concerning the use of printed patient information: 1) patient education discourse; and 2) patient empowerment discourse. The first is developed "from a professional perspective, rather than from a patient perspective" (p. 1425), and contemplates "patients as passive, there to be manipulated" (p. 1425). Besides this, "patient education discourse has tended to ignore patients' beliefs and concerns, or to treat them as irrelevant, inaccuracies" (p. 1424). On the other hand, in a patient empowerment discourse, "patients are seen as actively constructing the meaning of texts, rather than passively responding to a stimulus" (p. 1424). In any case, both forms of discourse presuppose that health information leaflets are made to be read by patients alone and never by professionals who have normally been regarded as the only existing group of people with expert knowledge. RDs (and chronic illnesses in general) have completely changed this perspective because patients have become experts as well. What is more, their leaflets aim to inform not only peer groups, but also physicians, for example.

Leaflets authored by the associations of RDs have at least the following functions:

1. *A unifying and socializing function*: Besides accomplishing the mission of making the public aware of the existence of the organizations, leaflets also serve to create a joint message, at a reasonable cost, with which both the associations and its members can identify. Furthermore, this type of document is a simple means to promote the group and to demonstrate that individuals are not working alone, but as a group.

2. *A networking function*: Leaflets are not only present at the central office of the associations, nor are their members the only distributors. Leaflets of a specific group may also be found in other social forums (especially

in the offices of other associations of patients, as well as in institutional centres somehow related to health and disease). This type of discursive projection is very important because it generates a network of contacts that, without any doubt, helps all those affected by a RD in their respective tasks. In addition, some associations explicitly include among their objectives the provision of information concerning other related diseases. This is an example noticed in the document of ANSA:

(1)

"The National Association of Apert's Syndrome provides information not only for the Apert's Syndrome, but also for other similar syndromes, like both Crouzon and Pfeiffer, and Saethe-Chozen".[3]

3. *An informative and publishing function*: Without doubt, the direct transmission of information is considered by patients as the highest priority in terms of the communicative aims of the leaflets. Associations speak not only to associated people, but also to the general public, which includes both individuals who could become new members of the associations, and individuals who, given their social, medical or political responsibilities, could improve the situation of people who suffer RDs. A patient states:

(2)

"The problem is resolved quickly with a plaster, but now they tend to put on dressings; this doesn't help us at all. When I approach a doctor, I always take a leaflet about my illness, just in case" (Perancho, *El Mundo*, 02/07/05).

For this reason, on the one hand, associations facilitate contact among all persons interested in RDs, and, on the other hand, guarantee that the social actors are aware of the difficulties that the sufferers must face. Because of their relevance, the range of readers of such documents are usually mentioned explicitly in the leaflets; in this sense, it is very interesting to note the presentation of FEDER, where three possible addressees are identified, through the following expressions: "a todos los interesados" ["to all those concerned"], "a la población española en general" ["to the Spanish population, in general"] and, thirdly, "a todas las familias afectadas" ["to all the affected families"].

The leaflet needs to be concise by nature, and, in most cases, it has a popularizing intention, which in turn requires the adaptation of the text in order to make medical and scientific terms more accessible. The following

fragment of a document written by the Spanish Association of Epidermolysis Bullosa shows an example of this kind of lexical and semantic adjustment by means of imagery and comparisons:

(3)

"E.B. is a family of genetic and hereditary diseases that brings about the defective production of 'skin glue', with the result that the skin comes off forming blisters at the slightest rubbing, which reappear continuously. The effect is a skin as delicate as the wings of a butterfly".

Indeed, on the cover of the leaflet, the expression "los niños mariposa" ["the butterfly children"] is used to identify the disease. In a document concerning imperfect osteogenesis, this technique of comparison is also used to explain that the collagen is "similar a la red de alambre que se usa como estructura antes de colocar el hormigón" ["similar to the wire network that is used as a structure before pouring concrete"].

Usually, in this type of document both the registration number provided by the administrative bodies, and a reference to the non-profitmaking character of the association are included. The registration number guarantees that it is not an association that acts in secrecy or outside of charity law. As for the reference to the non-profitmaking nature of the organizations, this allows us to focus on its key objective: the improvement of the patients' conditions at all levels. The further inclusion of postal or electronic addresses, phone numbers, URLs or full contact names (e.g. members of the board of directors) are details that help above all to consolidate a functional and transparent image of the association, free of hidden agendas. In addition, other actors involved in the preparation of the leaflets or in sponsorship are systematically represented in the text. Also relevant to the question of identification is the way that the name alone of an association or federation can indicate, on the one hand, its geographical scope (regional, national, or international), and on the other hand, the number of pathologies or syndromes for which it offers advice. The Spanish Association of Muscular Diseases (ASEM), the Spanish Federation of Ataxia (FEDAES), or the Catalonian Association against Dystonia (ALDEC) are examples of regional and national groups that cover more than just one disease.

