

Communication Strategies and Challenges for Rare Diseases: Medical Research as a Referent is being published in the hope that this book will become a reference manual in the information coverage of this type of pathologies. It is intended for students - either future researchers and doctors, or future journalists - and for active professionals in both these fields, as well as those affected, along with their relatives and the associations that they have formed.

This study destroys a myth, a commonplace misconception and a prejudice. The myth is that scientific research in the field of medicine has no desire or interest for social research. In this respect the Centre for Biomedical Network Research on Rare Diseases (CIBERER) has nevertheless given us an excellent opportunity to tackle an in-depth analysis and quantification of the journalistic discourse on Rare Diseases and medical research provided daily by written media. The misconception revealed was our idea that the press, under such stress to extend its readership, might have left Rare Diseases out of its information preferences. The prejudice clearly refuted by the results of our research is the impression that these uncommon pathologies would preferentially be covered in the specialised press circulating nationwide, with the Communities of Madrid and Catalonia producing most of the information.

One of the main values of this book consists in offering, for the first time, a quantitative and discursive analysis of the treatment of Rare Diseases in the Spanish press over one year. Another strong point involved being able to successfully combine endeavours by three different concerns: the CIBERER, the Universidad de Almería (through its ECCO research group) and Valencia's Universidad Ceu-Cardenal Herrera (represented in the GIDYC research group).

This book is also a result of the efforts made by the CIBERER to ensure proper dissemination of all the hard work seeking diagnoses and therapies for Rare Diseases done by the biomedical research groups in this country.

COMMUNICATION STRATEGIES AND CHALLENGES FOR RARE DISEASES: MEDICAL RESEARCH AS A REFERENT

A quantitative-discursive study of Spanish
printed and digital written press
(2009-2010)

*Antonio M. Bañón Hernández, Javier Fornieles Alcaraz
Josep A. Solves Almela, Inmaculada Rius Sanchis (Coord.)*



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CIBERER Presentation

When the Centre for Biomedical Network Research on Rare Diseases (CIBERER) was founded in November 2006, the concept of Rare Diseases was not very well known in the scientific field. It nevertheless represents a major sociomedical problem, as this term covers almost 6000 pathologies, most of them serious and limiting, affecting roughly three million people in Spain and from 24 to 36 million in the European Union.

Four years after the CIBERER's foundation, the work done by all the agents involved in Rare Diseases had helped to gradually give this concept a place in public opinion, in the institutional agenda, the health system and the production sector.

The CIBERER has, right since its beginnings, been very much aware of the importance of contact with society, and has developed a formal communication policy to help spread information about the research on Rare Diseases done in this country. We regularly arrange therapeutic conferences for researchers to pass on progress to people affected by RD and listen to their suggestions. We can be found in a large number of scientific, institutional, business and social forums, keeping in constant contact with the media, and we have organised three editions of the *Research means Progress* event as part of the Rare Disease Day, among many other measures. We have thus helped to highlight research in society and particularly among all the groups interested in the field of low-prevalence pathologies.

The CIBERER is well aware of the importance of society's learning about Rare Diseases and also of their proper treatment in the media. That is why we have cooperated with this ground-breaking piece of social research, which analyses the appearance of Rare Diseases in Spanish written and digital press, provides a diagnosis of the viewpoint created by journalists and proposes action for helping to ensure greater visibility for Rare Diseases.

The book stemming from this research will be simultaneously published in Spanish and English. CIBERER is thus committed to extending the proposals for action in the sphere of rare disease dissemination all over Europe. Due to the low prevalence of each of these pathologies considered separately, action in the continental area is particularly important in this field. Research networks, patients' associations and information systems are all moving towards creating synergies right across the European Union, and deontological proposals for proper treatment of these pathologies need to work in the same area. Neither should we forget that in this country we are also in a privileged position to act as

a bridge to Latin America and contribute to the proper appearance of Rare Diseases in the American media.

We would like to thank the groups involved in this research for the great dedication and enthusiasm with which they have worked on this: the Grupo de Investigación en Discapacidad y Comunicación (GIDYC), connected with the Universidad CEU-Cardenal Herrera de Valencia and the Universitat de València, and the Estudios Críticos de la Comunicación (ECCO) group at the Universidad de Almería.

Proper media treatment of the situation undergone by people affected by Rare Diseases and of the research being carried out to find diagnoses and therapies may doubtlessly turn out to the benefit of patients and their families.

Francesc Palau,
Scientific Director of the CIBERER

SOCIAL JOURNALISM AND MEDICAL RESEARCH: THE UNIVERSITY AS A POINT OF ENCOUNTER

The Centre for Biomedical Network Research on Rare Diseases (CIBERER) has given us an excellent opportunity to tackle an in-depth analysis and quantification of the journalistic discourse on RD and medical research provided daily by our press (printed and digital). This research is not far afield from the different work that we had been preparing over the last few years in the domain of what is known as social journalism at the Universidad CEU Cardenal Herrera.

In 2004 a group of teachers from what was then the Social Sciences Faculty proposed creating a research group on disability and communication, which produced its first work and studies in 2005. The group became more firmly established three years later, when it was joined by other teachers from the CEU-UCH, as well as Professor Sebastián Sánchez, from the Universitat de València, and through being assigned a research project on the treatment that Spanish media had given to the Beijing Paralympic Games, with financing from CEU-UCH itself. In 2009 it was commissioned with a further piece of research into the Valencian media's information coverage of disability, with financing from the Generalitat Valenciana regional authority, with final results that are soon to be published.

For all kinds of different reasons (personal, institutional, ethical, procedural, etc.) this Grupo de Investigación sobre Discapacidad y Comunicación (Group for Research into Disability and Communication) (GIDYC) has since it was created also been particularly interested in studying and considering the treatment given by the media to so-called "Rare Diseases" (RD). Just as they do with disability, the media build up an idea, a concept of these pathologies, which ends up becoming the social concept itself - the one that everyone, or almost everyone, accepts and uses. Furthermore, a sustained systematic analysis of this concept in relation with disability has always seemed vital to us in order to be able to take action to better this as far as possible, as regards the way it matches both the actual reality of the diseases and the people who suffer from these and the requirements and aspirations of a complex and changing society like ours.

That is why our contacts with the CIBERER and the Federación Española de Enfermedades Raras developed from 2008, and the reason why we heard of Antonio Bañón, a professor at the Universidad de Almería, the only scholar in this country concerned so far with analysing the way the media treat these diseases. Bañón has been able to create a research group called Estudios Críticos sobre la Comunicación (ECCO) which has already made a large number of major contributions to our knowledge on the discourse of Spanish media, not only on this matter, but also on health in general or on immigration.

Since 2008 we have always shared the aspiration to work on a journalistic-discursive analysis of the treatment that Spanish media give to RD. This study could firstly report on what the media “say” about these diseases, those affected, as well as about their families, the people researching into these, the institutions which manage the resources assigned to them, etc.. It would also involve explaining the importance of the actual journalistic production routines in the “conception” that the media have of these pathologies, and of the subjects and characters constituting the world of RD. Such a study would in short combine the analysis of discourse, strictly considered, with that of the causes producing this.

The occasion came up in April 2010, when the CIBERER and the GIDYC had a formal meeting to explore cooperation channels. Apart from other suggestions, our first proposal was to carry out the study which we are now presenting. This inevitably had to be done along with the ECCO group in order for the result to be methodologically innovative and socially relevant: this is the first systematic, exhaustive and in-depth study of the way Spanish media treat RD; that is the first analysis of the “concept” that the media build up and disseminate of these diseases and their symbolic universe, their actors and their themes, but which also explains the journalistic aspects lying at the core of this concept: the press’s valuation of news and its selection, the use of sources, the final construction of the information, etc.. It also looks at the impact that medical research is having on our society through those same media. In this respect the help given by CIBERER in supplying us with the press material has been invaluable, streamlining the analysis and its results.

The study starts with a chapter on communication and RD which may be seen as a general contextualisation of the subject dealt with in this research (Chapter 1). The rest of the work is divided into two major blocks: the one made up of Chapters 2 (procedure for quantitative analysis) to 5, in which the results of the quantitative analysis of the corpus analysed are given, and the one consisting of Chapters 6 to 9, in which we present the basic traits of the critical and constructive analysis of the discourse applied to press portrayal of Rare Disea-

ses in Spain. Finally, Chapter 10 sets out to be an exposition of its basic conclusions and also a proposal for action for all those who have to inform about this type of pathologies, or become sources for information on these (doctors, researchers, people affected by RD, relatives, etc).

We are indebted to the ECCO group for the chance to engage a study that is groundbreaking from the methodological standpoint and of great social importance, insofar as this gives us vital knowledge for the task of improving the life of RD sufferers. We are of the opinion that this will encourage a better concept of these people and more appropriate treatment by the media, but that this will also foster a better consideration of the huge task entailed by biomedical research into these pathologies, a vital source for better diagnosis and later treatment.

I should like finally to point out once again that the CIBERER is ultimately and mainly responsible for this major task having been able to materialise. Our most sincere thanks goes to its scientific director, professor Francesc Palau, to its manager, Verónica García, and to its communication director Miquel Calvet. We hope that the great effort that they have made and the trust they have placed in us will help this work to become a reference manual both for students – either future researchers and doctors, or future journalists - and for active professionals in both these fields.

Josep Antoni Solves,
(Grupo GIDYC, Universidad CEU-Cardenal Herrera)

1.

COMMUNICATION AND RARE DISEASES: CONTEXTUALISATION ¹

Antonio M. Bañón y Javier Fornieles
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1. SOME PRELIMINARY IDEAS

The European Union has on several occasions pointed out the importance of taking action on rare diseases (RD). Both the Parliament and the Council have indeed stated that these represent a singular case through affecting citizens' equality and fundamental rights, and due to constituting a precise example of a truly community action, since the action taken in this field exceeds national frameworks and requires cooperation between the different States in the Union. This is the reason why different legal initiatives have been promoted on orphan drugs and on the measures that the European Union countries must adopt. These have included certain research programmes falling within the preferential lines of work of the 7th Framework Research Programme (2007-2013).

In the field of communication and health (electronic health) the endeavours that have been got under way highlight the value of new communication and information technologies for carrying out certain priority tasks: updating records and databases on these diseases, disseminating information to professionals and patients for them to learn recommended practices and be able to access the services available. A few years later nevertheless, these measures have been seen to be insufficient in some aspects: the general public is still largely unaware of the existence of RD. Much the same thing could be said of the doctors who treat these patients for the first time. The patients' associations themselves – this is the case of the French RD Federation (FMO) – have expressed their dissatisfaction. Although the considerable step forward meant by the creation of Orphanet has been duly acknowledged, it has been affirmed that the new technologies do not guarantee access to the databases or resources that they offer nor dissemination among the population². It is indeed not enough to take action in the field of health, as other general initiatives are required

¹ The considerations in Chapters 1,7-10 of this book were possible thanks to R+D project FFI2008-03937 (Ministry of Science and Innovation), entitled Análisis lingüístico-comunicativo de las enfermedades raras en España (Linguistic-communicative analysis of rare diseases in Spain.).

² French National Plan for Rare Diseases 2005 – 2008, (20.XI.2004). Contribution of the FMO (Fédération des Maladies Orphelines) to the report for the National Rare Disease Plan (21.1.2009).

for healthcare professionals to be able to find the help that they need and for the education sectors, the media or citizens in general to learn of the problem and give the cooperation required.

The importance of taking up these initiatives with a more general scope can in fact be found in the declarations made in both Europe and in Spain. The third approach in the French Plan includes the aim of developing information about RD for the sick, healthcare professionals and the general public. The Spanish Senate has warned about the lack of social awareness and the usefulness of supporting campaigns intended to remedy this situation. To give one last example, action 29 of the Plan for Caring for People with Rare Diseases in Andalusia proposes 'Carrying out awareness-raising campaigns for the general public on RD'.

The associations' perception is nevertheless that not enough has been achieved in this field. The main dissemination initiatives would seem to be the endeavours connected with the RD day. These could perhaps be actions that are lacking coordination and which, through only taking place at a specific time, leave an ephemeral mark without ending up clearly imprinting the existence and nature of these diseases on the population as a whole. They thus fail to mitigate one of the basic problems affecting patients and their families: the sensation of isolation, of finding themselves lost in a sea of indifference, and of only finding any kind of relief in the small group of persons who have their own same problems. In any event the search for activities connecting with citizens better (Le nez rouge, Federito, popular races) should be stressed, as well as the importance of telemarathons, which in Spain's case have only been handled on Catalan regional television.

It stems from the above that action needs to be taken in the field of the media addressing citizens as a whole to make sure that the information and the achievements attained are taken advantage of right from the start by new patients and by doctors inexperienced in these pathologies; for people of school age to receive the care needed and for patients and relatives as a whole not to have the overwhelming sensation of exclusion. It is also necessary to carefully examine the information already appearing in the press, on the radio, on television and at the cinema, to find out whether this is correct, if it complies with ethical standards, if it establishes the appropriate image in the group imagination or if it could on the other hand create further rejection and misunderstanding.

These enterprises involving information also prove important through the fact that a large number of the people with these pathologies have to make up for the lack of information by seeking other sources by themselves, following any news on their pathologies with particular interest. One should also bear in mind that these same initiatives are the only ones that can reach groups with no access to new technologies: depressed districts, people with difficulties with written communication and handling numbers, groups of immigrants, the homeless, the aged and people with disabilities, to mention the groups that the Union itself considers are at risk of being excluded from the services offered by "electronic health" programmes.

Apart from all this there are other equally important questions in the matter of communication. We refer for instance to the obligation of improving the way this news is passed on to patients or the usefulness of advising the associations themselves about using the Internet, the need to create web pages providing information accessible to citizens of a different cultural level or to interact with the media based on knowledge of the needs, habits and routines of these media. Achieving these objectives requires a different strategy and measures that have little in common with the present action, aimed mainly at improving scientific knowledge and giving backing to the sectors involved – researchers, patients and relatives – over the Internet. The European Union schemes or the ones that are carried out nationwide or across autonomous communities (Spanish regional administration units) in this country do not however develop these initiatives. They warn of the need to disseminate knowledge among other citizens, but do not establish resources or specific programmes for doing this. In view of this position, we consider that action intended to promote information for the citizen in the media and for examining the presence of RD should be a pillar on which the general strategy of the European Union³ is also based. This will mean support is given to those affected, reducing their sensation of helplessness and increasing their trust in the healthcare system. Backing should also be given to the work done by associations, stressing the importance of combining efforts and preventing the impression that European programmes have nothing to do with their own particular situation. Finally, the campaigns undertaken for awareness-raising will enable completing and making greater use of the initiatives taken up by encouraging the agents involved to resort to the information and reference centres existing more quickly.

³ Certain journalists are indeed firmly committed to dealing with all the aspects to do with health and communication; this is José Luis de la Serna's case. It would be important to find this type of sensitivity when tackling the case of RD.

All the parties involved in RD know that there is a common priority objective: the development of research lines enabling the application of new therapies and treatments as soon as possible. We should never forget that a very high percentage of low-prevalence pathologies do not yet have any curative treatment.

Many of these same parties involved also point out that the intensification of research into RD with a social profile is an urgent matter. What is more, it would not seem surprising to defend that in fact medical-scientific research and social research are closely linked: identifying the degree of information about RD to be found in a particular social community can for example explain the level of justification of political and healthcare managers decide they have when they propose investments in studying this kind of pathologies. In this same sense, the observation of social-communication techniques used for generating a certain current of opinion about these diseases will partly explain a country or region's commitment to investing or not in scientific-technical research for the people suffering from a rare disease.

2. THE INITIAL REACTION TO AN EMERGING TOPIC: RD

In spite of all the progress made over the last few years, RD are a topic that could be described as 'emerging' for media professionals, just as they are for society in general (Aymé and Schmidtke, 2007:1477). At first it is no easy matter to succeed in including this subject in these professionals' agendas, whether we are talking about general media or media specialising in healthcare. Their emerging and novel nature, along with their specific terminology and complexity in the technical and sociomedical aspect, is very likely to mean that journalists find an initial barrier which could lead to further informative errors and dissuade them from writing about these matters, considering the difficulty that these may involve for their receivers: "Press coverage of rare and vivid events as compared with more routine and chronic risks may be an important source of public misperceptions" (Kasperson and Kasperson, 2005:82).

We might nevertheless not only be coming up against a new thematic genre, but also, as Francesc Palau (2010:161) mentions, a "new paradigm in clinical medicine" represented precisely in minority diseases. This new paradigm clearly has effects not only on the media, but also on all the actors involved. RD also need a socio-populational strategy requiring

common valuations, holistic slants, the incorporation of socio-cultural experience complementary to genetics, setting up multidisciplinary, preventive and integrating approaches and specific educational measures (2010:164).

3. DIFFICULT ACCESS TO SOCIAL DISCUSSION ON HEALTH AND ILLNESS FOR RD ASSOCIATIONS

If a subject like RD is no easy matter for professionals to deal with, one can only begin to imagine the work entailed for patients' associations and all the difficulties that they have had to overcome over these last few years in order to become visible through the media and to put across their claims, requests or demands to society. Several factors ought to be taken into account in order to appreciate all that this task involves. The interest in health as a news topic for the media has soared over recent years. This has resulted in very great competitiveness to find a niche: sociomedical workers, research, industries associated with health, healthcare managers and politicians, patients or relatives' associations and others are all forced to jostle to convince the media that what they have done, what they are going to do, what they have said or are going to say is worthy of their interest. What is more, not even the initial access to the media is the most essential factor in an attempt to gain social influence through these channels, since this contact may be occasional: the most important part is actually remaining in this discussion after gaining access to it. This means generating an interesting and constant discourse over months and years. Associations of people with RD have had to work very carefully to gain this ground, to become identified as constant sources for the media. For the time being, this venture could be said to have been more or less successful. Articles by medical professionals now include references to associations and even their specific addresses with some regularity (Ortiz et al., 2009:340, for example, talking about Friedreich's ataxia).

4. AGENTS INVOLVED IN RD: SPEAKERS, LOUDSPEAKERS AND SPOKESPERSONS

The efforts made by associations of patients with RD in setting up a network of actors committed to the cause has been a determining factor for getting some stable presence in the media. The roles that can be played by these actors are basically those of

'speakers', 'spokespersons', 'loudspeakers', 'projectors', 'references' and 'disseminators'. The original message comes from the patients, those affected and their families: these are the speakers. The spokespersons are those who talk as representatives of the patients' associations. The loudspeakers do not belong to the group of patients or persons affected, but can have great weight in society and assume the patients' claims as their own. Their involvement does not only consist in lending their image, but in speaking and participating in the public debate in some way. The projectors are, on the other hand, the people who lend their image for a specific time with the intention of having a particular group being associated with them, which has favourable repercussions in both cases. We use the term 'references' for RD experts who take part in the debates and who very often do so to back the conclusions passed on by the patients' associations themselves. We finally mentioned the disseminators, that is, the media whose role is to (re)convert a message and convey this to the greatest number of receivers, depending on their importance.

In the last three years, the number of people connected in some way with passing on the message of individuals and groups with RD has enhanced social knowledge about this type of pathologies. To mention loudspeakers, the case of Princess Letizia Ortiz could for instance be mentioned, having talked about these people's needs both in Spain and abroad. More recently, also in the political and institutional domain, so have Infanta Elena de Borbón, the Speaker of the Congress, José Bono, or the president of the Health Commission of the Spanish Parliament, Gaspar Llamazares. One frequent loudspeaker in the media has been doctor and journalist Bartolomé Beltrán. In a different field, some very important renown has been given to the RD cause by footballers Fernando Torres or Andrés Iniesta, by lending their image for campaigns over the last two years. People working in the media, such as Juan Imedio, who have lent their image, are also prominent agents. This type of public personalities boost the echoes from the people affected, though one should always avoid the danger of their fame overshadowing (and in the worst case cancelling out) the influence of the cause of solidarity. One should finally remember that the same person can act in several of these functions or roles at the same time, as is the case of journalist Isabel Gemio.

5. SOCIO-COMMUNICATION GENRES USED FOR PUTTING FORWARD THE NEEDS OF PEOPLE WITH RD

In any appraisal of the communicative importance of the work done by groups connected with RD, a careful analysis of the formulas (the socio-communication genres) chosen for public expression of the claims is needed. When and where such events take place are also aspects to be taken into consideration, as space and time may for example act as intensifiers or as attenuators of any social repercussions. In theory the most useful approach could be said to be the design of different genres, as that diversity could entail the transversality required to reach the greatest possible number of segments of society. These proposals should also contribute to strengthening the image and the discourse of the associative movement. As an example, consistency and formality must be conveyed in some cases, and a normal and natural manner in others. Congresses, symposiums or information sessions, participation in formal ceremonies are for instance genres where this consistency and formality needs to be ensured; the focus at concerts, sport events or competitions would need to be on normality and natural quality. From a different standpoint, the genres or sub-genres of press communication chosen to inform about RD are extremely relevant in the interpretation of the communication treatment proposed by each medium, as will be seen in later chapters.

For some years now, the worldwide associative movement for RD has designated 28th February as International Rare Disease day. Many people might seem to be rather tired of this type of calendar assignments, but the experience in the case of RD is that this has proved to be a tool with great social impact. It has also managed to make the activities connected with that day extend to others in the month of February, thus increasing the number of hits in the media, the essential first step for finding out whether access to social discussion has been gained or not.

The qualitative strategy must be the second step which in general has not yet been consolidated in Europe and in our opinion is starting to be urgent. Impacts are useful as initial impulses for gaining access to the social discussion on health and illness, for taking up a position, to put this one way. But after the ball has started rolling one must know which way to direct this. It is an unquestionable reality that the media have helped to make Rare Diseases and the patients suffering from these more visible; it nevertheless still remains to be ascertained whether the image conveyed has in general been the right one or not. This is one of the main objectives of this quantitative and discursive study.

These celebrations are however just as important for consolidating aspects to do with the internal communication of associations and the training of their spokespersons. This annual campaign naturally tends to be preceded by designing slogans which assume the general spirit of demands and which pinpoint interest on some specific aspect. During the 2010 campaign the slogan proposed by FEDER was: “We know what we want: rare diseases, a social and health priority”. The follow-up of this type of messages provides a sensation of uniformity in the discourse which in the long run is highly beneficial for the RD association movement in general. There needs to be some way of finding out if these slogans are kept to by the different spokespersons of the many associations forming FEDER and consequently if the uniformity transcends the communication media, repeating these messages through the voices of the different representatives of patients and their relatives. This is naturally not just a question of observing the repetition of the slogan, but also of conveying the indirect messages associated with this main idea. If we analyse this 2010 slogan (‘We know what we want’), for example, we can see that the Spanish Federation wanted to put across the strength that the movement has gained over the last ten years and its constitution as a reliable interlocutor, able to clearly identify its wishes and claims (the reason for the initial expression). These claims were also aiming to make RD not only a social but also a healthcare priority. The complementary messages for this slogan were intended to persuade health authorities of the importance of setting up centres, units and reference services (CSUR), and secondly, to promote research a great deal more. It remains to be seen whether this structure of contents reached Spanish media properly or not. It was also a great idea to draw up a document that was easy to remember and convey by being materialised in a genre with great media repercussions: the Decalogue.

It would be a different matter to find out if the great communication effort made by associations on this date is later materialised in the form of income to continue with the movement for demanding recognition (meaning the adaptation between some people’s saying and other people’s doing; that is, the persuasive capacity of discourse assertively claiming attention). The first impression is that such income is very modest and does not tally with the degree of visibility achieved during the month of February. Arrigo Schieppati et al., talk of the enormous progress in awareness-raising that has been achieved in the last twenty years and the poor response to this treatment as regards obtaining therapies and the need to increase investment in research (2008:2040-2041).

As regards space, the associative movement has also managed to convey its claims in emblematic venues over these years. Saying something in Parliament or in the Senate is not the same as doing so at a press conference in a hotel room, for example, even though the message might be identical. Over the last two years, Parliament and Congress have as a matter of fact been hosts for the acts organised by FEDER for the International Rare Diseases Day. The presence of representatives of the Federation has also been requested at a reception in La Zarzuela Palace by Princess Letizia

6. POLITICAL-INSTITUTIONAL DISCOURSE ON RARE DISEASES AND THE REPRESENTATION OF THE MAIN ACTORS

Political discourse is a good example for exploring the (not always direct) relations between saying and doing, the two basic facets of semiotic behaviour. To sum up what was found in our corpus, a table with six dimensions was drawn up, in which the relationships between what is said and what is done are placed on a time scale:

Past	Present	Future
(a) Having done in RD	(c) Being done in RD	(e) Things remaining to be done in RD
(b) Not having done in RD	(d) Not being done in RD	(f) Nothing remaining to be done in RD

Table 1. *Political communication and social-semiotic dimensions*

The typical speech heard from politicians with some degree of responsibility in the healthcare sphere about rare diseases is a combination of dimensions (a), (c) and (e). That is: “We have done things, we continue to do things, but we recognise that things remain to be done”. Sometimes the clinical, sociomedical or research complexity of RD may act as an excuse for justifying the lack of intervention in this field. Saying that ‘there must be things to be done’ is expressing the obvious, and one way of avoiding specific responsibilities from being claimed as regards these ‘things remaining to be done’.

As for the content, it is always advisable to look for quantifiers, meaning that it helps to observe if the discourse uses terms connected with the amount of things that have been

done, that are being done or that remain to be done: for example, “a lot has been done”, “little has been done”, “a lot is being done”, “little is being done”, “a lot is still to be done” or “little remains to be done”. It will understandably be difficult to find some politician in charge saying “not much has been done or is being done” if these issues have partially or absolutely been or still are their own responsibility. It will likewise be hard to find references in the press to a discourse in which such a politician states that little is left to be done. The lack of quantifiers determining a time or intensity of action also has one possible interpretation: the search for a more peaceful discursive space, where implication is not thought to be necessary or where the strategic importance of eluding responsibility is being considered. Chapter 7 provides an opportunity to see how these ideas are expressed in the press documents analysed.

7. ECHOIC DISCOURSE AND SIMPLIFIED TREATMENT OF RD CONTENTS

As all the agents involved tend to point out, when we talk about RD, we are in fact referring to roughly seven thousand pathologies, which is why the complexity of their information treatment is even greater. The journalist’s work must furthermore always include the facet of adapting to the receiver, of making the subject being discussed and what they are saying understandable. This has an informative function and a major effort in preliminary understanding and discursive simplification needs to be made. It is obviously not an easy matter to provide an alternative discourse to the medical-scientific approach, above all if one takes into account the practical non-existence of professionals trained in RD, and the little effort that the entrepreneurs sustaining these media tend to make to invest in specialised training. Another matter to be taken into account is that dissemination very often implies using more words than the ones found in the scientific source text or the reference declaration, which may go against the routines and spatial limitations typical of certain media or genres.

We thus come up against what we call the media’s echoic discourse as regards RD. This consists in repeating information with hardly any specific editing of the contents by the medium in question. It is true that this conduct may mean a greater number of hits, above all in digital media, as the textual processing involves simply copying the documents coming from agencies, which often stem from the press releases prepared by the communication departments of bodies, organisms and associations. The discursive content

prepared by the original sources is thus maintained to a great extent. It is also true that this echoic discourse also indicates a lack of creativity, little involvement in what is being told. In fact, this “cut and paste” approach sometimes even includes the errata that might be found in the initial document.

8. MANAGING THE DIVERSITY OF SOURCES IN RD PROPERLY

The large number of pathologies also implies some diversity of sources and spokespersons, above all if we are talking about patients’ associations. This diversity may give rise to some resentment towards the professionals, perhaps less accustomed to dealing with this type of groups than with sources and spokespersons from institutional fields. One of the characteristics of associations of people with specific fairly uncommon pathologies is that there are very often few people affected, a fact that journalists may interpret as being equivalent to scant representation. These are also associations without very much money to play with, which do not tend to have communication departments as a rule. This reality has obvious repercussions on the appraisal made of their messages. The fact that their resources, documents or headquarters tend to be very modest is not always construed in fair terms, differentiating the modesty of the forms from the reliability of the contents. Another point to bear in mind is that official or occasional spokespersons are not exclusively engaged in the matters championed by the associations. They are most often people or relatives of those affected, combining care for the sick with other work, and are thus spokespersons with limited availability, which comes into head-on collision with press routines. This lack of availability may be a threat to the associations’ use as primary sources in journalists’ agendas. Finally, the specific profile of these associations (few patients) means that it is common to find repetitions of patients’ testimonies (the journalists’ core interest). This may lead to a problem for the reporters handling health matters who are sometimes seeking originality and diverse points of view. One should also bear in mind that some RD have many discriminatory elements associated with them, which may make those affected and their relatives prefer not to be seen in the media, thus restricting the possibilities for disclosing life stories even further. In this respect, moreover, one would also have to observe if, in any event, attention is focussed on these stories or if space is also granted to promoting associations as a useful tool for the management of social problems at the same time as being helpful as reference information sources.

It is true that the existence of patients' platforms, agglutinating different associations, has made it very much easier to build bridges between journalists and accredited sources, also preventing a large part of the aforementioned prejudices and, quite the contrary, encouraging more positive appraisals. It is highly important to observe if the media inform of this role or not, given that the presence of this data in narrations will unquestionably boost the association's prestige.

Apart from this, there are individuals suffering from RD, as people offering their testimony directly. It is important to remember that when patients with RD are said to have "functional dependency on their relatives and on the healthcare system" (Plaza, 2009:193), they are also (though perhaps without being aware of this) talking about communication dependency. Very often indeed, one of the consequences of diseases may be precisely the loss of independence for communicating, the loss of self-sufficiency. This clearly does not necessarily mean any inability for communication in general. Attention needs to be paid to whether the media and their reporters provide the tools required to get the direct opinions of people suffering from RD, although this requires a greater effort or providing alternative forms of communication.

9. THE PACE OF INCREASING COMMUNICATION POWER OF RD SUFFERERS' ASSOCIATIONS AND DETERMINING ECONOMIC FACTORS

If the founding of the Federación Española de Enfermedades Raras is taken as a reference point, the associative movement of people with RD in Spain could already be said to be twelve years old, though some associations for this kind of pathologies had obviously already been operative for years before. This is the case, for example, of ADAC - Asociación para las Deficiencias que afectan al Crecimiento y al Desarrollo (the Association for Deficiencies affecting Growth and Development) or partly of ASEM - Federación Española de Enfermedades Musculares (Spanish Federation of Muscular Diseases). ADAC was in fact the embryo of the Federation and also very clearly expresses the initial tendency of minority disease sufferers to form part of "umbrella" groups, precisely in view of the low prevalence and consequently the lack of lobbying power assumed for this type of groups. From a different standpoint, however, this associative movement could be said to be hardly twelve years old. Though it may seem a long time, it is not actually so long if we realise that this has entailed the introduction and stabilisation of

a new participant in the discussion on health in Europe. This means that the pace of growth as regards influence on society has been really fast and has had to be on a par with the many social and communication commitments that this growth presupposes. Investment in human resources connected with work in communication and marketing has almost always been a sure bet for RD associations all over the world. Inside these same associations, even the most important ones, it is nonetheless possible to hear comments which seem to indicate that the communication business is a minor matter, something almost like ornamentation. If truth be told, at a time of shortages of funds, when limitations in growth options and even internal cuts are perhaps being considered, communication departments always tend to be the first on the list for redundancy. Some directors of the associations could possibly need greater preparation so as not to repeat this type of internal debates so constantly.

Ségolène Aymé, Anna Kole and Stephen Groft have talked of the community of rare diseases as an example of the empowerment of patients: "Patients with rare diseases and their support organizations are among the most empowered groups in the health sector, mainly as a result of their own fight for recognition and improved care" (2008:2050). This empowerment is, as they see it, due to several factors: their essential involvement in designing information and educational materials that can be accessed over the Internet; the smoothly operating establishment of transnational communities with people suffering from the same pathology; the fact of having generated the sense of belonging to the same community in such a short time and having established a kind of communication with sociomedical staff, with researchers, the pharmaceutical industry and healthcare managers preferentially based on cooperation, departing from previous prototypes in which these relations were more akin to estrangement (almost confrontation sometimes). Patients have in fact been given a central place in the agenda, to the extent that the very notions of 'Rare Diseases' and of 'orphan drugs' were established through consensus between all the aforementioned parties, the patients too (2008:2048-2049). If one stops to think about this, this resolute capacity for action has very particularly been a question of communication.

10. IT IS NOT JUST A MATTER OF PREVALENCE. TERMS AND DEFINITIONS USED FOR RD

When they discuss the definition of RD, Manuel Posada and Miguel García Ribes point out that the term rare diseases appears as early as 1978 in the journal *Pediatrics*, in an article referring to professionals' ignorance as regards treatment of metabolic diseases (2010:169). They state the following as regards the definition:

The definition of RD is a synonym of low-prevalence disease and the cut-point is different for each country. In the United States the absolute figure of 200,000 cases is used, which works out at 7.5 for every 10,000 inhabitants, and in Europe the figure of under 5 cases for each 10,000 inhabitants is applied in the EU. This is under 2 cases for every 10,000 inhabitants in Japan. The EU also includes in this definition rare conditions (special clinical evolution or different phenotype) of common diseases. It adds an aspect not linked with the figure of prevalence, consisting in that it must have a high impact on mortality or be chronically weakening, whether this is a rare disease or a rare condition.

Another important matter is the identification of a number of RD for which there is general consent. The aforementioned authors state that the estimated figure for this lies at over 7000, although there continues to be a problem of knowing what exactly is to be understood by the term 'disease' (2010:169).

The definition of RD is not a minor issue. If the media stick to a poor definition, the social significance of the sociomedical problem will be similarly poor. When we talk of rare diseases, we are talking of diseases that, apart from being seldom found, are also serious, difficult to diagnose, with few therapeutic alternatives, not well known and which generate a high percentage of major disabilities. This is precisely the aspect in which the media's reaction may well be to simplify a complex matter by associating this with others with which it is linked and which they master better. This is what happens with the thematic association between RD and disability⁴. The association might alternatively be established with subjects similarly linked with RD which arouse greater social controversy, such as the new cell and regenerative therapies based on the use of stem cells, or euthanasia.

It is not only journalists who may fall into this error - even healthcare workers may be found making it. In a study on Primary Healthcare and RD the following can be read: "The inter-

⁴ As Sylvia Plaza points out, the European Union also includes "the 'rare situations' of diseases that are not rare" in RD (2009:193).

pretation made of the term 'rare' does not express the seriousness or the repercussions entailed by these diseases" (Avellaneda et al., 2006:348).

This type of association is a difficult matter to handle because it may lead to certain collisions in communication strategies. Think of the case of the associative movements of disability and of RD, both closely linked since they share for example such important lobbying forums as the CERMI. In the assertive discourse of disability we are reminded for example of the importance of separating the idea of disease from that of disability (the 'demedicalisation' alluded to above). A person with a disability is not a sick person. It is quite true that this connection is extremely deep-rooted in our society and an underlying part of compassionate discourse, since disability is also seen as suffering, something which can also be connected with the presence of a religious basis in the social discourse used when discussing this matter (Stainton, 2008). To be quite frank, this disassociation between illness and disability is in any event difficult to assume when our analysis extends to another kind of group. Let us consider for example people with rare or seldom-found diseases and their associations. There are about three million people in Spain who have one of these pathologies, and there are over three and a half million people in Spain who have some kind of disability. It is evident that many of the seven thousand minority pathologies generate disabilities, some very severe, and the lobbying power of these people lies precisely in reminding of their status as affected persons, as sick people. This stance would in theory contrast with the idea of - we could say - normalising their status as people with functional diversity. Adjusting these two identities properly is a complex challenge, but necessary all the same. It is similarly complex to know to what extent it is useful to manage the public image of a group from the standpoint of extreme suffering or from the position of the balanced search (starting right from the name) for necessary solutions. Being recognised as a social interlocutor for some decades, as with the most important associations and federations of disability associations, is quite a different matter to having to vie for a place starting from a lack of knowledge and a lack of associations, as has happened with the RD association movement in Europe. In this second case the emphasis, at least in the first few years, on bolder and catchier messages and names could well be more understandable. After this niche has been won, it is time for lengthy reflection on a possible new phase in this management of external communication.

Another important issue is the name chosen to refer to Rare Diseases in Spain: "Enfermedades Raras". It is common to hear disagreement with the use of this adjective in public

forums, since it is claimed to generate an inappropriate and unnecessary estrangement. Patients' associations themselves nevertheless assumed this name from the beginning as a formula for priority identification, accepting the risk that might be entailed by it. The Federación Española de Enfermedades Raras is usually given the blame for adopting the term (García-Ribes et al., 2006:369). Why did it choose this word? One of the fundamental reasons was the need to call people's attention clearly and urgently to this type of pathologies and to the groups of people suffering from them. The starting point in respect of scientific and social knowledge of these was truly hopeless and the use of an eye-catching label was doubtlessly going to help to create special interest. The involvement of a person connected with the media when the FEDER was originally being set up, in the late nineties, also meant that this need was fittingly appraised. It is furthermore obvious that the English adjective 'rare' also exerted more or less direct pressure on the term used in Spanish – "rara/s" (strange, odd, funny, rare); one should remember that the North American association was set up in the eighties and had already been running for a long time when Europe was still getting off the ground. The adjective 'rare' in English moreover probably has less connotative power than 'raro/a' in Spanish and a meaning that lies further towards the idea of "low prevalence".

The risk to which we referred above very clearly materialises when this estrangement or oddity involves not only the diseases, but also the sick person. To put this another way, the attitudes that are linked to 'rara' (in the sense of odd) rub off onto the person, hinting at the idea that people with rare diseases are also themselves "raras" - odd. This curious association gives rise to a very negative impact in the social perception of those affected and their communicative interactions, above all if the pathology leaves clearly visible marks on the bodily surface of the sick people. Everything becomes more complicated if additionally another complementary association is made: this time between 'raro' (= odd) and 'dangerous', so that RD can, through ignorance, be considered dangerous. This is not only due to their possible evolution or disabilities stemming from these, but very specifically through wrongly thinking that they are, for example, 'contagious' and consequently dangerous for those who might be sharing activities or interactions with this type of persons. The isolating consequences of these arguments for both the sick people and for their relatives are easy to glean from this. This all entails an effort which may ultimately prove exhausting and lead to avoiding communication contacts in the most serious cases, through mistakenly thinking that this is the best way to avoid any funny looks or unfortunate remarks.

Other expressions used are 'orphan diseases' (Daina, 1994:1560), 'minority diseases', 'low-prevalence diseases', 'forgotten diseases', 'uncommon diseases'. Without a doubt, each lexical choice goes with a certain way of approaching the treatment in its concept and its attitude, particularly as regards assigning responsibility. 'Forgotten' or 'orphan', for example, also put some blame on the pharmaceutical companies or the institutions which is not found in the other options for these terms. Posada and García indeed assert that the terms 'rare diseases' and 'forgotten diseases' tend to be (improperly) used interchangeably, since according to the authors, forgotten diseases are the ones which "while being common in underdeveloped countries, are of low prevalence in the more developed ones" (2010:169). It seems obvious, in any event, that the term 'Enfermedades Raras' "is relatively young and its development is not proving harmonious" (2010:170).

One fact that cannot be ignored is that the expression 'Enfermedades Raras' is sometimes seen as the expression of a real situation – actually involving a "hotchpotch" (González, Aleixandre and Valderrama, 2006:478).

When we define RD we must point out the matter of prevalence. The figures that tend to be used in experts' discourses and the media's own treatment need to be detected. There is some agreement on the figure of three million people affected in Spain and around 25 million in Europe. It also tends to be agreed that there are around seven thousand RD and that about 7-8% of the population may be affected by one of these. Specific figures as regards affected family units do not tend to be used.

11. DISTANCING AND DRAWING MEANING CLOSER IN THE REPRESENTATION OF RD AND OF THE PEOPLE AFFECTED

Since low frequency is one of these pathologies' most essential characteristics, the initial position in respect of people suffering from them or people who are working to promote a better quality of life, more research or better diagnoses is often one of distancing. What we mean to say is that due to their "rare" (\approx odd) nature, the journalist may start from the preconceived idea of the readers' finding it hard to bond with the issue, since they will think that it is rather remote, that 'it is not going to happen to me or my family': "Any story about cancer, even a cure, which indeed is a good thing, is only news because cancer itself is so scary. The cure (good) story draws its news value from the threat (bad) that it

concerns. A cure for a rare disease that the reader has never heard of is also good news to a slight degree, but it is not big news” (Arno, 2009:66). Quite apart from this we know that everything referring to new and atypical matters, particularly in the sphere of health, has its media interest: “Disease stories tend to focus on illnesses that are new (Lyme disease), obscure (rare outbreaks of exotic diseases), unusual (environmental sensitivity), or near hopeless (certain cancers)” (Lawrence et al., 1993:69). Keith Tones and Sylvia Tilford (2001:364), also point out that: “Greater attention is given to health risks that are relatively serious and rare (e.g. Legionnaires’ disease and toxic shock syndrome) than to common, chronic health issues such as diabetes”. Clive Seale, one of the greatest specialists in health and the media, sees this in similar terms: “Medical threats work well if they are exceptionally rare or ‘terminal’; thus the terminally ill child with a rare form of cancer will always signal news value” (2002:32).

This being the case, if journalists have to deal with an issue involving RD, they are going to require tools for drawing the subject closer to the receivers, as it were. It is understandable that this should be the case, and also highly important to observe precisely what discourse and communication strategies they make use of for ‘bringing the story home’. They might actually succeed in this, or the interest in ‘selling’ a news item may take precedence over the interest for getting the reader involved in the story in a simple and balanced way.

Generally speaking, two of the most appropriate techniques for bringing the subject closer to the reader can be highlighted: (1) ruling out any use of the discursive structure fostering discursive metonymy (people suffering from RD are also rare (\approx odd) and discursive association (what is rare (\approx odd) is equivalent to dangerous or contagious, meaning that people with RD are dangerous); and (2) the drafting of messages based on the fact that we can all have a rare disease. As Erica Daina points out, for most people “Orphan diseases are not important unless you happen to have one” (1994:1561). There will be a third issue, which stems from the previous one: the patients and their associations find their assertive identity in the fact of there being very few of them, but at the same time, they have to design a good deal of their communication strategies alluding to the fact that as a whole they are a large group, over three million. “This is what has been called the paradox of rarity” (for example, 2010:162).

These techniques would be used precisely to attempt to prevent putting across sensationalist messages. Quite a lot of RD leave their trace on the face and on the body, providing

pictures which can be used by the media with the sole intention of surprising and causing an impression which is, as a rule, ephemeral and prevents any lengthier reflection on the messages which are being conveyed or on the logic of what is being claimed.

We need media professionals who are not satisfied with a facile representation of RD, a portrayal with a bias towards sensationalism. We also need professionals who can prepare representations with no fear of seeking responsibilities and avoiding telling stories as if they were only the patients’ and their relatives’ problem. This attempt to place the responsibility only on the patient and their family milieu can be verbalised by always talking in any event of difficult solutions and necessary resignation, or of recognition of people who are fighting a battle, “their own” battle (Lawrence et al., 1993:69).

12. REPRESENTATION OF COOPERATION AND CONFLICT IN THE SPHERE OF RD

The progress made and influence of the patients and their associations has been considerable over the last decade, and the search for areas in which professionals and those affected can cooperate has also produced appreciable results over this time. It is also true that major communication problems, assessed by each group in a different way, arise in the daily business of managing the disease. It is extremely important to observe how these conflicts are depicted in the narrations of doctors, patients or patients’ relatives appearing in the media. They often come up in Primary Healthcare, a field usually given little significance, but which actually constitutes an essential first step in the chain of identifying (or failing to identify) the diagnosis and later follow-up of the pathology (Senior and Knight, 2008:890). In an article on RD and training needs in Primary Healthcare, we read: “The Primary Healthcare doctor considers that informing patients of the diagnosis is at a very difficult stage, as an RD is actually taken more badly at the present time than in previous decades. Nowadays the reaction is to try and put the blame on someone and rebel against the doctor [...]” (Avellaneda et al., 2006:347).

Also from the standpoint of primary healthcare professionals, four members of the Work Group on Genetic and Rare Diseases of the Spanish Family and Community Medicine Association, Miguel García-Ribas, Ismael Ejarque, Estíbaliz Arenas and Vicente Martín, point out that family doctors who come up against a case of RD and refer the patient to

specialists “remain there in wait-and-see status in most cases, when not totally avoiding responsibility. This is because ‘the problem is more than they can handle’ and they merely act, at most, as mediators between the patient and the other specialists, whose loquacity is sometimes conspicuous through its absence” (2006:369)⁵. Precisely this avoidance of responsibility and silence lie at the root of a good deal of communication conflicts in which patients and relatives are involved. These problems may also date back to Primary Healthcare after establishing a diagnosis, since, as they assert, the family doctor may receive patients “with fear and lack of knowledge” (2006:370), not only because they have special needs and do not tend to have a cure, but also because they are patients and relatives “with a lot of questions for which there are few answers, whom disinformation has forced to be their own informers” (2006:370).

The following table represents the possible phases in the development of a conflictive interaction in the health sphere:

Typical interaction		
Not conflictive		
Explicit or cooperative		Implicit or non-cooperative
Non-existence of disagreement and active participation in fostering agreement		Non-existence of disagreement and no active participation in fostering agreement
Conflictive (through not doing things or doing them wrong)		
Explicit		Implicit
Indirect or mediated	Direct or not mediated	This comes forward in dissent or disagreements which do not end up in argument but which generate some degree of communication tension. This may end up in a request for general improvements, without pinpointing any direct responsibilities. Any clear expression of disagreement is avoided
This comes forward in genres such as protest, civil suits, formal complaints, accusation, petitions, etc. Some are more oral procedures, while others involve written communication. Depending on the cases, the parties involved are actors such as the patient ombudsman, judge, ombudsman, managers of the institution itself, etc.. Sometimes the media also end up participating	This is seen in disagreements, dissent or differences of opinion which end up in argument between actors participating, for example, in a medical clinic, but which do not transcend this interaction framework	
Settled (by means of persuasion, negotiation, abandonment.) / Not settled		

⁵ In this respect: “This generated excitement in the medical and scientific community not only because truly new diseases are rare but also because its cause might be new as well” (Treichler, 1987:277).

Contextualisation of the conflict (modelling and determining the prototype)	
Time	Space
When does the conflict emerge?	Where does the problem emerge?
Before the first consultations (delay)	Healthcare centre, hospital, congresses, etc.
At the first consultations (misunderstandings)	Where is the problem settled, if it is settled?
In the diagnosis process (absence, misunderstandings, errors or delays)	Same space: patient ombudsman, patient care service. The process is less conflictive and does not take as long.
In the treatment process (absence, misunderstandings, mistakes or delays)	Different venue: ombudsman, court, media. The process is longer and more conflictive.
How urgent is the settlement?	Does the conflict thus extend beyond the medical-healthcare sphere?

Table 2. Typical interaction generated by a previous health problem and contextualisation of the conflict

In the field of RD, conflicts between healthcare professionals and patients/relatives are very common, particularly in the phase of seeking the diagnosis. These conflicts are sometimes generated by the non-existence of clear decisions on what the interaction between these groups should be and on whether both have a common space in which to converge and cooperate, apart from only the hospital area. This type of decisions could prevent a lot of distancing. In a piece of work sent by Rosa Torres and Juan García, both doctors at La Paz Hospital, dealing with RD in general, but particularly with the Lesch-Nyhan syndrome, they ask: “what position should be taken by healthcare workers at associations of patients with rare diseases?” (2004:60). Further on they offer us their proposal: for professionals to assume their responsibility as people who can take on a great deal of prominence in stimulating and supporting patients’ associations (2004:60-61). This is an appropriate implication which should not in the least be understood as any steering of their activities or manipulation of their claims.

13. THE PROMINENCE OF THE NEW MEDIA IN THE SOCIAL MOVEMENT IN FAVOUR OF RD

The influence that Internet and Web 2.0 have had in developing social movements is obvious. The case of RD is no exception to this, quite the opposite in fact. The economic

factor should be taken into account as one of the aspects that have initially been of greatest influence in the use of the Internet for disseminating messages and making problems of great sociomedical significance more visible. The new media have not only been of great use for generating messages by the groups involved, but also for displaying the interest of the media themselves.

Ray Tomlinson, inventor of the electronic mail and winner of the Príncipe de Asturias award for Scientific and Technical Research in 2009, was interviewed by the magazine *XL Semanal*. The interview was published in issue 1.148, dated 25th October 2009, and in it Fernando Goitia asked him, amongst other questions, if he remembered having received some remarkably gratifying electronic mail. He particularly remembered one, in which someone had thanked him on behalf of a relative who was suffering from a rare disease, because this person had managed to get in touch with people with the same pathology precisely thanks to a group swapping emails. This circumstance completely changed the person's life and helped them to cope with all the aspects connected with the disease better. This famous engineer's reply said a lot about RD, but also about the importance of the Internet in developing a parallel communication world difficult to get under way, above all, when particularly stigmatised, discriminated or alienated groups are involved. The fact of the people affected and others being able to communicate easily over the web, in spite of the characteristic dispersion of the people affected by these pathologies, has been stressed in certain pieces of research about communication and new technologies (Schalken, 1998:163; Bucchi, 2009:57; Kamarck, 2005:227; Putnam and Feldstein (2003:226).

Internet has indeed been a very beneficial instrument for the activities of associations of people affected by RD (Cairncross, 1997:243). In one of the best-known manuals on health and communication, the one edited by Teresa Thompson, Alicia Dorsey, Katherine Miller and Roxanne Parrot, there is a work by Terrance Albrecht and Daena Goldsmith on social support, networks and health, in which we read: "Computer-mediated support groups may increase access to similar others for individuals who are physically disabled or who cope with rare diseases, reduce the stigma experienced in face-to-face interactions, increase comfort in disclosing difficult topics, and provide an opportunity to produce an uninterrupted narrative" (2003:276).

From a different standpoint, the major role of new information and communication technologies in identifying RD and managing these has also been stressed (Zöllner,

1995:279)⁶. This is also true of the search for updated information about treatments for this kind of pathologies, a search that Susan George associates with the desire to actually find 'miracles' (2006:44), which can partly lead to a biased stance in respect of the objectiveness with which RD sufferers and patients' associations tend to view therapeutic progress or their ability to discern well-structured and soundly supported proposals from mere hot air. RD constitute one of the foremost groups in the initiatives that can also be assigned to what is known as 'e-health'. This is the opinion of D. Silber (2004:6), who specifically highlights two information platforms: the London Dysmorphology Database and Orphanet. The last of these is described very well in the work by Aymé and Schmidtke (2007).

In his book *The 21st century media (r)evolution. Emergent communication practices*, Jim Mcnamara asserts: "Web 2.0 Internet sites can serve small specialist interest communities and even micro-communities. There are Web 2.0 online communities for stamp collectors, rare butterfly and bird watchers, lovers of niche music genre, sufferers or rare diseases, people who have suffered the loss of a child or partner, 'geeks' and 'wonks' interested in swapping experiences in writing open source software code –all interests and stories that rarely see the light of day in mass media" (2010:37). Three relevant issues come to light in this fragment: a) Internet has been very important for the group of people affected by RD; b) sufferers appear in a list of collectors' groups, associating them with something coming very close to atypical, eccentric groups, and c) the presence of RD in the media is rather infrequent.

Internet nevertheless also provides another less friendly, more anonymous, and sometimes more aggressive and violent stance - even towards matters which in theory arouse greater affinity and empathy, such as having to live with very serious and uncommon diseases. In another piece of work, for example, we dealt with the aggressive and unpleasant exchange of messages in an Antena 3 TV forum in which they talk about the Hallervorder-Spatz disease (Bañón, 2010).

⁶ The Internet has also been useful for improving professionals' knowledge about RD (Glueckauf and Lustria, 2009:170).