Both the geographical scope and the number of pathologies also presuppose a certain social significance. In the case of the federations, the most interesting figure relates to the number of associations that they include. This is precisely the case of the inside cover of the leaflet of the Spanish Federation of Rare Diseases (FEDER). On the second page, a numerical reference is made by means of an approximate syntactic structure with an emphatic function: "está formada por más de 50 asociaciones" ["it is constituted by more than 50 associations"]. The same structure is used by

FEDER to allude to the approximate number of rare diseases identified by the scientific community: "alguna de las más de 5.000 enfermedades raras" ["some of the more than 5,000 rare diseases"]. The format and the presentation (e.g. number of pages, inclusion of colours, photos, languages, etc.) give information about the financial support that different associations receive.

Normally, these leaflets explicitly mention the interests and objectives of the associations, as well as the services that they can offer not only to members, but also to affected people in general, even if they do not belong to the association. In addition, readers will find, if they wish, essential information regarding procedures of diagnosis, types of manifestation, levels of severity, treatments that are available or in development, etc. When describing the activities or the objectives of the associations, we are faced with a wide variety of claims.

Management of health information is, therefore, one of the most important tasks recognized by groups of patients. However, this function is more complex than it would appear at first, since in fact we are speaking of "seeking, avoiding, providing, apraising, and interpreting" data (Brashers, Goldsmith & Hsieh, 2002, p. 259), or more simply, of compiling, processing and conveying data. With respect to the compiling of data, it is not a linear process, as the end product is necessarily the result of a process of selection of complete and updated information extracted from objective and reliable sources. Thus, we observe the use of expressions such as "information in real time" (FEDER), or "the most complete information possible" (ASW). Concerning data processing we are mainly referring to the preparation of information in order to simplify the task of the future reader; to be precise, at the very minimum, we refer to a systematization and linguistic simplification of the contents. Finally, the conveying phase appears in verbs such as "to provide" (FEDER), "to popularize" (ACNF), "to encourage awareness" (ASIMAG), o "to inform" (AEE). Sometimes, "to guide" (AEE) is used, which not only highlights the didactic meaning of this communicative process, but also avoids the sense of mechanical transmission of information.

The second communicative task of the associations is, of course, persuasion. There is one verb that usually appears in this context: "to sensitize" (FEDER). Sometimes, there are explicit receivers in this process: for example, society and the medical community (AEEFEG). Thirdly, the associations also play a certain mediating role; thus, for example, they make use of the expressions "to bring together" (ASW) or "to represent the interests of the people affected before the government and other Institutions" (ASW). Both management of information and the tasks of mediation and persuasion may be carried out or encouraged by the same association; in the latter case, we move into a new semiotic level of both description and abstraction, namely, the *doing-doing* in order to "help in the creation of

Mutual Support Groups of affected people in other places" (ACNF), or the organization of meetings, congresses and seminars (AEE), or conferences (ASIMAG), which constitute the generic materialization of these iniciatives. Some associations even use explicitly the verb "to promote" (AEE). Taking this concept of promotion as a base, it is interesting to note the nuances transmitted by groups of patients with respect to the communicative functions that they may carry out in their interaction with scientists and medical researchers. In this respect, "To study the causes that produce the disease" (ASIMAG) is an example of a direct connection between an association of patients and research; so direct is the link that, in fact, associations sometimes want to suggest that they have direct responsibilities for scientific research. Journalists consolidate this suggestion with headlines like "Las familias de pacientes investigan las enfermedades raras" ["Patients' families investigate rare diseases"] (Redacción, *El Mundo*, 27/02/03) or "Una asociación investiga las enfermedades neuromusculares" ["An association carries out research on neuromuscular diseases"] (R.H., *El País*, 07/03/05). Without doubt, it could be, at times, an excessive assumption of responsibility given that promotion can exist at several levels: the first is represented by expressions like "To promote research" (AEEFEG), and the second one is expressed in items based on the combination of chain effect modalities of the type *to do something in order to get something done*: "To foster and support initiatives that stimulate research" (FEDER).

The associations do not just offer gentle persuasion and information, instead they sometimes adopt a more vigorous position, almost to the point of controlling the work of other actors involved. This strategy is fundamental in order to eliminate the idea that these groups do not have the right to demand, but only to implore. The tone that the associations adopt in their claims and demands give rise to a certain social image (good or bad) that is soon widely adopted. In order to claim, to inform, or to persuade, firstly patients must see that their existence is at least recognized, as we said above, and, likewise, that the existence of the disease that identifies them as a group is also recognised. This objective may be unnecessary in many groups of common pathologies, but not in the case of RDs, whose existence is often ignored. Indeed, making a disease "better known" (AEEFEG) or "spreading awareness" of its existence (ACNF) can serve this function of recognition.