14. BASIC ARGUMENTS AND COUNTER-ARGUMENTS ON FINANCING AND RESEARCH INTO RD

There is a basic range of arguments in the discursive treatment of Rare Diseases whose presence in the media will require great attention. It is connected with socio-economic and research issues of great significance in establishing an image for the present and future of RD. The first argument would be that of justifiability; that is, whether it is licit (it tends to be said) to make major investments to be able (or not) to finally obtain therapeutic measures from which only a small group of people will benefit. In this case, aside from the basic question (we should all have the same rights to be cured), the counter-argument is obvious: research is beneficial through its applicability in the field of common diseases too (Griggs, 2009:20; Daina, 1994:1560). The second argument is that of profitability: investment in research into Rare Diseases cannot turn out to be profitable for investors. Of course we now have evidence that this is not necessarily the case: “The supposed lack of profitability of orphan drugs is also starting to be demystified, at least for certain RD. At the present time different laboratories which have accepted the commitment to put on the market effective, safe and quality drugs for certain RD are proving that it is possible to make that investment profitable for industry” (Posada and García Ribes, 2010:170). The third argument deals with the difficult way to tackle RD: there are many of them, with very different profiles and thus impossible to handle properly. This type of argument ignores the possibility of making transversal approaches, with some progress being valuable not only for one pathology, but also for specific types (one could think for example of lysosomal diseases). Francesc Palau puts it like this: “it is the question of sharing problems and the need for common solutions which means that having an RD may get an appropriate response from the health system which is also useful for other RD” (2010:166). Another important argument in this respect is that of non-specificity; that is, of Rare Diseases in fact having the same problems as common diseases, setting aside their specific profile in respect of scarce epidemiological studies (Schieppati et al., 2008:2039), diagnostic delays, lack of treatments, knowledge deficiency even in the domain of healthcare workers and social discrimination ⁷. Another look will be taken at these matters in Chapter 9.

⁷ On this aspect see: Estudio sobre la situación de Necesidades Sociosanitarias de las personas con Enfermedades Raras en España (ENSERio) (2009)

15. RESEARCH INTO RD. THE FASCINATION OF THE MEDIA FOR TECHNOLOGICAL AND THERAPEUTIC PROGRESS AND THE ROLE OF PATIENTS

Novelties, as we pointed out above, arouse great interest for journalists. In fact health-care research itself already produces fascination for the media, which tend to give a hyperoptimistic representation of the progress made in research in respect of new drugs or therapies (Lawrence et al., 1993:69). Since these are also rather infrequent disorders, the discoveries of possible therapeutic measures will also have an interpretation in terms of the prestige not only of the researchers, but also of the country to which they belong, the institution or company for which they work, etc.. When the experiments fail, this sensation will clearly not be transferred as if it were their collective responsibility.

But it also true that the starting point of the research on minority pathologies is not precisely good. 90% do not have any curative treatment available. What is more, we cannot say that there is no research into RD; progress is being made in this field too. According to Giuseppe Remuzzi and Silvio Garattini (2008:1979), nevertheless, the hopes that arose with the legislation initially developed in Europe have not materialised in specific drugs for RD, and furthermore these drugs have above all concentrated on certain types of pathologies (certain cancers or certain metabolic diseases), seeming to shelve other types of minority diseases. Finally, this investment is scarce, if we compare it with the number of orphan drugs. Their article in *The Lancet* ends as follows: “Patients with rare diseases and their families have been waiting long enough. It is now time for action” (2008:1979). In the North American setting the approach is very similar (Mazur, 2003:55).

Do the media remember this situation? It is also common for them to use expressions connected with the fact that something is moving or that there are “encouraging signs” as it says in the editorial of *The Lancet* of volume 371, 2008:1972), but fewer expressions of materialisation of research are found. Do the patients in fact feel that everything is moving very slowly or that everything remains the same in research? How are these steps forward expressed in the media? Who make known this progress: the researchers, the financiers ...? In this respect, there has always been said to be a great distance between researchers and the media. Still, at the present time the public appearance of this type of professionals to inform on what is being done or intended to be done is not only useful, but starting to become a necessity, given that the investors

need to guarantee a market or justify that investment, and the public communication of intentions or results is a genuinely useful tool. It is important to take note that we have spoken of intentions or results, and this is a very important difference, given that it is not the same thing, for instance, to represent the former as if they were actually the latter.

It is not enough for scientists in the (basic or clinical) healthcare area to put forward an interesting project for a certain minority illness or a set of minority illnesses. They also very often have to argue the reasons for which they consider that it is worthwhile making that investment, steering these towards an alleged economic-healthcare profitability (cost-profit tends to be said, with some distancing, in the economic jargon).

Apart from this, are there any communication interactions between researchers and patients? Do researchers inform about the progress made or difficulties which they come up against along the way? The truth is that this interaction is starting to become fairly common, especially in genres that have turned into mixed events, such as congresses, seminars or symposiums. Associations of patients with RD increasingly do more work in the sphere of promoting research. In fact, there are people who confess that this is where the influence of people affected and relatives has proved most impressive (Aymé, Kole and Graft, 2008:2050). Patients want to find therapeutic progress, but also to receive honest information about this (Institute of Medicine of the National Academies, 2001:43).

When we talk of health research, pharmaceutical companies come into the limelight, since the concept of 'research' is one of the most highly valued when these firms are represented in public discussion:

	Concepts	Applicability of the concepts
What?	Profitability	We are talking about private companies whose nature is precisely to make money
Which?	Specialisation	A sector in which a particular pharmaceutical company works
How much?	Production	Portfolio of products and their success

How?	Research		The ability to generate new lines of production by investments in their own or others' research.	
Heading where?	(Social) influence	Information	Involvement in social problems or reuse of profits in social projects for generating greater social welfare	Transparency and information and clear communication policy

Table 3. Aspects of how companies are portrayed in discourse

The media have an essential function to inform society of all these issues, which could be expressed in the fields and in the subjects shown in the following table:

RESEARCH INTO RD			
Who?			
Researchers, doctors, hospitals	Public or private promoter		Public or private financier
What?			
Type of pathologies		Type of therapies	
How?			
Expectations (success or failure)	Dimension (transversal or not)	Method (isolated or in a network)	Sufficient or insufficient
Where?			
Reference (media) centres, reference services, reference units			
How much?			
Great investment		Little investment	
When?			
Initial phase		Other phases	
Why?			
Lack of treatments	Social justice		Interest for common diseases too
Whar for?			
Diagnosis		Treatment	

Table 4. Aspects of textual representation of research into RD

16. CRITICAL AND CONSTRUCTIVE ANALYSIS OF DISCOURSE AND ACTION (CCADA). APPLICATION TO A CORPUS ON RD

The structure covering a good deal of the considerations to be found in this chapter is that of the technical-procedural guidelines of Critical Analysis of Discourse (CAD) or what we prefer to call Critical and Constructive Analysis of Discourse and Action (CCADA). Generally speaking, we could say that CAD sets out to identify the different ways in which power is displayed in discourse, or inversely, the different ways to attain greater power by using certain discursive techniques and strategies. The discourse used by elites (scientists, politicians, teachers, media etc.) is of particular interest.

We are persuaded that a true critical analysis can only exist if it also provides proposals for improving inappropriate communication practices and if it tends to eliminate the difficulties encountered by some groups in gaining access to social discussion on (in the case now concerning us) health and disease. In other words, a critical analysis necessarily has also to be a constructive analysis. In this respect, it must also be taken into account that a critical and constructive analysis not only involves identifying bad communicative practice, but also detecting and promoting communication models. As a complementary guideline to CAD, some authors have talked of Positive Discourse Analysis (PDA) to refer to this type of communication intended to promote attitudes of solidarity towards underprivileged groups, for example (Martin, 2004).

In our proposal, critical and constructive analysis of discourse could also include a new facet: that of action. We naturally refer not only to the action of observing whether what is said (or not said) matches what is done (or not done) or not. This aspect enables, for example, studying how far the promises made by political leaders are complied with or not throughout the process. To comply with this aim it is important to perform work on extensive corpuses, which can be read and analysed as a whole and which thus ensure the compilation of relevant information in different time phases. This is the procedure used in this book, for which information for one year was consulted. It will unquestionably be of interest to proceed to research with an even greater time perspective.

In both CAD and CCADA, it must be a priority for the researcher to observe the discursive techniques and strategies used for appraising a particular object of study (or the actors connected with that object as main protagonists). At least four types of valua-

tion must be taken into consideration: positive, not negative, negative and not positive (Bañón, 2002:33)⁸. In «Discourse and Rare Diseases: Proposal for a Critical Analysis in the Spanish Context» (Bañón, 2007b), for example, we already looked at different strategies of textual manipulation of representative status, of responsibility and of the objectiveness of people and associations of people with RD. This occurs for example when their claims are negatively identified as victimist (the victimisation argument), as unable to identify priorities and progress (the prioritising argument), and too heterogeneous, if they are examined as a whole (the heterogeneity argument), and in some cases, even as competing with each other, for which reason they could never come to any agreement (the competitiveness argument). Other strategies can sometimes also be accumulated with the above. Hence the associations could be identified as having a weak structure, as being easily deceived or as groups claiming the impossible (the weakness argument).

The following table provides a typology of valuations which may be found in the discursive representation of people suffering from an RD and their relatives.

	Representation of people suffering from an RD and their relatives	
Positive valuation	Level 1	Cooperation
	Level 2	Commitment
Non-negative valuation	Level 1	Condescendence
	Level 2	Compassion
Negative valuation	Level 1	Trivialisation
	Level 2	Discrimination
Non-positive valuation	Level 1	Prejudice
	Level 2	Indifference

Tabla 5. *Types of representation of people affected and relatives according to valuation*

⁸ There has hardly been any interest for studying the discursive representation of RD (Bañón, 2007a; 2007b and 2010; Requena, in press).

The ideal situation would involve finding out if these practices come about intentionally or not and if they match certain socially shared mental patterns and models, which would mean the dimension of knowledge would have to be brought into the analysis of discourse, as Teun A. van Dijk has so wisely pointed out (2008, for example).

Another basic category for the critical and constructive study of discourse and of action is responsibility; that is, the different processes of assuming, assigning and refusing responsibilities etc... The degree of involvement or avoidance of this is directly connected with the way people talking about a particular subject handle this from a discursive standpoint, as will be seen in different chapters of the book.

2.

CORRELATIONAL STUDY AND QUANTITATIVE ANALYSIS OF RARE DISEASES IN THE SPANISH PRESS

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In spite of the increasing growth in research on news frames referring to social information (for example on disability, immigration or health), there is hardly any empirical and experimental evidence of the effects or influences which such frames have on the opinions and attitudes in respect of people with RD. The image that the media provide of scientific progress and of the people actually affected and their claims doubtlessly deserves a specific theory. It would also be necessary to examine the correlation of both qualitative and quantitative contents. This type of research has not been tackled so far. Just as “people with disability on an individual basis, as well as their representatives, consider that the way they are treated in the media is not good” (Díaz, 2007:189), the image of RD projected by the media runs a risk of falling into the same stereotypes, prejudices and discrimination based on ignorance.

Although, as regards the matter of disability, “the media treat people with disability and disabilities in an excessively simplifying, stereotyped, superficial and/or mistaken way” (Solves, Castaños, Muñoz and Mercado, 2008), it is true that the massive dissemination of specific information, for example about the Paralympic Games, “is gradually and positively favouring the image that society as a whole can have of people with disabilities” (Mercado, Sánchez and Guardiola, 2010:13). We should also take into account that “the media, as catalysts of social conscience, opinion leaders and mediators in reality, should guarantee these people’s presence with the right regularity and treatment” (Sánchez, 2010:4).

According to the European Commission, “rare diseases are also known as orphan diseases, through being “orphan” of a research focus and market interest, as well as of

public health policies” (European Commission, 2008). The media are in charge of giving them visibility, but we need to grasp what criteria are governing this presence in the media. This would stem from a discursive and epistemological analysis, since “disease is a very complex reality not only from the medical and scientific standpoint, but also from the discursive point of view” (Bañón, 2007:190). In this respect, to establish the specific compensatory action that people with RD require in the services given, the role of the media as regards this social minority, though numerically considerable group, has to be learned.

This piece of research is intended to fill a gap in research on the treatment of people with RD and of their families in the Spanish press. It also intends to observe how news on this reality is structured, as well as the themes and pictures that go along with the news. This work also creates an initial and procedural methodological framework with which further research into communication of RD can be activated, apart from helping to transfer this scientific knowledge, not dealt with up to now.

In spite of an increasing awareness of the problems represented by RD and of the decisions assumed by administrations, as well as the very great level of international work already done, today one can still hear questions displaying the lack of information existing about these highly disabling pathologies (What is all this about RD? - Did they exist before or is it something that has recently appeared?). Can we therefore consider that uncommon diseases are absent from the media? A quantitative and qualitative analysis, at least insofar as the printed and digital press is concerned, would provide replies to that question.

1. THEORETICAL FRAMEWORK

1.1. THE THEORY OF FRAMING AND RD

Most communication researchers accept that news frames are not directly associated with any particular subject, and for that reason their definitions for similar pieces of research may possibly be introduced in different ways. This assertion exponentially

complicates the way that a subject can be framed, since that framing can furthermore be adapted to several research themes. During the process of media communication, each frame applied by a news producer in an informative text can be represented as a “package containing a conglomeration of logical, arranged devices which acts as an identity set for a specific focus” (Van Gorp, 2007:63).

Frames are not however seen in their own right within the media content “unless these are revealed through other framing devices” (Cheng et al., 2009:42). If the framing package is able to provide a viewpoint, a definition, an explanation or problemisation, an evaluation of an event or even a number of logical conclusions, it is because, apart from the obvious message in its contents, there is another type of latent frame which indicates how the message should be interpreted. Hence this framing “is a form of meta-communication in the sense of specifying the relations between a number of elements connected to a text” (Van Gorp, 2007:68).

Over the last two decades, the number of proposals in social research which have made use of framing as a basic methodological corpus has risen in this field of knowledge. Its theory, applied to the wide range of communicative exchange today proves paradigmatic to understand the cognitive effects of the media, such as agenda setting or priming, amongst others (Reese, Gandy and Grant, 2001; Weaver, 2007; Scheufele, 1999). In this respect one important work is the monographic volume by Tewksbury and Scheufele (2007), which emphasises the great importance that these theories have had in social research and their extensive theoretical production. Furthermore, recent works review the evolution of theoretical production in the whole range of communication studies (Vicente and Rabadán, 2009:17; Bryant and Miron, 2004; Lombard, Snyder-Duch and Campanella, 2004), and provide significant data stressing the importance of the framing. Specifically, Bryant and Miron (2004: 693-697) consider this to be one of the 26 most relevant theories of the second half of the 20th century. Even more significantly, in an analysis focusing on the main contributions between 2001 and 2004 it takes the first place in references, far above perspectives such as agenda setting, cultivation theories, third-person effects, the uses and gratifications theory or the theory of selective exposure. All of this leads us to accept this theory both through its present relevance and validation and for its theoretical and empirical development. From this standpoint, Entman (1993:52), has established the specific definition of the media frame and indicates the key points of the speciality: framing as a strategic action generating four consequences in the discourse

(defining the problem, attributing causality, moral judgment and recommendation for treatment), and with four locations (communicator, text, receiver and culture) throughout the communication process.

After examining the integration of framing studies as a second level within the model of agenda setting (Reese, Gandy and Grant, 2001; McCombs, 1997), as opposed to other authors who put forward the theoretical Independence of framing and its complementary quality in respect of the agenda tradition (Scheufele, 1999), Grupo de Investigación sobre Discapacidad y Comunicación (Group for Research into Disability and Communication) (GIDYC)⁹ has proposed using framing and content analysis for discovering the information treatment of Rare Diseases in the printed and digital Spanish press, specifically based on the relationship of framing with the communicative interaction and social construction of reality (Van Gorp, 2007). This is done with the acceptance of using both quantitative and discourse analysis methods in an integrating approach (Reese, 2007:148-154), and with no differentiating thesis in either procedure. Hence, the coexistence of both these perspectives means that a high level of both reliability and scientific validity can be obtained (Matthes and Kohring, 2008), in this case the treatment of RD in the proposed media corpus. The analysis will be performed by means of an approach to the quantifying tendency from positions concentrating on the media field, and with a method mainly based on analysing content with computer support, paying special attention to the tendencies of research with similar methodologies (De Vreese, Meter and Semetko, 2001).

Although the treatment of disability in the media has already been the subject of research (Rius and Solves, 2009; Díaz, 2007), and more specifically the discursive portrayal of RD (Bañón, 2007a, 2007b and 2010), the specific area of disability due to low prevalence pathologies and its news frames in the media are not given any proper coverage. What is more, this information shortage means that it proves hard to emphasise or select certain media aspects of RD. This is why the cognitive responses that may be generated during the exposition of these news items – the so-called cognitive channelling (Valkenburg, Semetko and De Vreese, 1999) - have been unknown until now. The interpretation of social information, also in the case of RD, is defined by heuristics, one way of quickly and easily determining the cognitive reflection without much effort (Rodríguez-Bailón and Palacios, 2006), which may cause a distortion of the reality on these

⁹ GIDYC. Group for Research into Disability and Communication of the Universidad CEU-Cardenal Herrera, teaching cooperation with the University of Valencia

people with disabilities. For this reason the heuristic processing of news on RD may entail that these pathologies are presented in the media as a healthcare or research demand of little importance due to their low prevalence, or get superficial treatment in their exposition. This process will be accentuated with the inclusion of peripheral codes, which will undoubtedly induce a more superficial level in the cognitive process in this type of information.

In the context now concerning us, these peripheral codes are the so-called frames preferably and repeatedly used by the media in the process of producing news items, in this case on low prevalence diseases. All this disorder through omission could be causing a very simplistic media presentation of people with RD; it might be encouraging stories stemming from spectacularisation of clinical manifestations and from the fair claims of sufferers. It would therefore be forgetting the normalising and integrating nature of the media and implicitly heading further into tendencies close to stigmatisation and stereotyping. The way the information on RD is structured may thus influence what is thought about this reality and those affected, since “physical and temporal spaces, leading actors and actions taken on them, attributes associated with the subject of the study are clear indicators from which the latent structure and underlying dimensions of informative treatment can be rebuilt” (Igartua, Muñiz and Cheng, 2005). News frames act as references for a basic question on the editing of news items on RD: what is to be rejected, what included and what is to be stressed in an informative narration.

In this respect selecting (including or excluding) and emphasising any kind of information file (words, images, graphics, videos and so on) helps to give a standpoint, a perspective or a particular angle to a piece of information. According to De Vreese (2001:115) “an essential step for finding out the effects of frames in news is to know more about the way the events and issues are framed in the items, and in particular whether there are common models for the way news items are framed”. Framing can similarly be conceived as a measurable process, meaning that “it is possible to learn how to condition these frames in the generation of news” (Giménez, 2006:59), and for this reason it can be understood as “an idea arranging the contents of the news, an idea which provides a context and suggests what the issue in question is about through the selection, the analysis, exclusion and elaboration of some of its specific aspects” (Tankard, 1991:5). It can furthermore be pointed out that the central dimension of a frame “seems to be the selection, organisation and emphasis of certain as-

pects of the reality and the exclusion of others” (De Vreese, 2001:25). These analyses therefore turn the journalist or creator of information contents into the party directly responsible in building information frames. The results of the process of producing news nevertheless also include organisational pressures, journalistic routines and the discourse of the elite. The analytical inclusion of journalists as opinion leaders and of the media as compilers of information in their different supports proved vital for this piece of research

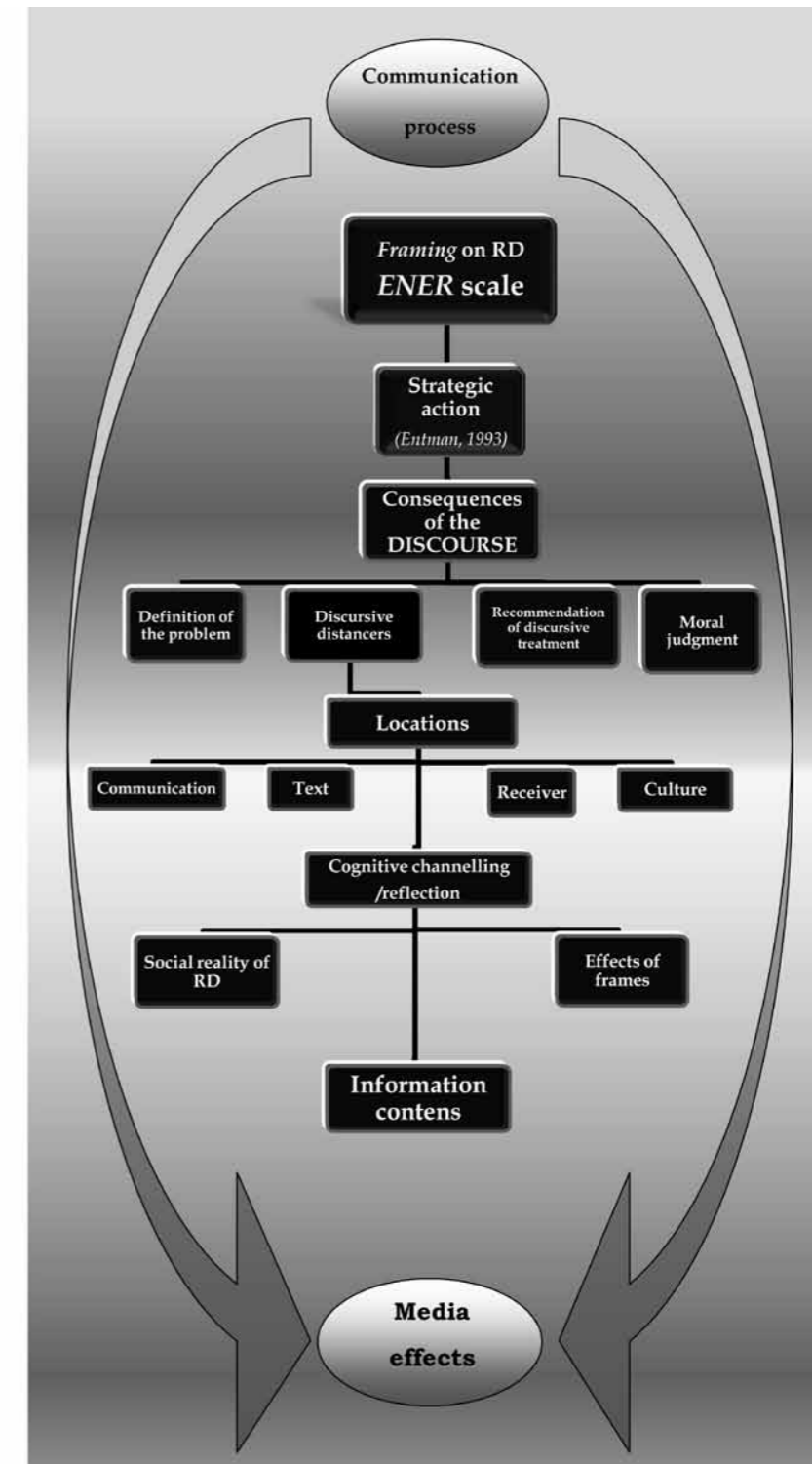


Diagram 1. ENER scale

1.2. METHODOLOGY AND CORPUS OF THE ANALYSIS

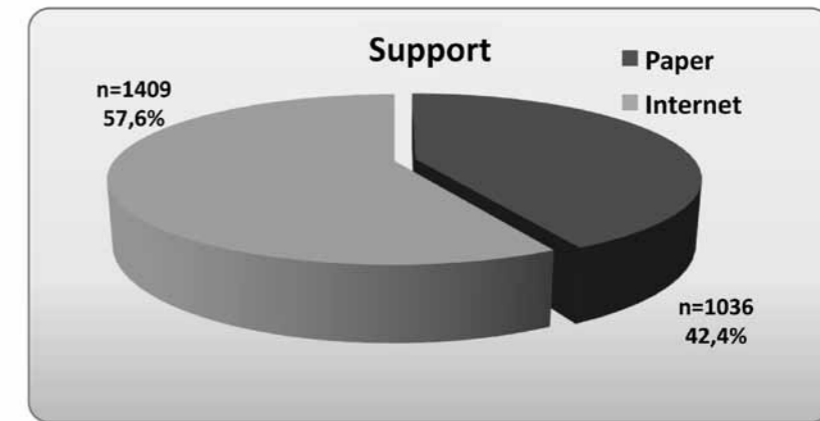
The main objective in this part of the research is to make a full analysis of the content, correlating the statistical data (thematic and interpretative frames) to provide an exhaustive identification of how the press describes people with RD, their relatives and the whole social structure around these pathologies. The basic corpus of our analysis is made up of the items detected by Press Index company from 1st June 2009 to 31st May 2010 (both inclusive) connected with the descriptors “Rare Diseases”, “Instituto Carlos III”, “Francesc Palau” and “CIBERER” in practically all the Spanish press.¹⁰ This corpus is specifically made up of 2445 pieces (in which 335 different RD are dealt with), and 319 press publications, from traditional paper media and digital media. This dual category was in turn divided into “specialised” and “general” media. As regards their geographical influence, the media analysed were identified as “regional”, “national”, and “international”. Table 6 shows the distribution into frequencies and percentages of the media analysed, the regional general digital dailies being the ones with greatest presence, (n= 114), 35.73 % of the total. The frequency of specialised paper press with an international scope was completely absent from the study: 0%.

Total corpus of media analysed			Frequency	Percentage
PAPER	Specialised	National	(n=26)	8,15%
		Regional	(n=5)	1,56%
		International	(n=0)	0%
	General	National	(n=6)	1,88%
		Regional	(n=80)	25,07%
		International	(n=1)	0,31%
DIGITAL	Specialised	National	(n=52)	16,30%
		Regional	(n=4)	1,25%
		International	(n=1)	0,31%
	General	National	(n=30)	9,40%
		Regional	(n=114)	35,73%
TOTAL			(n=319)	100%

Table 6. *Corpus of media analysed*

¹⁰ Press Index is a company which prepares the press clippings for CIBERER. This corpus was chosen for analysis for two main reasons: the fact of being the most systematic and exhaustive collection of material published in Spain on the field in question, and the convenience for our group in obtaining and handling the material thanks to CIBERER's commitment in carrying out this research

As a whole the percentage of traditional media on paper is below that of the digital media, as shown in Graph 1.



Graph 1. *Support of the media analysed*

The corpus chosen enabled us to study a very considerable sample of the Spanish media, including the seven general newspapers with greatest circulation (El País, El Mundo, Abc, La Vanguardia, El Periódico, La Razón and Público), most of the “general regional papers”, “specialised medical papers”, “general digital”, and “free press”, the press “specialising in disability”, “general magazines”, “economic press”, “scientific press”, “sports press”, “gossip newspapers”, “press specialising in communication” and “news agencies”.¹¹

¹¹ As regards agencies, it must be pointed out that we took into account some news agencies whose support is digital, some national and some regional: Ania, Atlas-News, Europa Press, Colpisa, Ical and Servimedia. These are not considered as a source here, instead being classified as supports.

Table 7 shows the frequency and percentage of the total news items analysed in the media described:

Nº news items analysed /media	Frequency	Percentage	Accumulated percentage
El País	71	2,9	2,9
El Mundo	38	1,6	4,5
La Vanguardia	28	1,1	5,6
El Periódico	23	,9	6,5
Abc	61	2,5	9,0
La Razón	40	1,6	10,7
Público	12	,5	11,2
General regional	940	38,4	49,7
Specialised medical	556	22,7	72,4
Free	132	5,4	77,8
Economic press	31	1,3	79,1
Gossip magazines	3	,1	79,2
Sports press	16	,7	79,9
Press specialising in disability	50	2,0	81,9
Scientific press	19	,8	82,7
Press specialising in communication	1	,0	82,7
Agencies	145	5,9	88,7
General magazines	44	1,8	90,5
Digital daily newspapers	165	6,75	97,2
Digital specialised newspapers	67	2,75	100,0
Total	2445	100,0 %	100,0 %

Table 7. Items by media

1.3. CODEBOOK, RELIABILITY COEFFICIENTS AND STATISTICS

After selecting a category system, a codebook was drawn up with SPSS v.17.0 software, in which it was specified how each criterion should be evaluated. This codebook was set up according to strict clarity and accuracy criteria, insofar as this “is an instructions manual in which it established what the nature of the corpus is, what it contains, what it is for, how this is to be interpreted, or from what angle its reading, hearing or viewing is to be broached” (Gaitán and Piñuel, 1998:305).

Apart from the statistical analysis of the hypotheses, the statistical contrast X^2 (Ji-square) was used, thus enabling us to decide if two variables are statistically independent (null hypothesis) or if there is on the other hand some association between these (alternative hypothesis). When the value obtained is under 0.05 ($p < .05$) the null hypothesis can be discarded, confirming that there is a significant association between the variables considered. This point is vital for learning the possible statistical leaning or dependency between variables considered to be important for discovering the treatment that the Spanish press gives to rare diseases; that is, finding out if the results obtained after the analysis of 2445 news items from 319 different media are simply something random or if this represents a tendency structured by means of specific journalistic parameters. The APA (American Psychological Association)¹² rule was used to inform of the results of the different hypothesis contrast tests in the text, as this is the most commonly used reference in publications in the field of research into Communication. The Phi coefficient, the (C) Contingency coefficient statistics, were also used to assess the strength of the association.

For the quantitative study of the research the ENER (RD News frames) scale was set up. This was used to establish the empirical methodology on which the strategy used for the critical variables necessary in measuring the news items could be supported. The ENER scale consists of 41 different variables distributed in several options or internal values (items and different groups). Table 8 specifies the 41 variables considered from the ENER scale as well as the values that form these. As shown in Table 9, it was also considered useful to use Cronbach's alpha (α) coefficient, whose most recommendable values are between 0.75 and 0.90 (Prat and Doval, 2003) in order to check the reliability or internal consistency of the empirical variables obtained for all the media analysed. We furthermore included an inter-rater reliability test, for which 500 news items (from the total number used in the research) were selected for analysis by two external appraisers who had not taken any part in encoding the previous data, obtaining a reliability percentage of 76.7 %.

¹² <http://www.apa.org/>

Variables (ENER scale)		Values (ENER scale)
Media	(MDC)	<i>El País; El Mundo; La Vanguardia; El Periódico; Abc; La Razón; Público; general regional; specialised medical; free; economic press; gossip press; sports press; specialised in disability; scientific; specialised in communication; agencies; general magazines; digital general daily newspapers.</i>
Support	(SOP)	Paper; Internet.
Diffusion	(DIF)	Numerical
Regularity	(PER)	Daily, weekly, fortnightly, monthly, others, not stated
VPB	(VPB)	Numerical
Size	(TAM)	Numerical
Nº pages	(NºPAG)	Ordinal
Section	(SECC)	RD; Innovation; Healthcare; Supplement; not stated
Cover/front page	(PORT)	If on cover/front page; not on cover; not stated
Page	(PAG)	Even; odd
Position on page	(POS)	Upper half; lower half; Internet
Opens section	(ASEC)	Yes; no; not stated
Nº Columns	(NºCOL)	1 column; 2 column; 3 column; 4 column; 5 column; 6 or more ; not stated
Inclusion of photos	(IFOT)	Yes; no; not stated
Inclusion of graphics	(IGRAF)	Yes; no; not stated
Inclusion of vignette	(IVIÑE)	Yes; no; not stated
Total nº photos, graphics, vignette	(NºFGV)	Total 1; Total 2; Total 3; Total 4; Total 5 or more; Total 0.
Genre of the item	(GENE)	Brief item; news item; article, criticism, column; interview; report; editorial; letters to the editor; not stated
Total nº of pages in article	(NºPAG)	1 page; 2 pages; 3 pages; 4 pages or more; not stated
Internet (text/photo/graphic)	(INTER)	Text only; text+photo/graph; text +video/audio; text +photo and/or graph + video and/or audio; not stated
Internet links or external links	(LINK)	Yes; no; not stated
Reader participation	(PART)	Yes; no; not stated
Authorship of news item (proper name)	(AUTOR)	Proper name; proper name and agencies; editorial team; editorial team and agencies; agencies; not stated
Agencies	(AGEN)	<i>Efe; Europa Press; Servimedia; others; not stated</i>
Source of the news item	(FUEN)	Associations and /or foundations; medical experts or researchers; people affected and/or relatives; CIBERER; FEDER; institutional
Character in the photo	(PFOTO)	Affected adult; affected child; personal carer; researcher and/or geneticist; institutional representative; doctor; parents of those affected; children of those affected; social and/or famous person; others; not stated
Location of the photo	(LFOTO)	Street; medical or research facilities; home; work; school; others; not stated
Talking in general of RD (yes/no)	(GEER)	Yes; no; not stated
Persons affected (what they are)	(AFECTQ)	Disabled; dependent; sick; worker; student; housewife; boy/girl; persons affected; patients; others; not stated
Persons affected (how they are)	(AFECTC)	Angry or critical; sad; brave; resigned; happy; others; not stated
Frame (professional carer)	(ECP)	Angry, critical; sad; brave; resigned; happy; not stated; others
Frame (researchers and/or geneticists)	(EIG)	Hard-working; wasteful; geniuses; wise; angry; providers of a possible cure; resigned; others; not stated

Frame (institutional representative)	(ERI)	Insensitive; critical; satisfied; resigned; others; not stated
Institutional representative (proper name)	(EINP)	Trinidad Jiménez; Francesc Palau; Cristina Garmendia; Elena Salgado; CIBERER; FEDER; Andrés Iniesta; Rosa Sánchez de Vega; others; not stated
Frame (doctor)	(EMED)	Insensitive; critical; happy; resigned; assertively demanding rights; others; not stated
Frames (relatives of those affected)	(EFA)	Angry or critical; sad; brave; resigned; happy; others; not stated
Frame (theme of the text)	(ETET)	Scientific research or discovery; denunciation or demand for recognition; institutional policy; formal event, commemoration or celebration; Dependency Law; personal testimonies or life stories; solidarity; others; not stated
Frame (topics in the text)	(ETOT)	Disability; solidarity or aid; adapted transport or facilities; Research, either study or report; institutional policy; employment; unemployment; economy; integration; alienation or isolation; illness; pre-diagnosis; diagnosis; post-diagnosis; education, schools, specific education institutions; integration school; Dependency Law; others; not stated
Frame (values of news item)	(EVN)	Number of affected persons; impact on the country; hierarchical level of the subjects involved; future development; dramatic quality; novelty; proximity; conflict; rarity/oddity or curiosity; others; not stated.

Table 8. ENER Scale: News frames for Rare Diseases

Totals Cronbach's Alpha (α)	Nº of elements	Mean	Variance	Typical variation	Scott's Pi (-1, 0, +1) (Inter-rater)	% reliability (Inter-rater)
,650	41	140,73	336,137	18,335	0.69	76,7

Tabla 9. Cronbach's Alpha (α) coefficient

1.4. THE MEDIA AS A DEPENDENT VARIABLE (MULTIPLE LINEAR REGRESSION ANALYSIS)

The multivariate technique of multiple linear regression was used to find out or check the effects of two or more variables considered independent on a dependent variable, through being highly effective in experimental research and in analysis of predictive contents (Iyengard, 1987; Naccarato and Neuendorf, 1998). This analysis enables making an evaluation of the dependency relations between the values of a single dependent variable or criterion (in this case "media"), and the ones corresponding to two or more independent variables or predictive/explanatory variables (in this case the 41 variables considered), since this has to comply with having at least 15 cases per predictive variable (Stevens, 1992). Table 10 shows a summary of the coefficients resulting from the bivariate correlation matrix among all the variables, allowing the possibility of verifying the degree of relations of the different predictors with the criterion variable. This data means the regression equation can be set up.

Variables /coefficients (a)	Non-standardised coefficients		Standardised coefficients			Collinearity statistics		Descriptive statistics		Reliability
	B	Typical error	Beta	(t)	(Sig)	Tolerance	FIV	Mean	Typic. Dev.	Cronbach's alpha (α)
(Constant)	5,837	3,350		1,742	,082					
(SOP)	3,030	1,200	,317	2,524	,012	,022	45,104	1,58	,494	,635
(PER)	,146	,103	,072	1,408	,159	,132	7,550	4,10	2,346	,588
(PORT)	-,088	,584	-,010	-,151	,880	,080	12,500	2,56	,534	,634
(PAG)	-,261	,270	-,045	-,967	,334	,162	6,173	2,37	,813	,627
(POS)	-,286	,297	-,054	-,963	,336	,111	9,048	2,29	,896	,624
(ASEC)	,007	,273	,001	,027	,979	,216	4,622	2,49	,695	,631
(NºCOL)	-,011	,094	-,005	-,120	,904	,186	5,380	5,48	2,170	,608
(NºCOL)	-1,176	,452	-,213	-2,603	,009	,052	19,108	2,33	,855	,624
(IGRAF)	,252	,572	,029	,440	,660	,083	12,058	2,56	,537	,634
(IVIÑE)	-,426	,945	-,046	-,451	,652	,034	29,689	2,57	,509	,634
(NºFGV)	,086	,085	,044	1,009	,313	,181	5,535	5,60	2,436	,602
(GENE)	-,084	,105	-,050	-,803	,422	,089	11,179	5,70	2,826	,584
(NºPAG)	,391	,183	,158	2,137	,033	,064	15,700	3,43	1,914	,596
(INTER)	-,220	,154	-,087	-1,423	,155	,094	10,621	2,81	1,865	,713
(LINK)	-,346	,322	-,045	-1,075	,282	,200	4,995	2,35	,613	,669
(PART)	1,165	,272	,167	4,282	,000	,229	4,372	2,30	,679	,670
(AUTOR)	,220	,050	,100	4,353	,000	,668	1,497	3,61	2,142	,632
(AGEN)	-,620	,073	-,186	-8,515	,000	,729	1,372	4,15	1,422	,674
(LFOTO)	,066	,059	,026	1,124	,261	,662	1,510	5,98	1,848	,635
(GEER)	-,229	,158	-,028	-1,452	,147	,958	1,044	1,41	,573	,654
(AFECTQ)	-,015	,035	-,009	-,446	,656	,930	1,075	7,89	2,645	,651
(ECP)	,229	,350	,012	,654	,513	,977	1,024	5,98	,255	,650
(EIG)	-,013	,049	-,005	-,259	,796	,883	1,132	7,23	1,907	,651
(ERI)	-,169	,097	-,038	-1,737	,082	,740	1,352	5,57	1,056	,648
(EINP)	,118	,068	,037	1,729	,084	,744	1,345	7,51	1,498	,649
(EMED)	-,041	,076	-,010	-,537	,591	,975	1,026	5,87	1,183	,652
(EFA)	,162	,099	,032	1,645	,100	,931	1,074	6,78	,929	,648
(ETET)	-,003	,033	-,002	-,079	,937	,836	1,197	4,50	2,901	,652
(ETOT)	-,024	,019	-,026	-1,296	,195	,871	1,148	8,00	5,050	,687
(EVN)	,136	,037	,074	3,704	,000	,883	1,132	5,84	2,562	,645

(a) Dependent Variable: Media

Table 10. Coefficients of the bivariate correlation matrix

The variables (DIF), (VPB); (TAM); (NºPAG); (SECC); (AFECTC); (FUEN); (PFOTO) have not been included in the list of independent or predictive variables for the linear regression analysis since these variables have an ordinal source and go against compliance or conditions for application of the statistical study of multiple linear regression (Cea D'Ancona, 2002; Field, 2000; Stevens, 1992; Tacq, 1997). Such variables as (SECC); (AFECTC); (FUEN); (PFOTO) furthermore make it impossible to include them in the established codebook and the corresponding quantitative analysis through the high number of values. For these variables their formal presentation as a hierarchically ordered adjoined list was thought to be appropriate.

To judge by the hypothesised regression values, the variables treated can be guaranteed to prove highly significant, as stated in value F of the ANOVA [F (30, 2410)= 15.095, $p < .0008$]¹³. Finally, a statistically significant relationship between the criterion or dependent variable (b) and the predictive variables (a) is seen, though it is true that in later sections the relation of Independence (null hypothesis) or of association (alternative hypothesis) of the different variables will be verified in detail by means of the X² contrast statistic. This is of great importance for the present research, as it alerts or reports of the need to understand the causality and the objective differences in the publication or information in the different media studied. It can thus be affirmed that not all the media studied and considered inform of RD in the same way, it therefore being vital to understand how and to what extent the people who suffer from Rare Diseases in Spain and their families are reflected. This piece of research attempts to go further into this matter.

13 We can see in the variance result that the model proves significant ($p < .0008$). The null hypothesis (random predictive variable) is thus rejected, admitting the existence of some kind of association between dependent and independent variables. Independent variables were: (Constant), Frame (news values), Agencies, Professional Carer, Frame (doctor); Talking in general of RD; Frames (relatives of people affected); Researchers and/or geneticists, Frame (institutional representative), Frame (text topics), People affected (what they are), Total Nº photo, graphic, vignette, Frame (theme of the text), Nº Columns, Authorship of news, Institutional representative (proper name), Where they appear in the photo, Opening the section, Reader participation, Internet links, Page, Regularity, Position on page, Internet, Genre of the item, Including graphic, Cover, Nº of pages, Including photograph, Including vignette and Support. The dependent variable: Media

3.

RARE DISEASES: JOURNALISTIC CAPACITIES, CHALLENGES AND SKILLS

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1. DESCRIPTIVE VALUES

We could not set out to tackle a piece of research with a sample focusing on the written Spanish press, in both its printed and digital forms, without considering different degrees of analysis right from the beginning: this would range from what is apparently more lightweight, more superficial if you wish, but similarly interesting (the descriptive aspects) to the more complex data (the hypotheses and their demonstration). For this purpose, fields of registration such as the support, the regularity, the inclusion or absence on the cover/front page, the number and place on the page or the section where these low-prevalence pathologies appear were the first elements to be studied. These are what we have called basic descriptive values, to which we add three more essential references: the sources of news, the authors of the information and those who could become the possible readers of these.

1.1. BASIC DESCRIPTIVE VALUES

It has already been specified that the research corpus was made up of 319 written communication media, as a result of the sum of 118 printed papers (31 specialised and 87 for general information) and 201 digital ones (57 specialised and 144 general information publications).

We initially set to work on the project with the idea that the specialised publications would be the most prolific in dealing with RD as a piece of information, and that the digital editions would exceed the printed newspapers. The first of these hypotheses turned out to be absolutely right. Digital newspapers devote more news items to RD than the printed

press. In respect of the second, the results showed something rather different to the initial perception. 88 of the (printed and digital) specialised media informed about RD in the year examined, as opposed to 231 general media, more than triple. Such common impediments as a more limited press run in respect of many of the general media could be an explanation for this. But we should also remember that the specialised journalism macro-genre covers a highly diverse range of possibilities: gossip, sports, newspapers for consumers, communication professionals, women and of course the ones specialising in pharmacy, health or medicine. This same range of possibilities was found in the research sample, where we could appreciate thematic diversity, but low real numbers of different specialised media.

The second factor to be dealt with focuses on how often the newspapers, in this case printed papers, come out: 32.4 % were daily papers, 6.0 weekly and 1.1 monthly. As regards front pages, RD appeared on these on forty occasions. In the general press they were on 18 front pages, 5 published by national daily papers¹⁴ and 13 by regional ones. In the specialised press we found 21 front pages for national circulation papers and only one in the regional press. If we associate the totals, the specialised publications helped to add points to the national papers (26), as opposed to the sum of all the regional ones (general and specialised, 14 front pages). *El Diario Médico* is the paper with greatest commitment to RD in the foreground, placing them there on 15 occasions. The publications *20 Minutos*, *Pronto* and *Muy Interesante* opted for stressing the drama and the “exotic” factor of the disease with titles such as: “Saving Laura is only a matter of money”; “Parents’ struggle to find bone marrow for their 6-year old son” and “Collection of mutants”, respectively. These were not the only ones. The top theme found on front pages is life (human interest) stories as opposed to other matters. For specialised newspapers, it is research and institutional policy (in respect of health, orphan drugs, the Centro de Referencia Estatal de atención a Personas con Enfermedades Raras y sus familias...). The sample of newspapers that we studied is so limited that no result is in its own right too significant. We could nevertheless say that this percentage used complies with the expectations envisaged for the following reason: What is to be highlighted on the covers of such publications as *El Diario Médico*, *La Gaceta Médica*, *El Correo Farmacéutico*, *El Correo Médico* or *La Actualidad Médica* if not themes of express interest for their potential public, that is, medicine professionals: research and budgets for research or improvements of the health system? On the other hand, how can a general information publication attract its readers

14 *El Mundo* (19/11/2009); *La Razón* (17/06/2009); *20 Minutos* (23/04/2009) and the magazines *Muy Interesante* (1/09/2009) and *Pronto* (12/09/2009).

to a topic of rare diseases, unless it is through life stories? We could also assert that this is not a morbid or sensationalist or economic interest (a greater number of readers and thus a bigger press run) using dramatic stories as a strategy. When stories come out, we see that it is through the real need of the subjects (either economic, or for medical care, treatment, etc).

What is more, the most categorical argument for confirming what we say continues to be the little interest of the media in showing RD on the cover or front page. Lest we forget: there were 40 news items on the cover in an ocean of 2445. Hence, the importance of uncommon diseases is recorded very little on the front pages of publications, their showcase pages, pointing to one of the objectives that is still to be attained.

With reference to the position of the item on the page, the results tend to even out. The editors’ preference for placing these news items on an even/odd page is practically the same: 21.5 per cent frequency on even pages as opposed to 20.5 on odd ones. The result is good, since the eye focuses more readily on the latter and the balance between the figures given leads us to understand equality in the sample analysed.

1.2. SOURCES AND AUTHORSHIP

Both the sources and the authorship of the news items very soon brought up a setback in the research. With the former this was due to the large number of existing sources and different combinations. With the latter, this was not only due to the number but also the great variety of authors. Since it was important in our study to find out where the information about RD was coming from in the printed or digital media and to detect the preference of these media for one source or another, we decided to create a register with eight fields for these: relatives and/or people affected, associations and/or foundations, experts (researchers and/or geneticists, doctors), institutional sources, CIBERER, FEDER¹⁵, international sources and lastly, other media. These eight fields were subdivided into as many as appeared in the media in their different combinations, as can be seen from the following tables. A field was also created in which the times the sources were not mentioned was recorded (unidentified) to obtain the corresponding percenta-

15 FEDER was removed from the group of associations through being a federation which agglutinates these, just as we were interested in learning the exclusive role of CIBERER, outside the group of expert sources.

ges. Alongside the unidentified sources we added the value of the other non-preferential, or dissociated sources (stated in the other tables) of the specific or preferential field given in each table.

Position	Source	Frequency	%
1	Persons affected and/or relatives (PA&R)	122	4,9
2	PA&R + FEDER	5	0,2
3	PA&R + international sources	1	0,04
4	PA&R + international + FEDER	1	0,04
5	PA&R + Media + FEDER	1	0,04
Total of the 5		130	5,3
Unidentified + Another non-preferential source		2.315	94,6
Total registered		2.445	100,0

Table 11. Sources: People affected and/or Relatives (PA&R).

Position	Source	Frequency	Porcentaje
1	FEDER	122	4,9
2	CIBERER	20	0,81
3	CIBERER + FEDER	3	0,12
Total of the 3		145	5,9
Unidentified + Another non-preferential source		2.300	94
Total registered		2.445	100,0

Table 12. Sources: CIBERER and FEDER.

Position	Source	Frequency	Porcentaje
1	International sources	12	0,49
2	FI + FEDER	2	0,08
3	FI + CIBERER	1	0,04
Total of the 3		15	0,61
Unidentified + Another non-preferential source		2.430	99,3
Total registered		2.445	100,0

Table 13. Sources: International sources (IS).

Position	Source	Frequency	Percentage
1	Media (M)	36	1,4
2	M + IS + CIBERER	9	0,36
3	M + IS	6	0,24
4	M + FEDER	5	0,2
5	M + IS + FEDER	1	0,04
Total of the 5		57	2,3
Unidentified + Another non-preferential source		2.388	97,6
Total registered		2.445	100,0

Table 14. Sources: Media (M).

Position	Source	Freq.	%
1	Associations and/or foundations (A&F)	210	8,5
2	A&F + Experts (doctors, researchers)	63	2,5
3	A&F + PA&R	49	2,0
4	A&F + FEDER	43	1,7
5	A&F + Experts + PA&R	13	0,5
6	A&F + international sources	7	0,28
7	A&F + CIBERER	6	0,24
8	A&F + PA&R + FEDER	4	0,16
9	A&F + Experts + FEDER	3	0,12
10	A&F + Experts + PA&R + FEDER	2	0,08
11	A&F + Experts + PA&R + Feder + CIBERER	2	0,08
12	A&F + international + FEDER	2	0,08
13	A&F + Experts + M	2	0,08
14	As/Fun + Experts + international	1	0,04
15	A&F + PA&R + M	1	0,04
16	A&F + M	1	0,04
17	A&F + Experts + CIBERER	1	0,04
18	A&F + PA&R + Ciberer + Feder	1	0,04
Total of the 18		441	18,03
Unidentified + Another non-preferential source		2.004	81,9
Total registered		2.445	100,0

Table 15. Sources: Associations and/or Foundations (A&F).

Position	Source	Freq.	%
1	Experts, Doctors, Researchers (EDR)	309	12,6
2	EDR + PA&R	29	1,18
3	EDR + CIBERER	29	1,18
4	EDR + MDC	20	0,8
5	EDR + FEDER	18	0,7
6	EDR + M + International sources	14	0,5
7	EDR + International sources	8	0,3
8	EDR + PA&R+ FEDER	6	0,2
9	EDR + PA&R + International + FEDER	1	0,04
10	EDR + M + CIBERER	1	0,04
11	EDR + PA&R + M	1	0,04
12	EDR + PA&R+ M + International	1	0,04
Total of the 12		437	17,8
Unidentified + Another non-preferential source		2.008	82
Total registered		2.445	100,0

Table 16. Sources: Experts, Doctors, Researchers (EDR).

Position	Source	Freq.	%
1	Institutional sources + CIBERER	21	0,85
2	Institutional sources + FEDER	1	0,04
Total of the 2		22	0,89
Unidentified + Another non-preferential source		2.423	99,1
Total registered		2.445	100,0

Table 17. Sources: Institutional sources I. (IS).

Position	Source	Freq.	%
1	Institutional sources (IS)	435	17,7
2	IS + PA&R	26	1,06
3	IS + PA&R+ FEDER	5	0,2
4	IS + A&F + FEDER	1	0,04
5	IS + PA&R + FEDER + CIBERER	1	0,04
6	IS + A&F+ M	1	0,04
Total of the 6		469	19,1
Unidentified + Another non-preferential source		1.976	80,8
Total registered		2.445	100,0

Table 18. Sources: Institutional sources II. (IS).

Puesto	Fuente	Frec.	%
1	IS + A&F	60	2,4
2	IS + A&F+ EDR	17	0,69
3	IS + A&F+ PA&R	13	0,53
4	IS + A&F+ CIBERER	6	0,24
5	IS + A&F + EDR + FEDER	5	0,20
6	IS + A&F+ FEDER	4	0,16
7	IS + A&F + EDR + PA&R	2	0,08
8	IS + A&F + EDR + M	1	0,04
9	IS + A&F + EDR + PA&R + International	1	0,04
10	IS + A&F + PA&R + FEDER	1	0,04
11	IS + A&F + International + FEDER	1	0,04
12	IS + A&F + EDR + PA&R + FEDER	1	0,04
13	IS + A&F + EDR + CIBERER	1	0,04
14	IS + A&F + DRI + PA&R + CIBERER	1	0,04
Total of the 14		114	4,6
Unidentified + Another non-preferential source		2331	95,3
Total registered		2.445	100,0

Table 19. Sources: Institutional sources III. (IS).