In the light of this, there can be no doubt that, in general, associations have fully understood that self-assertion is a process and that it is necessary to reinforce all its phases, beginning, naturally, with the group's identification, as well as with its gradual strengthening, above all by means of the increase in the number of members.

The Identity of RDs and Delegitimation

The allocation of a label to the pathology suffered by a person constitutes the nucleus of the *identification* process (and certainly of the diagnosis). Delegitimation of the identification of RDs will be based on strategies such as:

1. Mistaking the name of a RD. The government also makes mistakes in identification. In the journal *Gota a Gota* (Spanish Association of Sjögren Syndrome), we can read the following statement:

   (4)

   "Among the new arguments expressed by the Ministry, one may emphasize that it now names the disease correctly, given that in the refusal resolution of 1996, it referred to it as Sjörgen and not as Sjögren".

2. Selecting, among different possible denominations for a RD, the one which is most spectacular. Taking as a pretext the supposed difficulty of pronouncing or remembering the names of RDs, mass media reinforce this sensationalization with headlines like "¿La enfermedad del 'hombre elefante?'" ["Elephant Man disease?"] (M.N., *El País*, 27/04/03), referring to neurofibromatosis, in which confusion and the choice of a sensationalist name are working together because, as the journalist himself recalls, the so-called *elephant man* (Joseph Merrick) did not suffer from neurofibromatosis, but from Proteus' Syndrome. Conversely Inversely, it is possible to read headlines in which a characteristic of the group a person belongs to is attributed to a RD (personification), with the consequence that the discrimination of the sufferers is intensified: "Se elevan los casos de una rara enfermedad gay" ["The cases of a rare gay disease are increasing"] (P.M., *El Mundo*, 02/04/05). The illness is presented here as if could have a sexual orientation or as if a sexual orientation was a pathological entity. We should bear in mind these observations when we come to speak about *prevalence*.

3. Encouraging the use of a general label when speaking about different medical and clinical types or subtypes. Sometimes, the complexity of types and subtypes of uncommon diseases can be over-simplified by diagnoses which are excessively generic. An erroneous identification of a RD on the part of the mass media can give rise to unnecessary alarm among patients. Borja Ormazábal and Nieves Salinas wrote a full report

on RDs in which they stated that the boy Lucas "tiene una rara enfermedad, la glucogenosis" ["has a rare disease, glycogenosis"] (*Interviú*, 24/11/02), hiding the fact that in reality Lucas suffered Pompe's disease, the most dangerous kind of glycogenosis.

4. Interchanging types or subtypes in order to adapt them to interests that are harmful to the patients' condition. The gradual worsening of a patient's condition can indicate the degenerative nature of a pathology; however, some rare dangerous diseases do not always appear with the same symptoms or with the same *intensity* in their initial stages. This can lead people to think that patients are not really in need of urgent attention. This line of argument favours those who are particularly worried about money; pharmaceutical companies will often respond selectively to requests for compassionate use of their medicines in experimental phases, or indeed they may attempt to refuse such requests altogether. Thus, before commercialization these companies may categorize types or subtypes of diseases according to their economic interests, for instance assigning infantile patients to the juvenile group. In this way, by changing the type and, therefore, minimizing the hypothetical seriousness (*magnitude*) of the disease, they reduce costs. However, once the drug is commercialized, the same companies may state that the very same patients belong instead to the infantile group, and in this way put pressure on hospitals and health authorities to provide treatment as soon as possible.

5. Intensifying the prejudices that the assignation of a name for a disease always gives rise to. Naturally, the identification of certain ailments can entail the immediate association of numerous social prejudices. Indeed, there are diseases that, throughout history, have been sources of social stigma, whether by means of links with certain social or ethnic groups, for example, or by means of manifestations that are either external (e.g. behaviour, physical marks, pathological communication, etc.) or internal (i.e., real or supposed threat of infection) (Watts, 1997; Lachmund & Stollberg, 1992; Perez-Tamayo, 1988):

(5)

"'You have to understand the isolation and the anguish you feel when people ask you what the matter is, and you do not know what to say, to the point that some people think that you don't want to talk about it because it is contagious', explains María del Mar Simonelli remembering the experience" (Ormazábal & Salinas, *Interviú*, 24/11/02).