Puesto	Fuente	Frec.	%
1	IS + M	3	0,12
2	IS + M+ CIBERER	2	0,08
3	IS + M+ International	2	0,08
4	IS + M + International + CIBERER	1	0,04
Total of the 4		8	0,32
Unidentified + Another non-preferential source		2.437	99,6
Total registered		2.445	100,0

Table 20. Sources: Institutional sources IV. (IS).

Position	Source	Freq.	%
1	IS + EDR	199	8,13
2	IS + EDR+ PA&R	32	1,30
3	IS + EDR+ CIBERER	27	1,10
4	IS+EDR+International	8	0,32
5	IS+EDR+International+M+CIBERER	8	0,32
6	IS + EDR+ FEDER	7	0,28
7	IS + EDR+ M	7	0,28
8	IS+EDR+PA&R+CIBERER	3	0,12
9	IS+EDR+International+CIBERER	3	0,12
10	IS+EDR+M+International	3	0,12
11	IS+EDR+M+CIBERER	1	0,04
Total of the 11		298	12,1
Unidentified + Another non-preferential source		2.147	87,8
Total registered		2.445	100,0

Table 21. Sources: Institutional Sources V. (IS).

The eleven tables show the indisputable prominence of Institutional Sources, with a total number of 911 in the frequency value, which meant 37.2% in respect of the total. These are followed in importance by associations and/or foundations which agglutinate and represent RD sufferers and their families (value: 441, 18.03%) and expert sources, either doctors, researchers or geneticists (value: 437, 17.8%). Persons affected and relatives become a source for the media studied lying in fourth position, though a long way from the first three, with a frequency value of 130, which makes up 5.3 % of the total. FEDER obtained a frequency value of 125 (5.1%), followed by other media (value: 57, 2.3%). The CIBERER, with a frequency value of 23 and a percentage of 0.94 %, and international sources (value: 15, and 0.61%) were sources not used or referred to very much in the texts, during the period of study.

The institutional influence is not even surpassed when the values of persons affected, the associations-foundations representing these and FEDER are added up (total value: 696, 28.4%), or when CIBERER is added to the experts' source, obtaining a frequency value of 460 and a percentage of 18.8. For all these reasons we can affirm that journalists acquired their material mainly from institutional and political sources (37.2%); from the direct source of people affected by rare diseases, their relatives and associations

representing them (28.4%); and in third place, from medical experts, researchers and geneticists (18.8%). The other media and international sources had very little significance in the results analysed from the sample, with a frequency value of 72 (2.9%) between them. We would like to make a brief halt at the latter to look at news agencies. A total of eleven news agencies are cited in the news items examined: ACN Press (Canary Island news agency); Aragón Press, Atlas News (set up in 1998 and belonging to the Grupo Tele 5); Efe, COLPISA, PR Newswire (distributor of commercial news since 1954); Reuters, ICAL (regional and local information agency of Castile and Leon); Servimedia (specialising in social policies), ANIA (alternative information news agency) and lastly, the unquestionable leader in information agencies on RD in our study: Europa Press (appearing 467 times, as opposed to the 147 for the second position, taken by Efe). The variety existing can be appreciated: general, specialised, national, regional and one international. The total figure for the agencies as a source came to a percentage of 27.1 per cent; press offices and associations came to hardly 0.51%.

As regards the subjects dealt with, the most recurrent types are healthcare policy, the opening of the National Reference Centre for Rare Diseases in Burgos, the crisis and budget cutbacks along with dismissals of researchers, the World Rare Disease Day, the attendance of political representatives at medical congresses and complaints and articles with a denunciation angle. This is the reason why institutional representatives are unquestionably the leading figures for the media. Historically, all of this ties in perfectly with the communication system implemented in the western world since the development of the press for the masses, and particularly since the end of the Second World War, when the political bodies in all their forms and diversity became established as emitters and everyday centres of information, whatever support this may be disseminated on.

The distance between doctors, geneticists and researchers on one hand and those affected (in theory the real chief actors in this type of information and thus a direct source) on the other was highly appreciable. We would also like to stress that the CIBERER ought to have a greater presence in the records, through its importance.

What is the routine for choosing information by one of the media? The interest that this may cause for many people, the future ramifications that this may have, its emotional impact, its proximity..? To go by the sources consulted by professionals, failing interrelating this with other variables, which we do in later chapters of this book, it would seem that the importance lies in the preference figures, or to put this in other words in the hierarchical

level of the subjects implied in the news and – incontestably – in the effectiveness of their respective press offices.

As regards the authorship of the information items, over four hundred journalists set their initials or signature on the news items in our study, though they had not always written them themselves, as must be emphasised. News published by Europa Press appears in exactly the same form on the same days and in diverse printed/digital media, appropriated by reporters from the media and not the agency. On twelve occasions the signature on the piece was from a private individual as a letter to the editor. Lastly, the following are some of the journalists most often dealing with RD worthy of mention: Paola García Costas (frequency value: 27, 5.2% of the news items signed); Laura Díaz Ródenas (26, 5%) and José María Juárez and María del Mar Sevilla, both with a frequency value of 19, which represents 3.6%. The sum of these four alone constitutes 17.7% of the total of the information items signed. García Costas publishes in eight newspapers in the Community of Andalusia: *Diario de Jerez*, *El Día de Córdoba*, *Diario de Sevilla*, *Granada Hoy*, *Málaga Hoy*, *Diario de Cádiz*, *Europa Sur* and *Huelva Información*. The other three write in specialised publications: Juárez in the *Diario Médico*, Díaz Ródenas in *El Global*, *Diario Médico*, *Correo Médico* and *DMedicina.com*, Sevilla signs articles in the *Diario Médico* and *DMedicina.com*.

1.3. PRINTED PRESS AND FEEDBACK

One of the concerns when the research was tackled was to attempt to find out what readers' response might be to news on low-prevalence pathologies. A one-year observation period was a problem for taking on studies and methodological tools in a sociological sphere which included surveys of the potential public. This is specially relevant when the research should have correlated everything coming out printed or in the digital version on any matter directly or indirectly connected with the matter being studied and in such an extensive geographical area as the whole of Spain. The only option left to us was to record readers' spontaneous replies through the mechanisms provided by the media. In the case of printed editions this came down to letters to the editor, while the equivalent in the digital editions was the section for web users' comments. In the year that we analysed only twelve letters to the editor (twelve information items) were published, from a sample made up of 118 printed media and from a total number of 2445 documents.

In spite of the poor results, it seemed advisable to proceed to analyse these. Three were published in national dailies (*El País Semanal*, *El Mundo* and the free daily *20 Minutos*); a further eight letters appeared in the autonomous community press (*Europa Sur Algeciras*, *La Mañana Diari de Ponent*, *La Voz –de Avilés–*, *Nueva Alcarria*, *La Vanguardia*, and three letters on different days in *El Periódico*). The last was edited by the magazine *Pronto*. As a whole the main theme is denunciation, along with demand for recognition (on ten occasions), as opposed to the minority theme, which is gratefulness or thanks (only two)¹⁶. As sub-themes we recorded the need to inform about these diseases, institutional policy, the economic problems of the sick and/or their relatives, the situation of alienation, isolation and dramatic elements, symptomatology, requests for help and solidarity and the demands made of institutional policy, when not actually criticism of this.

No outstanding preference by gender was observed, with half of the people signing the letters being women and the other half men. Eleven of these were relatives of the sick and one was signed by a patient. RD were approached from a general standpoint on seven of the occasions and from specific angles on five: Fibromyalgia (on two occasions) Chronic Fatigue Syndrome and MCS; Landau-Kleffner Syndrome, Cystic Fibrosis, West Syndrome, and Histiocytosis X. Neither were any preferences for specific months observed. There are no more letters coinciding with the World Rare Diseases Day, for example. The month with most insertions was, curiously, June with three, followed by January, December and April with two and October, November and the aforementioned month of February with an insertion on the 19th. May, July, August and September did not have any readers' letters in any daily paper from the sample examined. Hence we could not argue, for instance, that the letters were being included in summer months when there is a information drought, for example, or in the months of the Christmas pre-campaign or campaign where the call to solidarity is a recurrent theme, to mention another case, or on 27th February, continuing to reinforce the day assigned to RD¹⁷. There does not seem to be any pattern in a journalistic sense, either for those writing letters or for those publishing them. There is always a possibility of a newspaper being swamped by letters from readers on the same subject and the editor in charge deciding to publish only twelve, although it must be acknowledged that if such a case were to arise in real life, surely this hypothetical editor would be likely to make a greater effort to publish them¹⁸.

¹⁶ *La Vanguardia*, 28/04/2010 and *Pronto*, 10/04/2010

¹⁷ Although the World Rare Disease Day is on 28th February, the day on which most information was published in this research was 27th February. That is why we are specially highlighting this date

¹⁸ *El Periódico* did so on three occasions over these eleven months: October and December 2009 and January 2010

On the other hand, there was the question of whether the same thing happened when access was via computer, when the journalistic approach was digital. With no possible filter, the reply to our questions gave a different result. All of this brought up further questions: Who were interested in Rare Disease in printed publications – doctors and experts, relatives and RD sufferers? The figures are clear, but so are the chief actors in these, always people close to the subject, through being relatives, friends, acquaintances of those affected, as was already seen in the twelve cases of the letters to the editor. It should be remembered that researchers, geneticists, doctors and experts in general are readers of specialised media, which could in theory rule them out from that journalistic feedback which we talked about. It is also nevertheless generally believed that when a doctor wishes to inform about something, he or she writes an article and not a letter to the editor, while the average citizen resorts to this section to make him or herself heard. For the latter, the main vehicle of expression as regards the present subject nevertheless appears to be not so much the printed press, but the digital interactive option, also including specialised web forums, forums for those affected and relatives, associations and bodies of all kinds that represent them, direct contact through experiences, symposiums, congresses, seminars, and so on.

So, are the traditional Spanish written media therefore not so much a tool for information for the potential interested parties as an instrument for dissemination of RD to the rest of society, rather like an instrument for making their claims? Does it form part of the media's concern to spread and provide knowledge about this subject to the "general public"? The reply should be a categorical "no" as regards the printed media that we consulted, recorded and analysed. Of course those involved want those who are not to know about their situation, but this is not in the least a priority for them when they are acting on so many fronts. As we moved on we became increasingly aware that the great majority of the information selected by communicators covered diagnoses, treatments or drugs, tying in perfectly with the interests of affected people and their relatives. If these were the themes, then it stemmed from this that the reader-party involved was very especially concerned with getting a diagnosis, a treatment, a specific drug or drugs... Finding a way out of medical orphanage, setting a name to the symptoms, now become a recognised disease, leaving behind all the traipsing from one outpatients' clinic to another and from hospital to hospital trying to find out what was happening to them. Perhaps that was why they did not write, or wrote so seldom, and therefore failed to generate the feedback that we were seeking in printed publications. Judging by the contents published, their priority lay in something more necessary and urgent.

2. FRAMES

Different objectives are covered in frames. One can thus distinguish character frames (both of the text and of the iconic material), and also of how they come forward, how they feel and of how the media depicts them. The aim was therefore to observe the conceptual categories, the roles, any missing action and reciprocal action with others.

2.1. AFFECTED PERSONS AND RELATIVES

Frames were approached from different angles that will be examined throughout this work. In this first phase, the frame of affected persons who appear in the text of the publications, this is done with one precise objective: that of generating conceptual categories. Conceptual categories concentrate on the way people, in this case, those affected, are mentioned. The ones with greatest frequency in the values recorded were selected from these. That is: sick person (value: 449, 18.8%), patient (value: 286, 11.7%), boy/girl (value: 223, 9.1%) and affected person (value: 182, 7.4%). One of the most striking pieces of data to be stressed was the effort not to call them anything at all, concentrating not so much on the patient as on the disease. It also proved curious to see the way those affected were to a large extent distanced from the conceptual category of dependent (value: 19, 0.8%) and disabled (value: 9, 0.4%).

The percentages for classifying sufferers by aspects defining them separately from the disease, that is, by roles, are very low. These include student (value: 2, 0.1%) and worker (value: 9, 0.4%) as the ones used most and display the very scant importance that these roles take on in news items on RD.

As regards relatives, the results swung between anger, criticism and bravery. On a second level they were seen to be happy and resigned, and lastly, sad (0.4%). Firstly the conceptual category was not of as much interest as the actions missing, i.e. the ones concerning what they wanted to obtain. Secondly we wished to observe reciprocal action, the action taken by others in respect of those affected, as well as for the relatives - for example, economic subsidies, lack of attention, unfair situations, solidarity, and so on.

2.2. DOCTORS, RESEARCHERS AND/OR GENETICISTS

Doctors do not obtain as much recognition as researchers or geneticists in the results of our study, though sometimes both categories coincide or are mixed. When dealing with RD patients, research doubtlessly becomes the item providing greatest hope. Scientific findings and progress also constitute a priority subject of interest for journalists, along with events of other kinds: sports competitions, political elections, and so on. Hence, while doctors are seen to be critical (1.6%), happy (1.1%) and hardly assertive (in the demand for recognition) at all (0.3%), researchers were hard-working (5.8%), providers of a possible cure (4.5%), geniuses/wise (2.1%) and not seen to be very angry and wasteful (0.8%) or resigned (0.5%).

Scientific symposiums, congresses and encounters, along with awards for research, mean that some news items occasionally cover several dozen experts in a single piece of news. The complexity found in multiple references again meant a problem when the total was over 200 names, particularly in the specialised medical press. A list is therefore given below including the ten names of researchers and/or geneticists playing the most important roles in the media analysed during the period of study:

1. Francesc Palau, Scientific Director of the CIBERER (26 appearances).
2. Carlos López Otín, Molecular Biochemistry Professor at the Universidad de Oviedo (24).
3. Elías Campo, Clinical Director of the Centre per al Diagnòstic Biomèdic del Hospital Clínic de Barcelona (22).
4. Ángel Carracedo, Legal Medicine Professor at the Universidad de Santiago de Compostela (18) and CIBERER Group Leader.
5. Paul Nurse, Nobel Prize for Medicine 2001 (14).
6. Celso Arango and Julio Sanjuán (13). The first is Scientific Director of the CIBERSAM, and the second tenured professor in psychiatry at the Medicine Faculty of the Universidad de Valencia.
7. Guillermo Antiñolo, Director of the Genetics, Assisted Reproduction and Foetal Medicine Unit of the Virgen del Rocío hospital complex in Seville. Coordinator of the Clinical Genetics Plan of Andalusia Regional Authority (12) and CIBERER Group Leader.
8. Javier Martín, Miguel Pocoví and Shomi Bhattacharya (9 appearances). The former is the Head of the Research Group at the Instituto de Parasitología y Biomedicina López-Neyra in Granada. The second is professor of Biochemistry and Molecular Biology at

the Universidad de Zaragoza and researcher attached to CIBERER. Bhattacharya is an expert in genetics and biomedical research, and director of the CABIMER.

9. Bernat Soria, José Ángel Berciano and María Blasco (with 8 appearances). The Valencian scientist Bernat Soria, ex-Minister of Health, is professor of Physiology at the Universidad Miguel Hernández in Elche. Berciano is the scientific director of the Centro de Investigación Biomédica en Red de Enfermedades Neurodegenerativas and head of the Neurology Service of the Hospital Universitario Marqués de Valdecilla in Santander. María Blasco is the director of Basic Research of the Centro Nacional de Investigaciones Oncológicas.
10. María Jesús Sobrido, of the Fundación Pública Galega de Medicina Xenómica, and Ignacio Basagoiti, Medical Director of the Technologies for Health and Well-being Group of the Universidad Politécnica de Valencia, both with seven appearances.

In the case of doctors, through involving a lower frequency value, we made a list of the five mentioned most from a total number of 162 names:

1. Pilar Garrido, haematologist at the Hospital Miguel Servet de Zaragoza and director of the Fundación para el Estudio y Terapéutica de la Enfermedad de Gaucher (15 appearances).
2. Alberto Fortea, Hospital Universitario Miguel Servet de Zaragoza (13).
3. José María Cortina, Head of Department of the Hospital 12 de Octubre (12).
4. Elena Arana, a plastic surgeon in private healthcare, Joan Pere Barret, Director of the Burns and Reconstructive Surgery Unit of the Hospital Universitario Vall d'Hebrón, and Justo García Yébenes, head of Neurology at the Fundación Jiménez Díaz de Madrid (7).
5. Manuel Arias, head of the Neurology Section of Conxo, Complejo Hospitalario Universitario de Santiago de Compostela (6)

We should emphasise the close relations between these doctors, experts and researchers, the posts that they hold and the institutions at which they work, as well as the information significance, displayed by autonomous communities.

2.3. INSTITUTIONAL REPRESENTATIVES

Institutional representation complicated the study even further, with double the references that had already appeared in the previous sections on experts. It should also be pointed out that although some of the names coming up were already mentioned through being

doctors, researchers and/or geneticists, these are now included again through being at the head of bodies depending on public institutions. Even so, the huge volume of names in this section comes about through the direct involvement of politics –and politicians– in everyday information work. The opening of the Centro de Referencia Estatal de Atención a Personas con Enfermedades Raras y sus Familias (CREER) in Burgos, as already mentioned, gave rise to a plethora of appearances of politicians responsible for public health, to give an example. The sheer number of names found once more led to drawing up a list of the ones given most. Any appearing under the sixth position is excluded, through the mentions being too many and not very relevant.

It is quite easy to understand that the leading position in institutional representation should have gone to the then Minister of Health, Trinidad Jiménez, with 74 appearances, well ahead of the others in the four categories coming after her. Two ex-ministers of health immediately before Jiménez's succession continue to appear in the information insertions in the newspapers, but this time without much representative status. Elena Salgado takes seventh place, with five appearances, while Bernat Soria comes tenth with only two. We should also stress the absence of political representatives from the Partido Popular and Izquierda Unida: the eighth position is taken with four appearances, by Ignacio Burgos, a senator from the PP and the seventh, with five, Gaspar Llamazares (IU).

Following Trinidad Jiménez in information frequency, with 33 appearances, is Cristina Garmendía, doctor of Molecular Biology, appointed Minister of Science and Innovation on 11th April 2008. Her appearance in the media sampled during the period examined was to a large extent connected with budget cutbacks. The three positions following her lie at quite a distance from the first two, possibly through the fact of not being politicians, with two exceptions:

- Third place (9 appearances): Fernando Lamata, Castile-La Mancha Regional Minister for Health and Social Welfare; Jordi Cruz, President of the Asociación de Hemoglobinuria Paroxística Nocturna; Miguel Ángel Ruíz, Director of the CREER and María Jesús Montero, Regional Minister of Health of the Andalusia Authority.
- Fourth place (8): José Jerónimo Navas, director of the ISC-III of the Ministry of Science and Innovation.
- Fifth place (7): Francesc Palau, Scientific Director of the CIBERER, and Humberto Arnés, president of Farmaindustria.

The frequency values make it quite obvious that the personality's political influence is the most important reference for the journalist. Lesser presence of the Royal Family is found, with the figures of three ladies: Queen Sofía, Princess Leticia and Infanta Elena.

3. GAUGES OF PRESS INTEREST

3.1. POSITIONING, OPENING SECTION AND COLUMN

The positioning of Rare Diseases press on odd and even pages in the press was discussed above, as second priority choice – the first would entail selecting the item for the cover or front page – by visual preference. The distribution of the information space on the same page is connected with this matter: Were RD the opening subject of the section in which they appeared? Did they occupy the upper – and more relevant - space of the page or were they conversely at the bottom? Both questions have different replies, without determining one hundred per cent any absolute decision to give priority to this type of information. While they were allocated the upper, visually more relevant, half of the pages on which they appeared on 730 occasions, as compared with 282, they did not on the other hand constitute the news item, information etc. opening the section on 685 occasions, as compared with 285.

Along with the positioning the aim was to find out how much space they occupied as regards the number of columns, in order to have further data to measure the absence or presence of information relevance, from the standpoint of the media professional. In this case the results are at the very least curious. We divided the importance between the lowest value, information in one column, and the highest value, the item occupying six or more columns (the case of a two-page report, for example). The results put the information in a single column (273) in first place. This was followed by information in five columns (200), in four and in three columns (144 and 133 respectively) with the information in two columns and in six or more columns (122 and 117 occasions in each case) getting the lowest scores. The results do not coincide with the genre of the pieces recorded, and there is an explanation for this. Although the highest value is the one for a single column, this does not mean that the brief article is the genre most widely used, although it does take a relevant place.

3.2. PRESS GENRES AND PAGE MAKEUP

We established seven genres to classify the items: the brief article, the news item, the article/critical review along with the letters to the editor - as third category - the interview, the report, and the editorial. Each genre was assigned an importance value from 1 to 6, following the order described, with the exception of the letters to the editor, which shared value 3 with articles, reviews and chronicles.

The news item is the Rare Disease genre par excellence, with 450 appearances, getting a score of 2 out of 6, as noted. This is followed by the brief article, with a low value (1 out of 6) scoring 204. In third place we have the articles/reviews/reports, with an intermediate value (165 records).

Among the genres with the highest value assigned reports should be stressed (153). Editorials are very seldom, with only 5 hits. Opinion, whether this comes from the emitter or the receiver (see the section on feedback of printed newspapers), does not seem very highly developed yet in the RD issue. If what is being sought is to make society aware of these, and thus to make them a public and political talking point, the objective is still far off. On the other hand reports are seen to be gaining some presence in the press, though a long way from the news item and brief article. Again, life stories are great favourites.

As regards page makeup, this would be the last of the factors included in our records with regard to pages. Here the number of pages devoted to a piece of information is measured. The results must obviously and undisputedly be connected with both the genres and the columns that were already measured. Going on with what is expressed in the last two, occupation of a single page is the top result, with 886 appearances. Much less often, two pages are dedicated to the subject (81), or four pages or more (26). Right at the back we find three pages (12 occasions).

To conclude, RD preferably take up the top of the pages of the printed publications analysed, either on odd or even pages, but they do not tend to open a section, and are placed on a single page, in one column, and in news item format. It can similarly be affirmed that opinion is scarce, both from the emitter and the receiver of the information, and that this shows little interest, or effective work at awareness-raising in the field in question. There is furthermore no outstanding concern for extending the information, either in space (by columns or by pages), or for giving it first-rank information preference

(presenting this on the cover). These items are not even the first thing to be read in the section assigned to them. But there is one very positive side that should not be forgotten: 2445 pieces of information were published over 365 days; that is, an average of 5.8 news items per day.

3.3. RANKING BY AUTONOMOUS COMMUNITIES

Since the results very soon showed the preference of regional publications for RD, as compared with nationwide press, we made a list by autonomous communities (Spanish regional administrative units) to observe the position that these occupied and the interest that they provided in their respective written media. The following tables show both the sum of the two fields of written press (printed, digital), and separately, though the ones in the first positions will be seen not to change much.

Posit.	Autonomous Community	Frequency	Percentage
1	Andalusia	242	9,8
2	Galicia	96	3,9
3	Murcia Region	82	3,3
4	Castile and Leon	75	3,0
5	Valencian Community	69	2,8
6	Canary Islands	53	2,1
7	Catalonia	50	2,0
8	Castile-la Mancha	38	1,55
9	Basque Country and Cantabria	37	1,51
10	Asturias	32	1,3
11	Aragon	28	1,1
12	Madrid	22	0,89
13	Navarre	20	0,81
14	Balearic Islands and Extremadura	15	0,6
15	La Rioja	5	0,2
16	Ceuta	2	0,08
17	Melilla	1	0,04
No specific identification		1.578	64,5
Total registered		2.445	100,0

Table 22. RD in the Spanish written media

Posit.	Autonomous Community	Frequency	Percentage
1	Andalusia	171	6,9
2	Galicia	53	2,16
3	Castile and Leon	52	2,12
4	Catalonia	41	1,6
5	Valencian Community	37	1,5
6	Basque Country	30	1,2
7	Murcia	26	1,06
8	Castile-la Mancha	23	0,9
9	Cantabria and Canary Islands	22	0,8
10	Navarre	17	0,6
11	Asturias	14	0,5
12	Aragon and Balearic Islands	12	0,4
13	Extremadura	8	0,3
14	La Rioja	4	0,1
15	Madrid and Melilla	1	0,04
16	Ceuta	0	0
No specific identification		1.960	80,1
Total registered		2.445	100,0

Table 23. RD in Spanish printed media

Posit.	Autonomous Community	Frequency	Percentage
1	Andalusia	71	2,9
2	Murcia	56	2,2
3	Galicia	43	1,7
4	Valencian Community	32	1,3
5	Canary Islands	31	1,2
6	Castile and Leon	23	0,9
7	Madrid	21	0,8
8	Asturias	18	0,7
9	Aragon	16	0,65
10	Castile-la Mancha and Cantabria	15	0,61
11	Catalonia	9	0,36
12	Extremadura and Basque Country	7	0,2
13	Ceuta	2	0,08
14	La Rioja and Melilla	1	0,04
No specific identification		2.109	86,2
Total registered		2.445	100,0

Table 24. RD in Spanish digital media

Andalusia, Galicia, the Murcia Region and Castile and Leon stand ahead of autonomous communities such as Catalonia, Madrid or the Valencian Community. This aspect must be mentioned first of all. The accounting of the records worked out in benefit of Catalonia thanks to such media as *El Periódico* and *La Vanguardia*. Though circulating nationwide, these publications are considered regional and not national press, through the place where they are published. This is the case because there are no daily versions of these publications expressly created specifically for autonomous communities outside Catalonia. On the other hand, the Madrid Community was the only case of nationally published press, and thus, papers like *Abc*, *La Razón*, *El Mundo*, *El País*, *Público*, etc, were not classified as Madrid newspapers, but instead as national publications for general information. In spite of this we must insist on the deficiency of media with an interest in RD aside from the ones named, both for Catalonia and for Madrid Community.

The Valencian Community is also mentioned through having only three provinces and 13 publications, but still taking positions 5, 4 and 5 in the above tables on the other hand. In the first case (total for paper and digital) it was ahead of both Catalonia and Madrid. In the second (adding the values found in the printed press and in view of the explanation given about newspapers such as *La Vanguardia* and *El Periódico*, with a greater press run and diffusion) in the position immediately after Catalonia. As regards the table on the digital press it was again a long way ahead of the other two autonomous communities.

The second aspect we shall talk about is the presence of Andalusia, leading the ranking in the three categories given. There are several factors to explain this. This is the autonomous community with the greatest number of provinces, which also results in the greatest number of newspapers – forty – and the same piece of news can thus be reproduced by more than one of these at the same time. This common practice for both journalists working in a business chain owning several papers, and for the free-lancers attempting to publish their works in the greatest possible number of media, facilitates constant reproduction of some news. In the case of items on RD, this is very useful, since the resonance, the echo effect of a piece of news at first rather remote from the interests of average readers, ends up installing this in their memory and perception thanks to this communication effect.

In parallel to this, the Andalusian press has been fuelled with constant information about health over the last few years: the 3rd Andalusian Health Plan, Decree 127/2003 esta-

blishing the right to a second medical opinion, including confirmation of a diagnosis of a rare disease as one of the eight cases allowed to request this. Two years later, a new Decree, 156/2005, regulated the Pre-Implantation Genetic Diagnosis (DGP), creating the Comisión Andaluza de Genética y Reproducción. The Clinical Genetics and Reproduction Unit of the Virgen del Rocío university hospital became a reference centre, also for information. That same year, the Regional Health Ministry and FEDER signed a framework cooperation agreement in order to improve the living and health conditions of people affected by RD¹⁹. In 2006, the Andalusia Genetics Plan was presented, with the aim of guaranteeing the supply of comprehensive genetics services to people and relatives residing in Andalusia with genetically-based diseases or a risk of undergoing these. Access to care and attention for those affected by RD is considered, setting up reference multi-disciplinary units and forming a work group with the participation of experts, associations of people affected and patients. A set of initiatives to be implemented from 2008 to 2012 stemmed from this, and was reflected in the media, as was discovered in the year examined.

Another of the information landmarks for Andalusia in the media during the period studied was directly connected with the Medical Genome Project, a ground-breaking endeavour worldwide under the management of doctors Guillermo Antiñolo, Joaquín Dopazo and Shomi Bhattacharya. The press depicted this as the greatest step forward in genetic research since the complete sequencing of the human genome in 2001. In February 2009 Antiñolo again took the limelight in Andalusian media, where he is regularly seen, through the birth of the first genetically selected Spanish baby (second in the world) seeking to cure his brother, affected by a serious genetic disease. Shomi Battacharya was written about through taking up the post that had been held by Bernat Soria when he was appointed minister, as director of the Centro Andaluz de Biología Molecular y Medicina Regenerativa.

Galicia took second place, the printed press opting for RD more than the digital news, in a community behind Andalusia (40) and Catalonia (21) in the number of daily papers (19). Along with the profusion of written media, certain events which triggered off the appearance of information on RD could be highlighted. The first was in February 2009, when the Rey Jaime I 2009 award for Medical Research was given to Ángel Carracedo, the Galician professor of Legal Medicine at the Universidad de Santiago de Compostela, for his work

19 Published in the Plan for Care for People with Rare Diseases 2008-2012. Issued by the Andalusia Authority Regional Health Ministry

in the field of applied genetics. The ceremony, held in Valencia, was presided over by the Prince and Princess of Asturias, which attracted not only the attention of the Valencian press but also the Galician media through the prizewinner's origin. This leading figure in the Galician media on more than one occasion was called "the month of January's Galician", by the Grupo Correo Gallego in 2003.

The second of the important events, again in the month of February, found its way into the press with the publication of an international study in the journal *Nature*, on 7th February 2009. Carracedo, along with researcher Celso Arango from Madrid and Valencian Julio Sanjuán, formed the Spanish team taking part in this research and representing this country alongside a further thirteen European countries in a study which completed a major part of the genetic puzzle of schizophrenia.

In September that same year his name was again seen in the media, this time along with that of Doctor María Jesús Sobrido. The Asociación Gallega de Ataxia (AGA) gave a cheque intended for research into Ataxias to the Fundación Pública Galega de Medicina Xenómica, whose director is Carracedo.

In January 2010 the Federación de Enfermedades Crónicas de Galicia was set up. Getting the Administration involved is again the press key which switches on all the mechanisms of media attention. This type of associations exceeds the mere lobbying context and has a good deal of social, medical, employment and cultural implications, generating information on a continuous basis. This is the case of AGA, referred to above, which aside from its continuing activities announced in the media, presented 25th September as International Day for Relatives and Patients of Ataxias, involving social reporters in all of this.

The most outstanding reference however is the third place taken by Murcia, which, though it has only 6 newspapers, and is not prominent in the written press, does indeed manage to complement its news interest on RD in the digital editions, where it comes after Andalusia. The prominence of the Murcia Region, and particularly the town of Totana, in the ranking displayed, is mainly due to its active associative work. This activity has helped to create a National Encounter for Rare Diseases, which is held at the Centro de Formación Permanente de Hemofilia in Totana. Since it was created on 29th October 2008, around a hundred relatives and people affected meet every year, accompanied by representatives of associations and by a wide range

of experts. As part of their activities they hold a congress of experts: the Congreso Nacional de Enfermedades Raras. The second aspect deserving mention is the hard work done by the busy association D'Genes, another organiser of the National Encounter. All of this has made it part of an information agenda covered by the Murcia written media, with the months of October or November, depending on the year, being one of their reference points. The importance of the congress, its national scope and the affluence of outstanding personalities in medicine and research in the field of RD generates considerable information interest. Apart from this, the local institutional politicians' interest and their involvement in the acts generates added value for the Murcia press.

We will lastly refer to the third position of the Community of Castile and Leon in the written press – in our record table – stemming from the 17 newspapers published in this community, to which we add the involvement of a specific news agency for the region, Ical. The press interest for the new Centro de Referencia Estatal de Atención a Personas con ER y sus Familias was present in our research on the date of its opening on 30th September 2009, as well as on successive days. The CREER, a rare disease centre installed in Burgos under the auspices of the IMSERSO, was set up as a centre for promotion, development and dissemination of knowledge, innovative experiences and methods of care for people with TD. This venture, unique in this country, got press coverage as a highly specialised centre for services supporting families and carers, services for precautionary measures, promotion of personal self-sufficiency and the participation in society of people with these diseases. The presence of personalities from both the scientific and political world as well as the minister herself, Trinidad Jiménez, at that time, generated a huge amount of information for Castile and Leon, also in the months after its opening.

We thus believe that such diverse factors as the potential number of written media (printed or digital), along with associative work through nationwide activities, research work into RD and political cooperation (openings, visits, legal and economic backing, etc.), all marked a considerable difference in appearances in the news, leading to some autonomous communities standing out over others.

4. ICONIC-TEXTUAL VALUES

4.1. TOPICS, THEMES AND NEWS VALUES

We take topic to mean the general theme with which RD, in this case, are associated in the news item studied - in other words, the thematic stereotype by direct association. The higher the value, more topical association; the lower this is, the greater the distance. There are unquestionably four topics: research (22.7%), the disease (20.7%), institutional policy (18.8%) and solidarity (11.7%). The markers show us that there is a great distance between these four thematic topics and the others. To wit: disability (0.6%), transport or adapted facilities (0.2%), employment (0.2%), the economy (3.5%), integration (1%), alienation or isolation (2.5%), pre-diagnosis (0.9), post-diagnosis (1.3%) and the Dependency Law (0.3%).

In the text frame theme, scientific research or discovery (20.7%) is what interests people and is published most. This is followed by denunciation or demand for recognition (16.9%) and institutional policy (12.1%). The theme of least interest as regards RD is the Dependency Law (0.2%). In the section of news values - the value governing the journalist's decision as to whether to inform of something or not - this follows in our case the same correlation as the one already recorded. The news value that was most associated was novelty (18.7%), proximity (18%), rarity/oddity or curiosity (12.9) and future development (10.1), the hierarchical level of the subjects involved (8%), dramatic quality (7.9%), the impact on the country (7.1%), conflict (6.7%), and the number of persons affected (5.9%).

4.2. GRAPHICS, INFOGRAPHICS AND PHOTOGRAPHS

The preconceived idea from which work was started in this research was that a lot of pictures would be found, since dealing with diseases without showing these seemed a priori rather illogical - even more so when such diseases were characterised by being rare. It was similarly expected that infographics and graphics would be in more than widespread use for journalists in handling this matter through being rare diseases connected with research and scientific innovations. Yet again the results were puzzling, and our first expectations were inevitably disappointed. To start with, photographs

accompanied the texts on 622 occasions, that is 25.4%. Graphics and infographics were seldom used: 51 and 18 references, respectively, equivalent to 2.1 and 0.7% of the total number of pieces. When the times in which iconic resources appeared were added up the result again showed us journalists' low preference for these. 18.7% of the times it was a single illustration, two illustrations 3.1%; three 1.4%; four 0.9%, five or more 1.9%.

Several readings can again be made in respect of the cataloguing of illustrations by themes. First of all the media continue to display a preference for people (1,087 appearances) in comparison with buildings, parts of the body and/or of the diseases (46). The most representative groups are researchers and/or geneticists (230); institutional representatives (196), sick children (147); sick adults (145); doctors (135); relatives of the sick (107); social personalities and/or celebrities (68); associations and/or foundations (43 appearances, 8 of which are of FEDER); lastly there are professional carers and/or healthcare staff (16).

A second count by groups displayed similar results to the above. Group 1 (researchers, doctors, healthcare staff, research centres, medical centres) is the unquestionable favourite for photographs in the sample and period studied, with 400 entries²⁰. Group 2 (the sick, relatives, associations and foundations representing them) appears on 335 occasions. Third place is taken by Group 3 (institutional representatives) with the figure already mentioned of 196 and social personalities and/or celebrities with 68.

We should also say that on 49 occasions expedient photos were used, and that the photos of buildings were of only two types: medical buildings (hospitals, outpatients' clinics, etc.) with 13 appearances and education institutions, with only 2. We are obviously aware that matching pictures and texts may involve many variants. One of these is as regards the context in which the message appears, the format of the support (in this case paper or digital), its regularity (daily, magazine, weekly, etc.), its typology (general or specialised), going by the space and lines accompanying the picture, its size, its location on the even/odd page, in the upper or lower half... Neither should we forget that another determining factor is the actual observer of the image. Hence, a photo of a geneticist recognised by someone who sees this will be interpreted differently to someone who does not know either the person or anything about the subject in question. In any event,

²⁰ Only three of this total are of the CIBERER and 2 of the CREER

the conclusion to be drawn is that there is a synchronisation between the thematic importance stressed by journalists and the one provided by the pictures. It could also be asserted that these never act as substitutes for the text (always with a greater information content in the case of RD, as has been observed), but instead accompany this. In RD at least, a picture would not seem to be worth a thousand words.

5. THE LESS RARE DISEASES

In one year the Spanish written media provided news items on 335 different RD²¹. There would be little point in naming them all here, but a list was made of the ones most preferred by the media, looking at the ten most frequently named. The frequency numbers are low, given that these were shared out among a total number of 569 appearances, around 29 for the most common one and 7 for the least in the list that we made up. It should also be clarified that the data was recorded on condition that the media classified this as a rare disease, though we were surprised by the mention of some which seemed common knowledge or ordinary conditions for the general public. The media tended to include these as RD as soon as certain characteristics were found, for example, inheritance, chromosomal disorder, the involvement of genetics, the characteristics of chronic disease or not being sure of what caused the disease.

We will now list each of these including the frequency number in brackets, in a list that goes from 1 (the one appearing most) to 10 (the least): Paroxysmal nocturnal hemoglobinuria (PNH) (29), Chronic lymphatic leukaemia (27), Systemic sclerosis (25) ALS (18), Ataxias and Gaucher's disease (17), Williams' syndrome (15), Pulmonary arterial hypertension (14), Loeys-Dietz (13), Muscular dystrophy, Histiocytosis and Fanconi anaemia (11), Marfan Syndrome (9), Autism, Rett Syndrome and HHT (8). In the last three places we have: Hereditary Spastic Paraplegia, Cerebral paralysis, Parry-Romberg, Mastocytosis, Ectodermal hypoplasia, Neurosensorial deafness, Aniridia, Wilson's disease, mucopolysaccharidosis, Cystic Fibrosis and Lupus (7 appearances each)²².

²¹ A total number of 569 entries were made, but the figure given of 335 is the number of rare diseases with a single entry, not repeated

²² Some diseases have different names, which may have an effect on the frequency of the appearance observed. For example, we could mention Pompe's disease, also known as glycogenosis type II or acid maltase deficiency

Rare Diseases have an importance place in the press analysed on 27th February, the prelude to World RD Day. A quantitative study of this was made, obtaining the following results. There were thirty news items published in all, in this case by 23 different media, 18 general ones (10 national and 8 regional) and 5 specialised ones, all national. It did not call our attention that papers with bigger circulations such as *Abc*, *El País*, *La Vanguardia* or *La Razón*, as well as the free press, except for *ADN*, should not publish anything that day, as the information surge went on until 1st March. The event was made use of to put forward demands (for more resources, more professionals, more centres...). Five of the pieces of news on that day stress this theme, and there are a further 4 from researchers, all four being the same news item published in different media: “Neurologists clamour for more media and resources for researching into RD²³”. Along with the demands made by the latter, they also talk of the progress made in research (5 news items), with general information about these infrequent pathologies and about the celebration of the Rare Disease Day (6 items). Four also talk about political investment in healthcare and three are for activities with solidarity purposes and life stories.

The information continues on the same day this event is held, 28th February, but with 6 news items being found. On this occasion life stories are the unquestionable favourites (four of the six). One day later, there is another gush and no less than 42 news items are published. In this case they are found in 14 different publications. At the head there is the general press (12) as opposed to specialised publications (2); the national papers (10) come at the front and the regional ones (4) at the rear. Lastly the free press as a whole brings out these items²⁴. Agencies become not only a support but also a source. We observe that the titles are very often repeated in different media and places. The media that reflect the World Rare Disease Day are: *Sport* (1), *Abc* (2), *El País* repeating this time with three news items, the same thing occurring with *El Mundo*, *ADN* (6), *El Periódico* (1), *La Vanguardia* (4) and *Europa Press* (10 appearances)²⁵. *La Razón*, *La Opinión* (Tenerife) and *El Global* publish one news item that day; *Yahoo* (3) and the free papers *20 Minutos* (4) and *Qué!* (2). The themes have very similar dynamics to the previous days. Again research is found in first place (11 news items), followed by solidarity, demands and the commemoration of the day in its own right, all with 8 news items each. Lastly, there is a life story, an expression of thanks (“Angels in white laboratory coats”) and a further two explaining symptoms of these pathologies.

²³ Published in *ADN*, *Europa Press*, *Siglo XXI* and *La Información*

²⁴ Seven on paper and the rest, up to 42, in the digital press

²⁵ These papers produced a surprising result when all the news items were accumulated in the three days: *El Periódico* (2), *El País* (4), *El Mundo* (4), *La Vanguardia* (5), *ADN* (7) and *Europa Press* with 11 news items, no less

So, over 27th and 28th February and 1st March 2010, all of these assigned in news terms to the RD Day, the balance is 78 news items, no less. The media quite clearly responded positively to the call, and not on one day, but three.

6. SHORTCOMINGS AS REGARDS THE DEPENDENCY LAW

After coming into force on 14th December 2006, the Spanish Law on Promotion of Personal Independence and Care for people in a dependency situation and families, better known as the Dependency Law (LdD), laid the foundations for building the future National System for Dependency Care, which is to finance the services needed by dependent people. The legislation also covers the meaning of dependent person (through disease, accident or old age). Presented on 5th March that same year by the president of the socialist government, José Luis Rodríguez Zapatero, it reached the Council of Ministers on 20th April and was finally passed in the Plenary Session of the Parliament by a comfortable majority on 30th November. In the year covered by our study the LdD was therefore a common theme in the press. Dependency is nevertheless something alien journalistically speaking - very residual in the records - to those affected by RD, as they appear in the written and digital media studied. This was shown in the frames of section 1.2.1 and will be seen again in the following chapter. It was further confirmed when we sought to register the frame of professional carers, who were conspicuously absent in the 2445 news items analysed, only being found in 0.73% of these. The contrast becomes even more evident when compared with the research that we have been doing on disability and the media since 2009 in the written press, where the Dependency Law takes on unquestionable social and political prominence. In this work being done by members of the GIDYC –still under way – the first results very visibly bring out complaints about the delay in application of the LdD as regular news items.

Disability, RD and dependency come forward as three worlds apart, absolutely disconnected from one another in the sample that we analysed. In the media studied for this research RD coverage took a medical approach more closely connected with health and its world (hospitals, treatments, drugs, science and research) than with aid through dependency or disability, in the case of this being given. If an explanation of this situation is sought, one reason might be that the Dependency Law refers to certain degrees of disa-

bility, as occurs in discussions of old age or certain sick people, whether or not they suffer from one of the estimated seven thousand rare diseases. The diversity of the possible subjects regulated by the Law could be another explanation.

In thematic topics the connection with disability (0.6%), with the LdD (0.3%) or with transport of adapted facilities (0.2%) is residual).

7. THE CIBERER AND THE PRESS: 2009-2010

The low value that the CIBERER had as a source for the printed and digital media in the sample studied was detected. In the frames recorded by persons, nevertheless, its director, Francesc Palau, came second place in appearances, only surpassed by the Minister of Health, Trinidad Jiménez while this study was being done: 74 appearances as compared with 35 for Palau. The scientific director of CIBERER came up in the list of doctors, in that of researchers and in that of institutional representatives, the second category getting the highest appearance frequency score, as already explained. The figure of the institution, of the research centre, was referred to as a source on 20 occasions, 3 times in photographs and 10 in headlines. The media's inclination for personalisation is clear in this case and has its journalistic logic, one might add. What arouses more emotion – a person or a building? What symbolic representation power gives more direct impact: a person or an institution? The recognition of the facts being narrated generates greater interest if we can identify these and thus bring them closer home. The media therefore use the resource of personalisation to reach the public: a name accompanied by their picture, rather than one of a group or an institution, an actor rather than a film or a producer, a footballer rather than a club, and a musician rather than their group... It is thus not surprising that the director of the CIBERER should appear rather than the CIBERER itself.

Since its beginnings, this network research centre took special care with getting a communication plan under way to bring its work, results, projects and research on Uncommon Diseases closer not only to those affected and their families, or other experts, but particularly to the media. A social bulletin and a press office were set up to supply these

media by keeping in constant contact with them. They made use of new communication technologies by setting up a web page. On World RD day, the CIBERER annually organises a dissemination day under the motto: Research means Progress, a unique chance for direct encounter with associations of people affected, relatives, media and society in general. On 27th February 2010 the media brought out 30 news items on RD. Two had the biomedical research centre as their source, though they did not include this in the headlines. These were a piece published by the newspaper Siglo XXI: "A biobank will make samples of rare diseases available to the scientific community" and the news published by the Galician daily Xornal with the title of "The CSIC is the first Spanish public body to get the first designation of an orphan drug". On the two days after, 28th February and 1st March, this did not appear in the media.

We were also surprised that the Valencian newspapers only took this into account on two occasions in Las Provincias and in a further two in Levante, with the absence of Información and Mediterráneo. No Valencian publication assigned part of its pages to RD on 27th and 28th February and 1st March, as stated in the final conclusions of the book, this could be one of the future fields of action open to the CIBERER.

The centralising image policy, meaning the power that the Spanish capital may have to get greater repercussions in the information media, could leave out other aspects that we consider relevant. The RD day is a day for RD in each autonomous community, or should be at least. Geographical inequality in information is very marked in this respect, and to some extent was seen to be a matter which revolves around two points. On one hand, it is based on associative action and how involved and how close these associations are with the public authorities in their autonomous community. It is also sustained on autonomous community political bodies and their relations (involvement, closeness or distance) not only in respect of the actual RD associations, but also of the research centres. Proximity, such a vital aspect for the journalist's information selection as this was revealed in our research, is lost.

The CIBERER could improve its presence in the media at particular times which are of great interest. We could think of the opening ceremony of the Centro de Referencia Estatal de Atención a Personas con ER y sus familias (CREER), which took place in Burgos on 30th September 2009, on one hand, and also the 2nd Encounter and National Congress on RD held in Totana in late November 2009. It seems important to make specific efforts in this direction to boost the CIBERER corporate identity as the Centre on which

most of the research done about RD ultimately depends. We consider that this approach should involve becoming top sources on professionals' agendas, getting greater presence on covers, in the headlines, etc.

4.

NEWS VALUES, FRAMES AND RARE DISEASES

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As has already been explained, news values (meaning the importance criteria involved in selecting a fact) are used by journalists to choose the information texts or news that they are going to publish and thus to define which kind of events are sufficiently interesting and significant to become news and which are not. This selection and control process, which entails a form of processing reality, marks public agendas, social imaginaries, the public opinion, symbols and traditions, ultimately the way we see the world (Martini, 2000).

The news values considered in this piece of research are the ones defined by Carl Warren when he detailed the characteristics that an event has to involve in order to become news (Warren, 1975): novelty, proximity, relevance (hierarchical level), oddity, conflict, suspense, emotion or human interest (drama), consequences or significance. For the purposes of the research the suspense criterion was ruled out and the last of the ones considered by this North American is extended. Significance can therefore stem from the number of people involved, the impact on the country or the future development, based on the revision of news values made by Mauro Wolf (1991: 212-214).

In this chapter the values obtained in different items will be listed, the aim being to obtain more in-depth conclusions about the way the press studied has represented uncommon diseases by crossing different variables. As was already explained, the study of news value in the sphere of RD provides a list of values in which the easily outstanding ones are those of novelty and proximity, with frequency values of 458 and 441 respectively. The first of these is intrinsically connected with the "news" concept, understood as a recent circumstance which is not known, and the second associated with proximity as a value of vital importance insofar as it expresses a preference for a piece of information originating

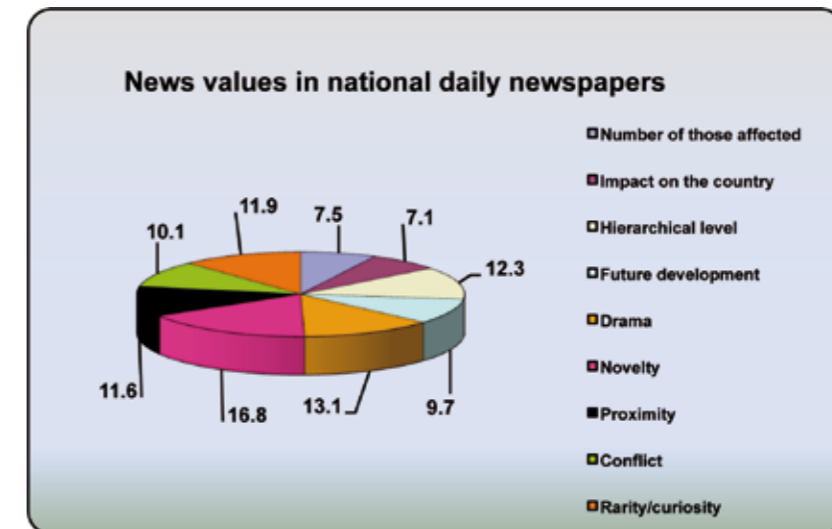
locally, in the most immediate surroundings. The local sphere has an effect on building the identity, the subject feels involved and in this respect it proves of great interest for the public. The significant role played by the regional press in covering orphan diseases was furthermore already pointed out.

The third of the news values is curiosity, with a frequency value of 316. The unusual or unexpected as a criterion for newsworthiness, as a component of the information frame, is a vital aspect when talking about what are known as rare diseases through having a prevalence under the standard rate, in short, through being minority matters or, amounting to the same thing, unknown.

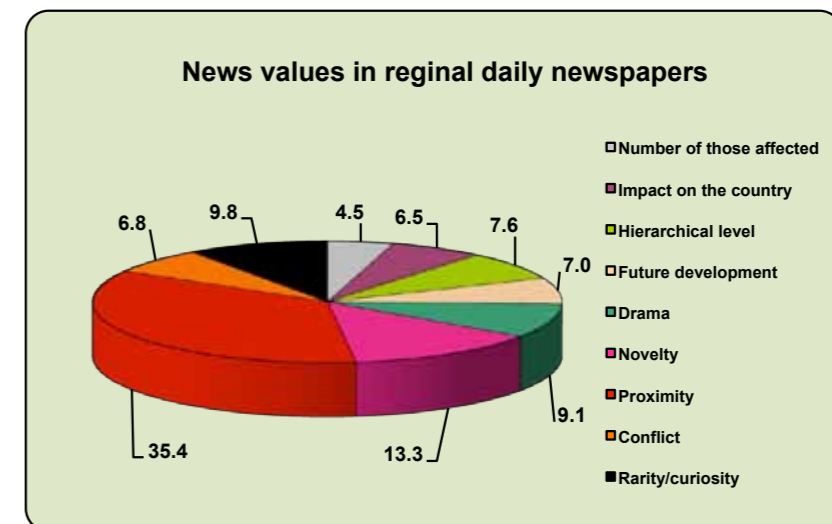
The drama factor, stemming from narrated life stories, lies half-way down the list, above the hierarchical status of the subjects involved, the number of persons affected, and the impact on the country, in spite of the institutional representatives being the undisputed favourites of the media. The notion of conflict, of vicissitudes or tragedy, is also here, with a frequency score of 193, coming forward as a marked dimension in the information stories analysed given that this predominates over a less emotional approach.

The relationship between the type of medium and the news values presented in the information on RD is proven through the statistical formula $\chi^2(171, N=2443)=673.537$, $p<0.0008$ and from the values obtained.

The news values most appreciated in the general national daily papers (El País, El Mundo, Abc, La Vanguardia, El Periódico and Público) are, as already stated, novelty, with 16.8 per cent of the total number of insertions recorded. In second place, there is human interest or drama, in 13.1 per cent of the information items selected by these papers, followed by the hierarchical status of the subjects involved (12.3 per cent). In the regional press, two of these values are not found among the three most prominent ones, being replaced by rarity/oddity or curiosity (9.8 per cent) and above all, by proximity, in 55.4 per cent of the news items, and shifting novelty to second place (13.3 per cent of the records).