The use of expressions like "coger la enfermedad" ["to catch the disease"], causes an uncommon pathology to be associated with contagion, even on the part of health professionals. On spastic paraplegia, we read the following testimony:

(6)

"I had to go almost every week to the emergency department of the Hospital, and for the physicians and neurologists, who were different each time as you never coincide with the same one, it was the first case that they had seen of this disease and they ask you, 'What does this consist of?' 'Where did you catch it?'" (*PF,* IV, 8).

It is easy to find uncommon diseases being distinguished also by their communicative characteristics. Moebius Syndrome, for example, is a congenital anomaly that involves an insufficient development of certain nerves of the face and that, from a communicative point of view, is precisely apparent through a lack of facial expression. The ultimate consequences of this disease are, among others, difficulties in directing the gaze, problems in pronouncing words and inability to smile, all fundamental elements, as is well known, for the pragmatically adapted development of any communicative interaction. Another example is neurofibromatosis type I, a disease caused by an anomaly in gene 17, which involves the appearance of neurofibroms and tumours all over the body. The illness may result in disfigurement, bone deformations, etc., which make affected people an especially visible group, and very prone to social rejection (Quer, 2002, p. 30).

The Prevalence of RDs and Delegitimation

As indicated above, *prevalence* of a disease is another fundamental variable for any study regarding communication in health interactions. The adjective *rare* suffers, frequently, a semantic process of manipulation that nullifies its original meaning. Firstly, that which is rare is set up in juxtaposition to that which is normal, establishing a contrast which is more qualitative than quantitative. After this semantic transference, a series of associations takes place according to which that which is normal would be, for a certain cultural community, something which is logical, adequate, and advisable, whereas that which is rare would consequently become something which is illogical, inadequate, and inadvisable (Gadamer, 2001, p. 90-92). For this reason, several associations of RDs reject the adjective *rare*:

(7)

"Not rare, instead unknown and misunderstood, says Felisa Justo, president of Spanish Association against Dystonia (ALDE)" (Iglesias, *El Mundo*, 28/04/02).

Sometimes, a kind of metonymy according to which patients who suffer a *rare* disease are also regarded as *rare* is added to this complex process. Frequently, patients themselves promote this confusion:

(8)

"Physicians did not know this syndrome and they were unable to diagnose it. However, I perceived that my son was odd" (López, *El Mundo*, 16/05/03).

Conclusion

Cooperation between discourse analysts and healthcare professionals in the specific field of RDs should be a permanent objective for scholars interested in both disciplines (Candlin & Candlin, 2003, p. 142). Moreover, in order to further our understanding of the interrelation between discourse and medicine, interdisciplinarity should be promoted as the most relevant approach (Barton, 2001). Thirdly, this connection needs to find a point of reference in the representation of health and illness in mass media discourse (Seale, 2003). These three arguments have constituted the basis of this article, in which we have mainly focused on the discursive analysis of legitimation and delegitimation with respect to RDs.

The nature of RDs is little known by the sectors involved in the social debate concerning health and disease. Moreover, people affected are considered as a minority group with few possibilities of influencing political and social affairs. For this reason they are systematically excluded from the most relevant discussion forums. A striking example is the difficulty there is for such diseases to appear in communicative macropocesses. The image of associations of patients who suffer infrequent diseases is often manipulated in order to delegitimize them as valid interlocutors.

The patients associations, in turn, have their own textual strategies in order to assert themselves and to legitimize their existence as groups able to carry out useful functions and to significantly contribute to the improvement of the mental and physical condition of affected people. This is evident from our analysis of the leaflets of various patients associations. These leaflets

likewise show us that patients' representatives sometimes manipulate the levels of responsibility assigned to each of the actors with the intention of magnifying the importance of their own role.

We also note that the characteristics of less prevalent pathologies are subjected to an intentionally fuzzy discursive treatment. Their *identity* is manipulated by means of sensationalization or simply by the erroneous identification of the pathology. On other occasions we find that they are associated confusingly with factors that generate fear (contagion, for example). Further manipulation occurs in cases of *prevalence* of RDs, which is one of their basic characteristics. The most noticeable rhetorical mechanism is the association of concepts that can lead to the representation of the patient who suffers a RD as being *rare* him/herself.

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Notes

1   Published by the Spanish Federation of Rare Diseases.
2   ACFN: Catalan Association of the Neurofibromatosis; FEDER: Spanish Federation of Rare Diseases; ASW: Spanish Association for the Investigation and Aid to the Wolfram Syndrome; AEE: Spanish Association of Scleroderma; AEEFEG: Spanish Association of Patients and Relatives of the Disease of Gaucher; ASIMAG: National Association of People Affected by the Cri-du-chat Syndrome.
3   This and other translations of Spanish documents are mine.

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