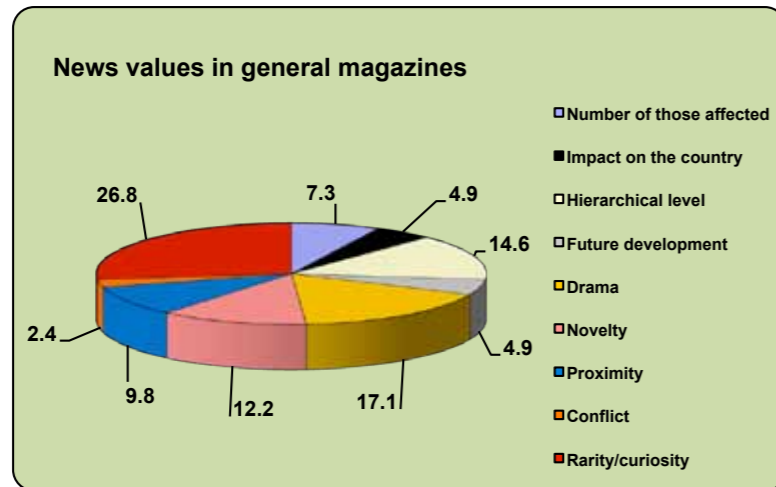


Graph 2



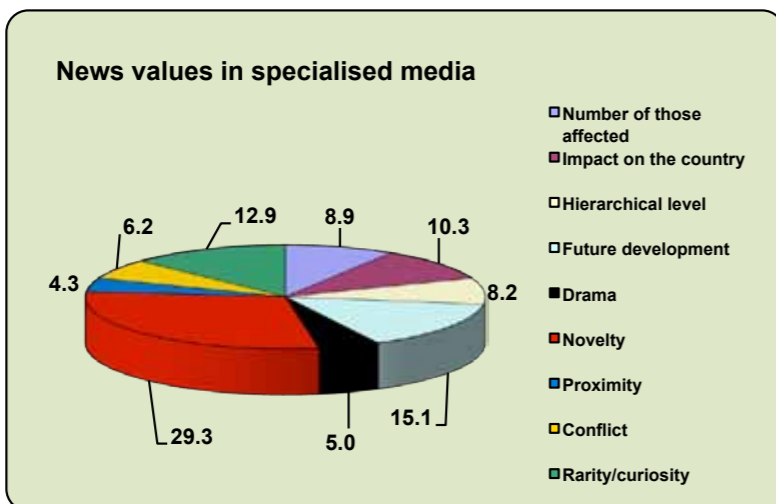
Graph 3

In general information magazines less dependent on current affairs through coming out weekly, the news values of rarity/oddity or curiosity are prominent, with 26.8 % of the total number of insertions recorded, and drama, with 17.1 % of their news items. The third of the prominent values is the hierarchical rank of the persons involved (14.6 %).



Graph 4.

Novelty is also the news value predominating in the selection of information in the media specialising in medicine or science, with a higher percentage than in the case of general papers: 29.4 %. In these media however, the second place is taken by future development (15.2 %) and the human interest drops out of the prominent values with 4.5 %. Oddity or curiosity is the third of the prevalent values, in 12.9 % of the insertions, followed by the impact on the country (10.3). The importance in these media of news values such as future development or impact on the country for selecting the information, along with the lower significance of human interest, shows the different angle from which specialised publications tackle treatment of RD - with greater weight in their thematic agenda.



Graph 5.

1. MINISTERS, SCIENTISTS, FOOTBALLERS AND THOSE AFFECTED. HIERARCHICAL IMPORTANCE AND IMPACT

One of the important criteria involved in defining the news item is its protagonist's relevance, an argument which has been associated with the variable "proper names/representatives of institutions", as has already been mentioned. When the subjects linked with some institution, concerned in the information on RD, and appearing with most frequency are associated, six names stand out above the rest: Trinidad Jiménez, Francesc Palau, Cristina Garmendia, Elena Salgado, Andrés Iniesta and Rosa Sánchez de Vega. The names of two institutions are also included: CIBERER and FEDER. The statistical test gives positive results and enables a high degree of association between the institutional representative value and news values to be established: $\chi^2(45, N= 2445)= 299.699, P < 0.0002$.

From the intersection between the news value variable and that of the institutional representative the major role of the Minister of Health stands out during the period studied, as has already been described. In the case of Trinidad Jiménez there is a prevalence of the criterion associated with the effect of the information on the population, the number of persons affected and the interest generated by the hierarchical position held by her. The novelty and future development of the information are also involved, though to a lesser extent.

Second place in this count is taken by the name of Francesc Palau, the scientific director of the Centre for Biomedical Network Research on Rare Diseases. The principle of novelty, of the impact on the country and the future development of the news item come forward as the predominant news values.

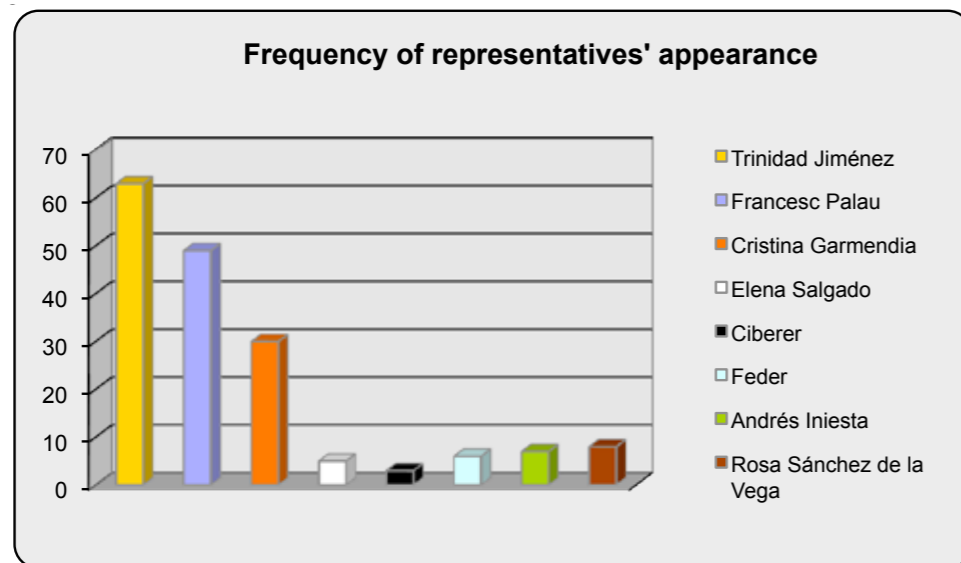
The Minister of Science and Innovation, Cristina Garmendia, appears in third position in this inventory. Along with the hierarchical importance of the post and the impact on the country the value of conflict emerges, based on the budget reduction undergone by the ministry which she is responsible for, and the effects that this cutback generates on research work.

The other three proper names seen on the list provide much lower figures and no particular news value stands out over another in the conversion of the information into news. The institutional representatives are Elena Salgado, Minister of Public Administrations in

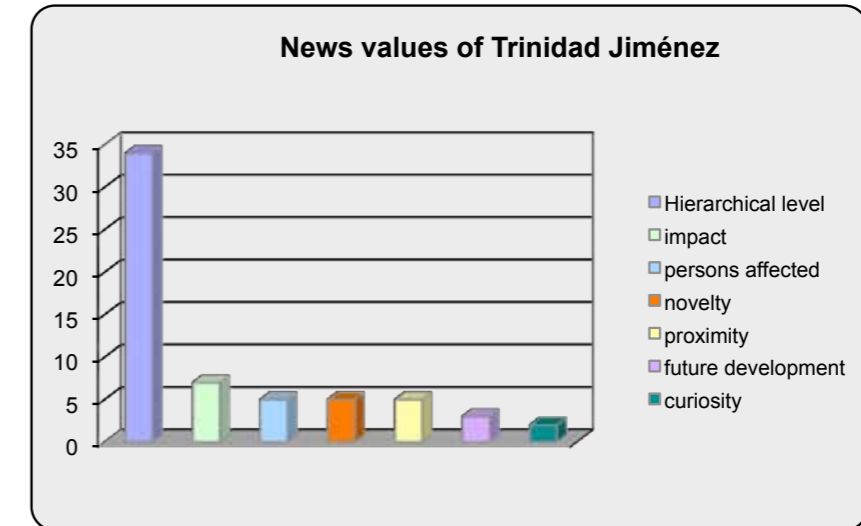
the period studied and later on of Economy and the Treasury, Andrés Iniesta, a Spanish footballer from Spain's first division Barcelona F.C. and a member of the Spanish team, and Rosa Sánchez de Vega, president of the Federación Española de Enfermedades Raras. In Andrés Iniesta's case the outstanding factor is his relevant position as a footballer, the proximity, future development and drama, since he is associated with an act in support of the D'Genes association in the struggle against RD. The relation between Rosa Sánchez de Vega and the criteria of number of persons affected and impact proves relevant, as these premises are connected with the current scope of FEDER, which is made up of roughly two hundred associations of people affected by different uncommon diseases.

When the two institutions included in the study, CIBERER and FEDER, appear in the media without being linked to their representatives, FEDER gets rather more presence in the media studied, though these are low frequency values. All the same, this repercussion ought to be conditional in both cases on the appearance of the proper name of the representatives of each concern, thus amplifying their echoes in the titles analysed.

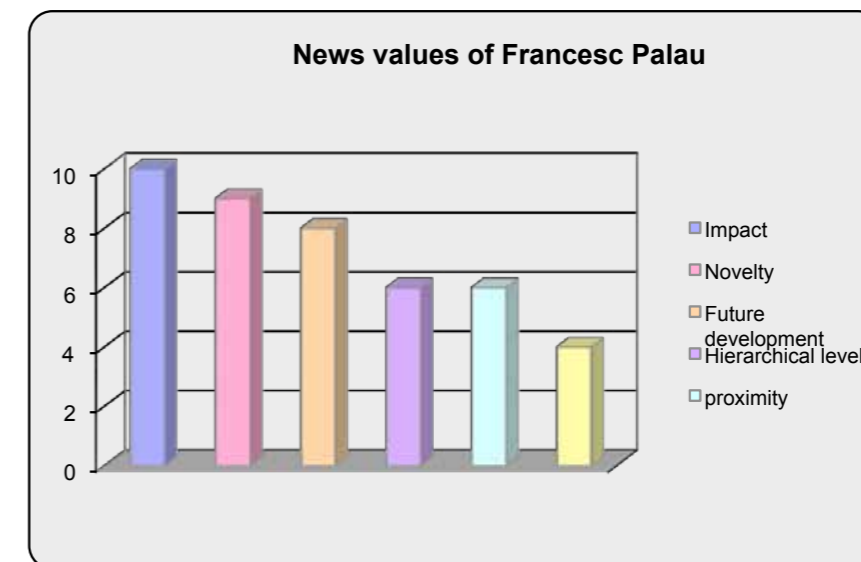
The following graphs represent the news values stemming from the three most relevant names through the frequency of appearance.



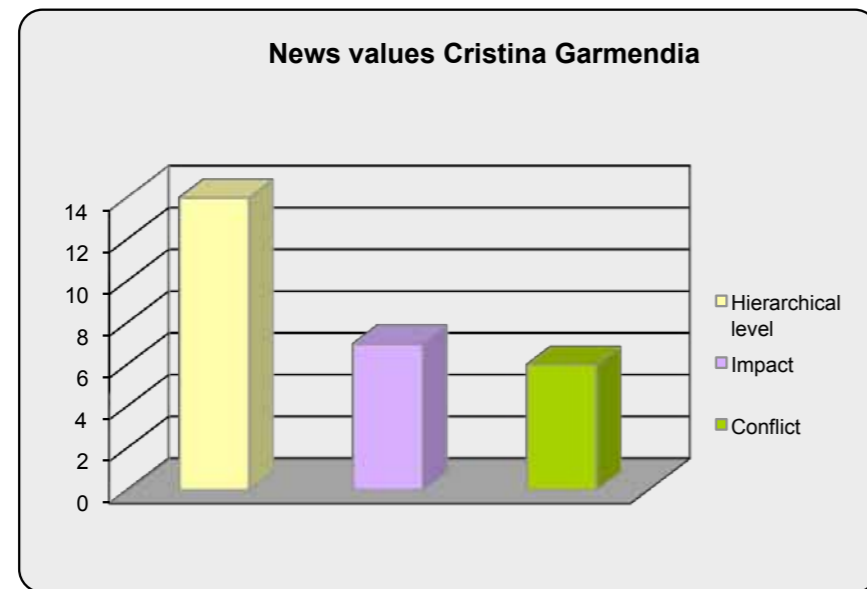
Graph 6



Graph 7



Graph 8



Graph 9

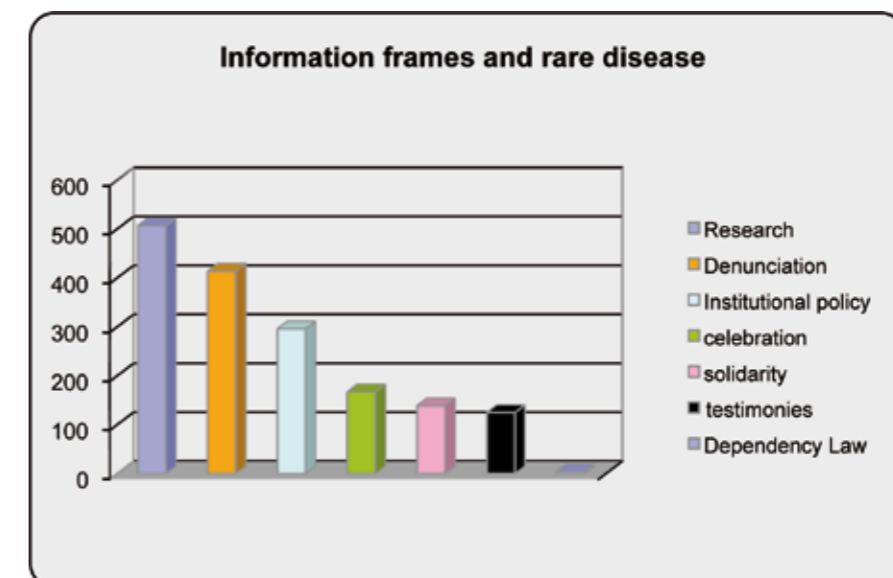
2. PREFERENTIAL INFORMATION FRAMES: RESEARCH AND DENUNCIATION, A POWERFUL PARTNERSHIP

In this work the application of the Frame Theory allows us to describe the media treatment which the subject of RD has been given during the period analysed, specifically the news frames which have been prevalent in its media coverage. The frames, central ideas organising the information context, are patterns of thought which guide the interpretation process. Hence, this analysis will concentrate on the generic frames (or subjects) and on the specific frames (or topics).

The way news items on RD are narrated and the fact of providing these with a frame helps to accentuate or mitigate certain values in this treatment, which has an effect on the creation of a social framework (Sádaba, 2001). The framework created becomes a general tone which has organisational and social but above all psychological implications. The journalist tells us what is happening and brings his or her own viewpoint into this, as something inherent and necessary in the journalistic product (1996). The reader will therefore observe reality through one frame or another as a result of the journalist's intermediation.

As was already stated in the previous chapter, the first of the frames used in studying RD in the texts analysed which should be mentioned, through the frequency of its appearance, is that of discovery or scientific research, with a frequency value of 507, this being the news frame with greatest impact. The triad of Rare Diseases, sick people and research displays the most customary media approach and insists on the necessary research to take prevention action and find diagnoses and therapies for those affected. As a result, the second and third most repeated frame is that of denunciation or demand for recognition, with a value of 414, and that of institutional policy, with 296. Both of these are connected with the development of orphan drugs and specific healthcare policies for uncommon diseases. They are followed by the celebration of formal events with 167, as a formula for awareness-raising and diffusion of illnesses, solidarity, with 139, testimonies or personal stories, with a frequency value of 129 and lastly the Dependency Law, with only 5 hits.

The media steer the reader's attention towards research and demand for recognition as has already been concluded, expressing the two most significant facets of Rare Diseases.



Graph 10

2.1. NEWS FRAMES ON THE THEME AND THOSE AFFECTED BY RD

This section lists those affected as regards the way they are identified in information texts, with the news frame that has been given to the theme. Hence there is a significant relationship between “what they are” for the journalist, what is being talked about in the medium and how the information is framed, as shown by formula: $\chi^2(80, N= 2445)= 517.050, P<, 0003]$.

The most frequently used terms used to refer to the subjects of the news item are “the sick” and “patients”, followed by the word “children” and to a lesser extent “those affected” or “dependents”, as was stated above. The terms “worker”, “disabled person” or “student” do not reach any significant frequency, which confirms that the sick subject is not talked about in their role as an active person, but neither are they linked to disability. The analysis of the texts thus reveals a general form of referring to the “who” of the news items by the extended use of the sick person-patient twin term, while the frequency of appearance of the child category stresses the link found between uncommon diseases, mostly genetic, and the impact on the child population.

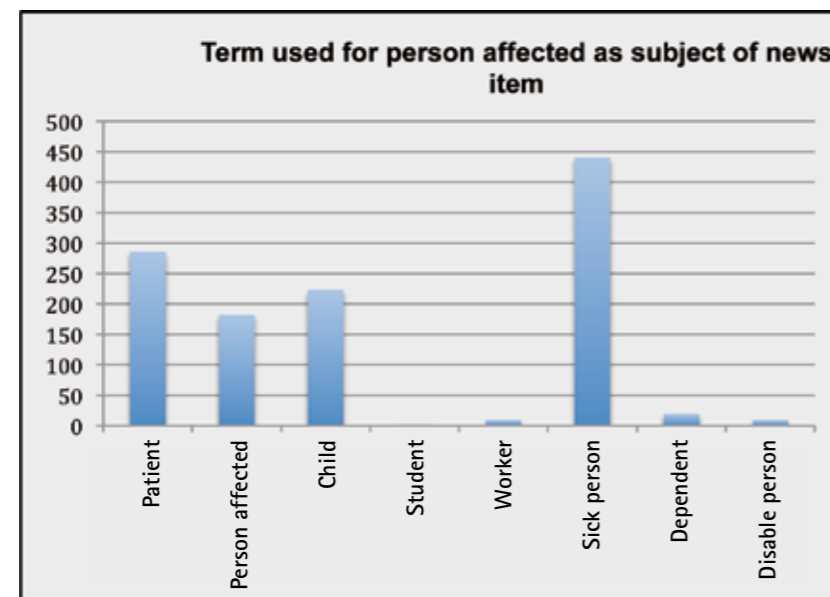
If one stops to look more closely at the analysis by categories of those affected differences are again found. In the designation of “sick persons” the most reiterated news items associates these with medical discoveries, with a value of 112. This figure very closely associates this concept and thus RD with research, but it similarly relates them with denunciation, since a value of 81 is recorded. From the sick person’s position the clamour about the need for research and for institutional policy to be changed is prevalent over any other approach. It is also at the same time concluded that the need to become visible leads the sick to appear in a high number of life stories (17), of calls for solidarity (15) and formal events (14), as shown by the figures.

The most frequent thematic field in the “patients” group is Scientific Research, with a value of 89, as occurred with the term of the “sick”. This is very closely followed by Denunciation or Demand for Recognition with a value of 52. There are finally the frames connected with Institutional Policy, with 18; Celebration, about a day for a disease being established, or Testimony, with 8 each. Again, there is no mention at all of the Dependency Law.

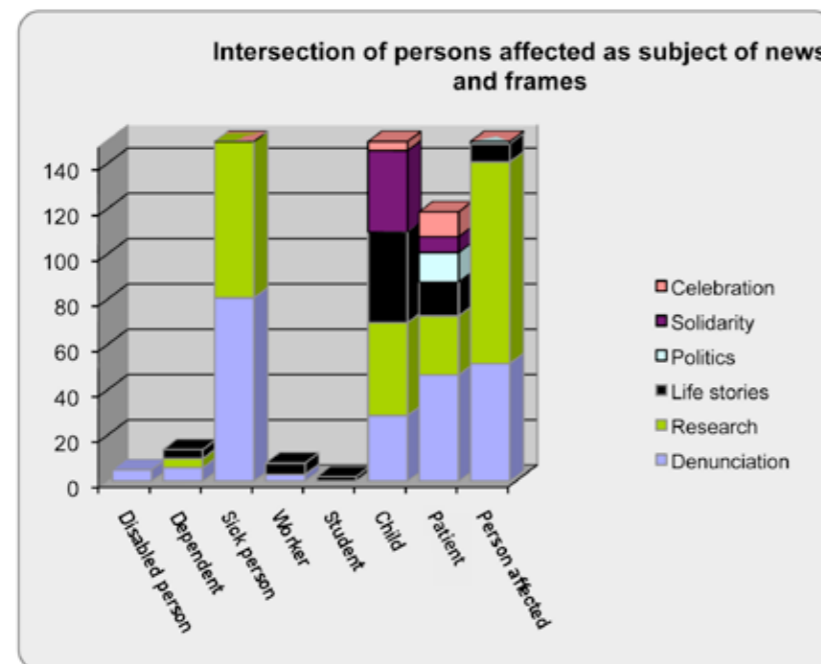
As regards the condition of “affected people”, Denunciation comes forward as the top thematic frame, with a value of 47, followed by Research and Personal Testimonies or Life Stories. Institutional Policy, Celebration or Commemoration and Solidarity are rather less forceful, and the Dependency Law has no presence at all. Again, the approaches already described for previous groups are repeated.

Different thematic frames are shared as regards the news in which reporters talk about the group of “affected children”: personal testimonies, research, solidarity and denunciation. The combination reflects the different fronts that are active. On one hand the subjects of life stories lobby for the urgent need for research into uncommon diseases as the only way out for the sick, and then there is a parallel call to people’s fraternity to obtain funds allowing the application of medical treatment that sometimes has to be given abroad. In this respect, the solidarity variable is present with greater impact in the group of children than among affected adults, as confirmed by the figures of from 2 to 7 for adults as compared with 36 for children.

Apart from this, one of the terms with lowest values obtained in the texts analysed is the “Denunciation or Demand for Recognition” theme, the highest frame with a value of 5,.. This is what happens with the “disabled” group. This approach is followed by Institutional Policy, Formal events and the Dependency Law, though with fairly insignificant figures. For the “dependent” the most repeated frame is similarly that of “Denunciation or Demand for Recognition”, with a value of 6, followed by Research and Personal Testimonies. Likewise, in the categories of “worker” and “student”, with a similarly rather insignificant presence in the information on RD, the information frame focuses on denunciation and personal testimonies, an information angle identical to the one for the groups already considered.



Graph 11



Graph 12

2.2. Information Perspectives and Nature of the Medium

A closer look at the general press will be taken now, to see whether there is a prevalence of any particular frame in the treatment of RD, whether there is a significant relationship between the news frame used for the information and the typology of the medium, and the statistical formula shows that there is: $\chi^2 (152, N= 2445)= 401.614, P<, 0002]$.

The figures lead to the conclusion that there is a dominance of two frames in the treatment of RD, that of research (which gets a value of 59) and that of demand for recognition (with 58); the desperate situation in which those affected are found is denounced, as well as talking about research. One aspect of this is the demand for the urgently needed excellence research, helping to take preventive measures and provide appropriate treatments; the other is newspaper reporting on the progress made in the sphere of biomedicine. El País, El Mundo and Público thus give priority to the research approach, and La Vanguardia, El Periódico²⁶ and Abc to denunciation. El País is the newspaper which uses the research frame most and Abc that of denunciation.

We should also stress that of all the general newspapers on paper examined, the ones with the greatest percentage of information on RD are the daily El País with 2.9% and Abc with 2.5%. The rest obtain rather lower figures: El Mundo and La Razón get 1.6%, La Vanguardia 1.1%, El Periódico 0.9% and Público 0.5%.

The frame observed in third position is that of Testimonies, with a frequency value of 28, followed by that of Institutional Policy, with 26. In the case of Life Stories, combined with an attitude of denunciation, Abc obtains the highest figures (9), while El País is the medium with the greatest focus on institutional policy. Behind all these news frames comes the one for Celebration or Formal event with 21, and Solidarity with 19, in which the most prominent paper is El Periódico, obtaining a value of 6. The frame of the Dependency Law – LdD - proves non-existent, and is not covered in any of the general daily papers analysed.

Let us go on to look at what occurs with the regional general newspapers on paper support that we examined. Again, the conclusions referring to the national papers are extrapolated to the regional press and so the frames involving research and de-

²⁶ As an exceptional case, in this section we include the newspapers La Vanguardia and El Periódico in the national circulation general press

nunciation exceed the rest, registering a value of 340, followed in third position by institutional policy with 115. The other approaches attain lower amounts: personal testimonies (65), solidarity (61) and celebration or commemoration (59). Right at the back of the scores is the Dependency Law, with only 3 mentions, in spite of the regional press being the only papers to present the LdD as an information approach. The media thus express their standpoint, an angle which gives priority to some values and puts others behind.

The sample of specialised press on paper was made up of 31 publications²⁷, and the analysis concentrated on the specialised medical journals. The frames of discovery or research again stood out among these in first position with 131 hits, which is understandable, given the nature of the media, as well as the one for institutional policy and claims for recognition, with 75 and 70 entries respectively. At a considerable distance there are the news frames of the formal event (30), of solidarity (16), of testimonies (12) and the Dependency Law (0).

The economic press also uses the research frame in pride of place, though connected with monetary matters. In the sports press, however, the main information treatment is not that of research but solidarity, a value embodied mainly in the figure of Andrés Iniesta. The newspapers specialising in disability have formal events, commemorations and celebrations based on the international day for a disease as their pre-eminent frame. There is also a mention of the Dependency Law, which was something new. In the scientific press, the dominant news frames are demand for recognition, along with institutional policy and research.

As for general magazines, the information frame most often repeated is that of discovery, followed by life stories. In the sphere of the general digital press, made up of a group of 144 media, the prominent frames are research, denunciation and institutional policy. An identical approach to journalism is seen in the specialised digital press, consisting of 56 publications. Here the demand for recognition, research and institutional policy gain the highest percentages. Finally, in the free newspapers section, the angle of discovery, denunciation and institutional policy is the prevalent approach.

²⁷ Medical, economic press, gossip papers, sports, disability, scientific publications and those specialising in communication.

In view of the results displayed the conclusion to be drawn shows the existence of a persistent image, an information frame which is constantly repeated: this is research, a scientific angle prevailing over all the others.

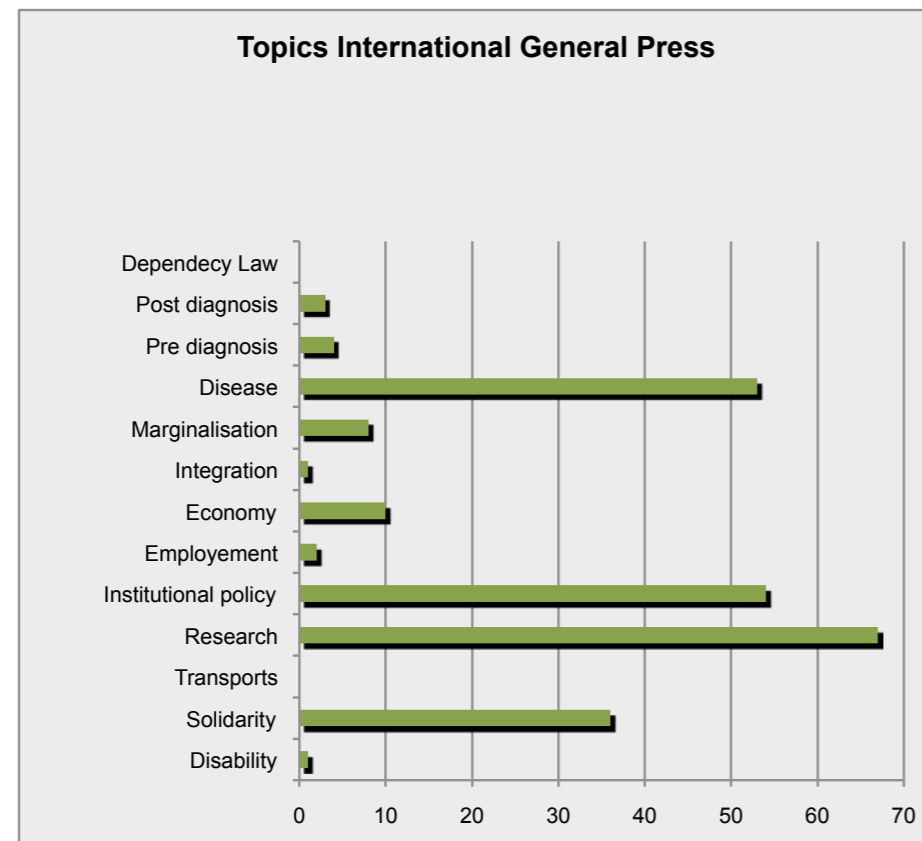
2.3. SPECIFIC TOPICS OR FRAMES AND TYPE OF MEDIUM

After examining the general information structures, the study will now determine how far certain specific topics or frames have been used by the media in their coverage of uncommon diseases. These specific structures form part of the predominant frames in the treatment of RD in the press. Which has been given most emphasis? What perspective does this frame suggest? Which do not fit as topics? Is there any relationship between the type of medium and these information frames? These are some of the questions that we shall attempt to answer.

The statistical association stemming from “specific topics or frames” and “media” variables is positive, as shown by the following formula: $\chi^2(1266, N=2443)=557.053, P<.0009$, which confirms the existence of significant aspects in the inter-relation between both variables.

In the field of general newspapers with nationwide circulation the same conclusions as the ones stemming from the analysis of general frames were drawn. Qualitatively, this small group of newspapers is the one giving greatest coverage of RD issues. In these papers the most relevant topics were framed in terms of research and institutional policy. This is what is found in *El País*, *El Mundo*, *Abc*, *La Razón* and *Público*. On the other hand, the most often repeated topic is solidarity for *La Vanguardia* and *El Periódico*, though closely followed by research and by institutional policy. Again, it is the newspaper *El País* which gets the highest figures in the predominant specific frames.

Some topics can also be seen to have no place as specific frames in the treatment of RD. The little presence, if any, of the topics of disability, transports, adapted facilities, as well as employment, the economy, integration, alienation, or the Dependency Law confirm this. Journalists are once more expressing a stance which forms a hierarchy, a correlation between uncommon disease and specific information frames, with the research frame coming out strongest.



Graph 13

If a closer look is now taken at the connection between specific topics or frames and the general regional press it will be seen that, as happened in the previous category, it is the disease-research-institutional policy relationship which attains the highest frequency value: 199, 172 and 165 respectively. One should nevertheless stress that the solidarity variable emerges as a powerful factor in this type of local press, with a value of 124. The regional newspapers become excellent platforms for publicising charity events and calls for solidarity in order to collect funds to help someone affected by RD. It is also in this setting where such questions as alienation, integration,

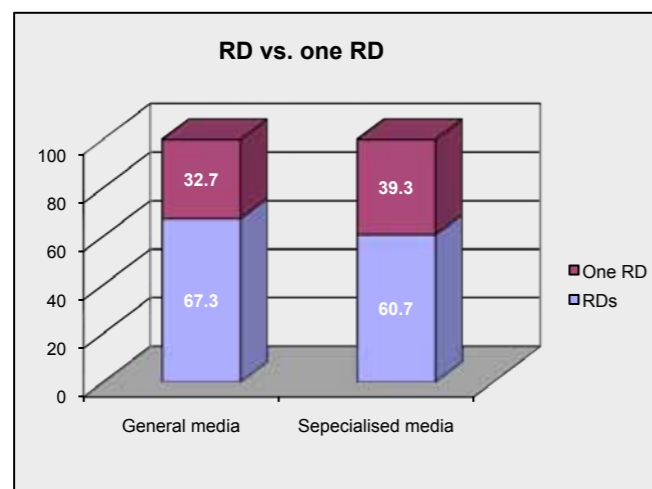
the Dependency Law, economic aspects or disability are brought into the news, as ingredients which normally come along with life stories published. These frames form a more complex approach through combining aspects and arguments not found in the national press. The local sphere as a synonym of closeness expresses less simplistic standpoints, with a polyhedral approach to rare diseases linked to the support created for those affected (Álvarez and Ramírez, 2010). This happens in the same way for the free press as it did in the national publications, with the highest frequency values being found in the topics affecting research and politics. What is more, as also occurred in the national press, the free papers exploit the concept of solidarity or help, with a frequency value of 16 as compared with the 35 for research. Likewise, the same journalistic patterns of action can be found in the specialised press. In the scientific newspapers the specific frame focuses on politics. In medical papers the information covers the topics given for the general press, characteristics of rare diseases, policies, and above all references to medical research that is being carried out. In the economic press research is also the most repeated frame, but now giving priority to aspects connected with the economic facet for the first time. For the press specialising in disability attention is split between institutional policy, research and solidarity or aid. In contrast to all of these, the sports press gives priority to the solidarity frame, which means providing the press treatment of RD with an essentially emotional quality, a facet connected with the emotive discourse proper to this type of media. The analysis of value frequency also gives similar data in the case of information from agencies. The highest values lie in the topics of disease, politics and research, followed by solidarity. Similar conclusions are attained for general magazines: disease, politics, research and solidarity, as the most commonly repeated values. The same thing happens in the study of digital papers, in both the general and specialised ones, where the most relevant topics have been framed in terms of research, institutional policy and solidarity.

The analysis thus reveals the enormous power that the media give to the research approach, which appears to be a rising value in most of these.

3. RDS VERSUS ONE RD IN THE THEMATIC AGENDA

The media come forward as necessary instruments to end the social invisibility of RD, taking into account that the way the information is structured has an effect on how this reality and those affected are thought of, as explained in the methodological chapter. In this respect, it is of interest to find out whether the media have an influence on the aim of either considering RD as a whole, needing common policies, or whether they report on one of the thousands of individual RD, stressing singularity as regards the type of medium, the frame or the information topic. This slant stems from the European Commission's assertion that "rare diseases call for a global approach based on special and combined efforts to prevent significant morbidity or avoidable early mortality, and to improve the quality of life or socio-economic potential of affected persons"²⁸.

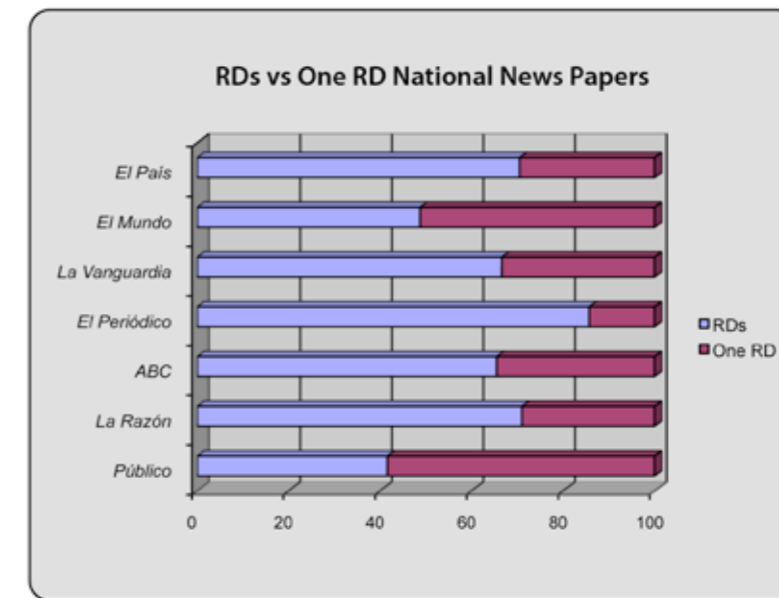
The statistical association stemming from the variables 'RD are talked about in general or not' and the type of medium is very high: $\chi^2(38, N=2445) = 76.194, P < .00001$. In 60.7 per cent of the insertions recorded the general media refer to 'RDs' as opposed to the 32.7 per cent of the occasions when a specific RD is dealt with. In the specialised media the proportion of items in which information is given about aspects connected with an RD in particular increases, with a percentage close to 40 per cent (39.3).



Graph 14

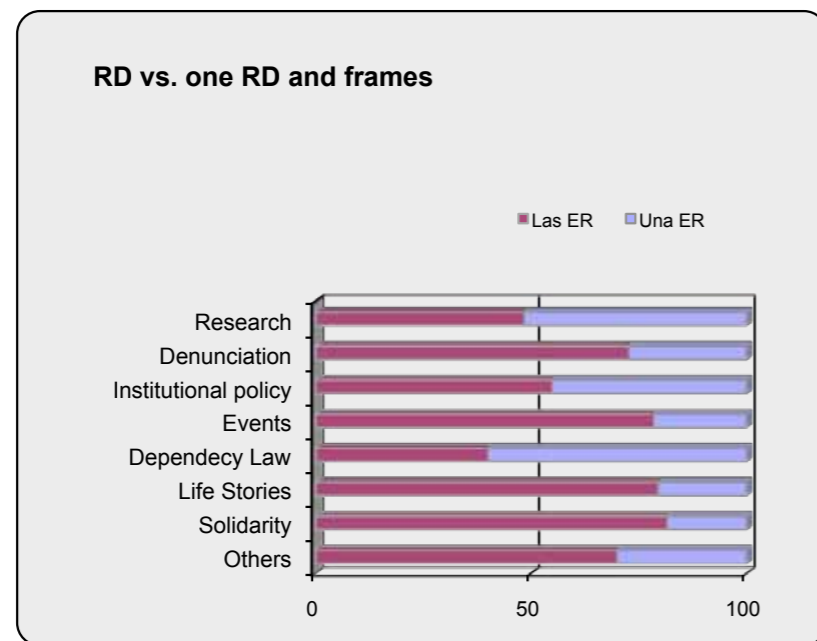
²⁸ Rare diseases: a challenge for Europe, Communication of the Commission to the European Parliament, to the Council, the European Economic and Social Committee and to the Committee of the Regions. Brussels, 11/11/2008

If we take into account the insertions of printed editions of paid-for national daily papers, El Periódico is found to be the one which informs about topics connected with RD in general to the greatest extent, on 85.7% of the occasions. This is followed by La Razón with 70%, an almost identical result to El País, with 70.5%. La Vanguardia and Abc offer a very similar percentage as regards covering RD in general (in 66.6 and 65.5% of the pieces respectively). El Mundo and Público are daily papers informing more often about one RD in particular than about matters connected with RD in general (48.7 and 41% respectively), as can be seen from the following graph.



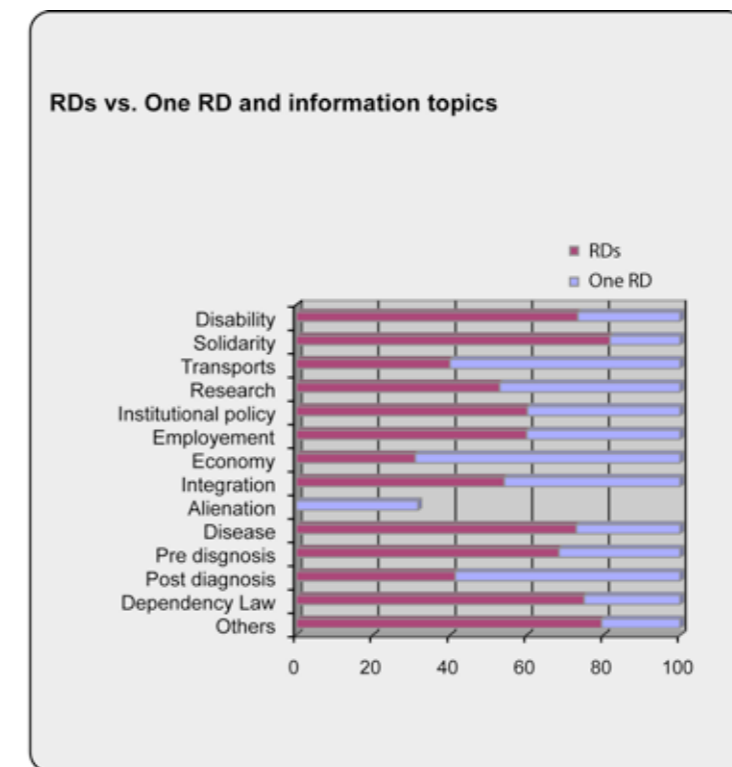
Graph 15

Test χ^2 also shows the relationship with the thematic frame of the piece: $\chi^2(16, N=2445) = 188.636, P < 0.0001$. Hence, in over 80% of the pieces on Solidarity they refer to RD in general. There are also references with high percentages - over seventy per cent - to RD in general and to the Life Stories frame, specific cases which are structured in the general problem of RD (79.5%); in Events (72.6%) and in Denunciation (72.6%). The Scientific Research (48.4%) and Dependency Law (40%) frames are seen to get under fifty per cent, that is, referring to a greater extent to a specific RD).



Graph 16

A similar statistical result is produced by crossing with information topics [$\chi^2(28, N=2445)=264.437, P<0.0002$]. The topics in which the appearance of RD is highlighted as a global term are again Solidarity (in 81.7% of the pieces), followed by the Dependency Law (75%), Disability (73.3%) and Disease (73%). On the other hand, they allude to one specific RD to a greater extent when information is given about problems referring to the Economy (69%), to Transport or Adapted Facilities (60 per cent of the occasions), and Post-diagnosis in 58.6% of the pieces registered. In this respect, differences could be pointed out as compared with the Pre-Diagnosis topic, in which there are more commonly references to RD in general (68% of the information).



Graph 17

4. DIFFERENT ROLES FOR EACH INSTITUTIONAL REPRESENTATIVE

The relationship established between the “institutional representative” and “frame” categories proves highly significant: [$\chi^2(72, N=2445)=323.278, P<.0001$]. This means that the spokesperson of an institution is seen preferentially associated with a particular number of information frames, revealing the viewpoint of whoever drew up the information and consequently with a clear influence on the reader. Hence, the name of former Health Minister Sanidad Trinidad Jiménez is found predominantly connected with the institutional policy frame, with a frequency value of 26, and also, though to a lesser extent, with that of formal events, with a score of 8. On far fewer occasions it is linked with research, denunciation or LdD frames, with only 4, 3 and 2 hits respectively.

The CIBERER representative is usually found in the frame of demand for recognition, through claiming greater visibility for RD in society, and in that of research (with a frequency of 12 and 7 respectively). In this respect, for doctor Francesc Palau his profile as a

researcher is prevalent, due to being identified with the policy of the institution to which he belongs. He is nevertheless also associated with other information frames, though of lower weight: formal event, testimonies, Dependency Law and that of solidarity. The figures obtained by the institution which he represents alone are not very significant. Additionally, the names of ministers Cristina Garmendia and Elena Salgado are associated with the frame of institutional policy, with 17 and 3 frequency values respectively. Footballer Andrés Iniesta is related only with the solidarity frame, where he gets 3 entries. The representative of FEDER, Rosa Sánchez de Vega, has hits in the information structure of denunciation through lobbying for an action plan for RD: a clear association can also be found between the proper names of the institutional representatives and the topical frames in the analysis on the treatment of these diseases in the media. Crossing both variables shows a clear relationship, as shown by the formula: $\chi^2(126, N=2445)=365.495, P<, 0003$].

Journalists preferentially get the material for their information from institutional sources, which is why the frame of institutional policy is prevalent, as has already been pointed out. The results of the research therefore turn out to match those found in the general frames. The name of Trinidad Jiménez gets high figures in the institutional policy frame, with a value of 30, in the research frame with 9 and in that of the economy with 5, all of these being aspects inherent to the post that she holds. In the texts in which Minister Cristina Garmendia appears there is a prevalence of the institutional and economy frames, connected with budget cutbacks, and research, as confirmed by the numbers of 13, 9 and 6 obtained. The same frames are used in news on Minister Elena Salgado, although the numbers are much lower. The specific frames of research and institutional policy are used as a priority in the news items in which Francesc Palau appears, with values of 11 and 16 respectively.

In the news items in which the name of sportsman Andrés Iniesta appears the value of solidarity is used as their specific topic; in information covering the representative of FEDER the topics used are the frames of institutional policy, solidarity and alienation, with values of 4, 2 and 2. Again, when talking about CIBERER or FEDER the numbers recorded are rather low. The discourse on the former has as priorities the frame of institutional policy and the economy, with a value of one in each of these, while in the case of FEDER institutional policy is the main approach, with a value of 4, and research and solidarity, with a frequency value of 1 for each of these, as arguments clearly associated with the objectives pursued by each body.

5.

RARE DISEASES: INFORMATION HIERARCHY AND THE READER'S PARTICIPATION IN GENERAL AND SPECIALISED MEDIA

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Do news items about low-prevalence diseases usually appear on covers? How often do they do so? Is there any paper in which any inclination to presents news on RD on the front page can be seen? Can this conduct be extended to any kind of media? The conclusion is that it cannot, as was already pointed out at another part of the study. Low-prevalence diseases seldom manage to get onto the front page of the media, so the newspapers analysed do not reveal any special sensitivity or predisposition to locate information on RD on the cover. There are no preference criteria in the publications leading to the selection of these news items in designing covers or front pages, as is confirmed by the statistical formula: $\chi^2(38, N=2443)=432.192, P<, 0002$] in the analysis of the relation existing between both variables.

The front page is seen as a fundamental item in newspapers: the appearance on the front page or not and the order of the news items constitute a double criterion forming a symbolic language for the reader. The front page of a newspaper represents the culmination of the efforts that the newspaper makes to call the reader's attention, but this also involves an editorial decision at the same time, because the contents are valued and some are preferentially displayed above others. This is thus an advertising lure but also one that forms the identity of the paper. It can therefore be concluded, since failure to include information about these pathologies on the front page is widespread in all the newspapers, that the publications analysed are expressing a stance as regards the subject of seldom-found diseases. There was not much information on RD on either the summary front pages analysed or on the appeal covers, where the reader's attention is sought from a single news item. Quite the opposite in fact: in the general press on paper the values range from the frequency of 40 obtained for the daily *El País* and 6 for *Público*. The same thing occurs with the specialised press, with the general magazines, with the digital dailies or with the regional general press. In the latter there is a predominance of failure to appear on the front page, with a value of 482 as compared with the figure for cover location, which is 13. The same conclusion can be drawn as regards the specialised medical press: RD slip into the different news items on the front page in 22 publications.

1. RELATION BETWEEN THE POSITION ON THE PAGE AND THE TYPE OF MEDIUM

As already occurred with including RD on the covers or not, the location given to the news items on the page of the newspaper indicates a valuation or hierarchy-positioning exercise²⁹. The value of the information is related to the dimension of the news item, that is, the space assigned and the position on the page, whether this is on the top half or the bottom half. This aspect bears relation to the reader's visual travel:

The process of reading the front page is held to be circular, starting in the upper left-hand corner and moving clockwise [...]. For this reason, the main piece of news is placed in the upper left-hand corner (...). A second theory divides the page into two horizontal halves and two vertical halves. It considers that the upper part is of greater value [...] and the left-hand side more than the right [...]. According to this theory [...] the eye starts in the upper left-hand corner, goes on moving horizontally to the right, drops to the lower left-hand side and concludes at the bottom right-hand side. In both theories the upper left-hand side [...] is the place where the most important news item in the paper must be placed (González and Bernabeu, 2008:28).

The most important news is located on the upper half of the page and the least important or even the fillers are placed at the bottom or on one side of the main item. That is why the upper left-hand corner is the most sought-after position. This is followed by the right and then the bottom half. Location on an odd or even page is however, also a factor of influence in this valuation exercise. From this point it was considered useful to go on to observe the relationship between the "position on the page" variable and "type of medium", after checking that there is a significant association: $\chi^2(38, N= 2443)= 440.291, P<, 0006$.

In the nationwide general press on paper there is a prevalence of the layout of information on seldom-found diseases on the top half of the page. In the study carried out the values talk of 33 hits on the upper half as compared with 6 on the bottom half for El País, or of 20 on the top half of the page and 4 at the bottom in Abc. In the regional general daily papers there is also greater location at the top than at the bottom, with a value of 324 as opposed to 165. A similar pattern can be observed in the general magazines, in the digital general daily press, in the economic papers and the free or medical press. The only exception is found in the sports press and agencies, in spite of the figures not being very striking: 7 hits in the lower half as for 5 at the top in the sports press and one value in the bottom half for the agencies. Hence, although it has already been seen that the news

²⁹ The digital version of the newspapers does not allow us to discuss positions on pages due to the idiosyncrasy and layout of these media. The hierarchy becomes more vague and one can only observe the totals referring to hits on the Internet

items on RD do not as a general rule obtain headlines on the covers or front pages of the media, there is indeed a clear trend to locate these same items in the top corner of the inside pages, a corner with the greatest visual impact.

We will now look at the relationship between the type of medium and the location on an odd or even page. The formula $\chi^2(38, N= 2443)= 420.150, P<, 0006$ reveals a clear association in the relationship between both variables. In spite of it being estimated that the odd pages are the ones read most, the prevalence of odd pages over even ones or vice-versa does not prove significant in the general daily papers on paper analysed, where the sums are similar: In El País, 21 hits on even pages as compared with 19 on odd; 12 on even and 13 on odd in the Abc; 6 on even in El Mundo and 9 on odd; 3 on even and 4 on odd in Público, etc. In La Vanguardia both totals are similar and only in La Razón does the location on even pages easily exceed the odd ones. with a value of 15 as compared with 6.

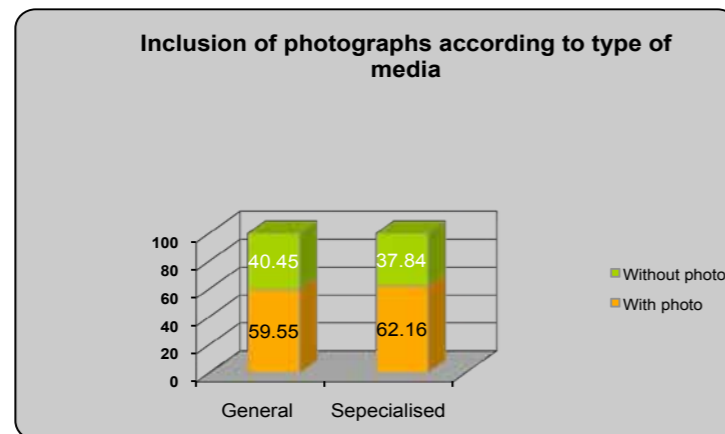
If we now stop to look at the regional general press, the numbers also reveal similar values on even and odd pages: 250 hits on odd pages and 247 on even ones. Something similar occurs with the specialised medical papers (145 on odd and 153 on even), also in the free press (11 and 9) and in the general magazines (16 and 11). The figures nevertheless show ties in the specialised economic press (9 for each of them) and in the sports press (6 for each of the locations).

2. PHOTOGRAPHY IN INFORMATION ON RD

Through the sheer fact of being on the pages of a newspaper, the photograph is a preferential focus of attention, acting as a magnet for the eyes, pulling them towards it. From this first contact, the receiver will be more easily 'hooked' by the reference information. It acts at the same time as a major factor in establishing hierarchies, as an illustration juxtaposed to the printed text, clearly distinguishable from this, and insofar as it occupies a part of the page. This means that it has an influence on the apparent importance of the news item as a factor of its "valorisation" (the emitter providing information value for the receiver) (Alonso, 1995:9). Photographs, (and also graphs) are items of great importance in the visual architecture of the pages, which is why their use forms part of the strategy of catching the reader's interest (Manfredi, 2000:115).

Some of the questions coming up as regards photography and information on RD are therefore whether their greater or lesser use is connected with the type of medium or with the thematic frame in which the piece is structured. In both cases, the reply is affirmative: there is great statistical association between the inclusion of photographs and the type of medium - $\chi^2(38, N=2443)=420.716, p<0.0004$ -, on one hand, and also in respect of the frame - $\chi^2(16, N=2445)=83.017, P<0.0005$ -.

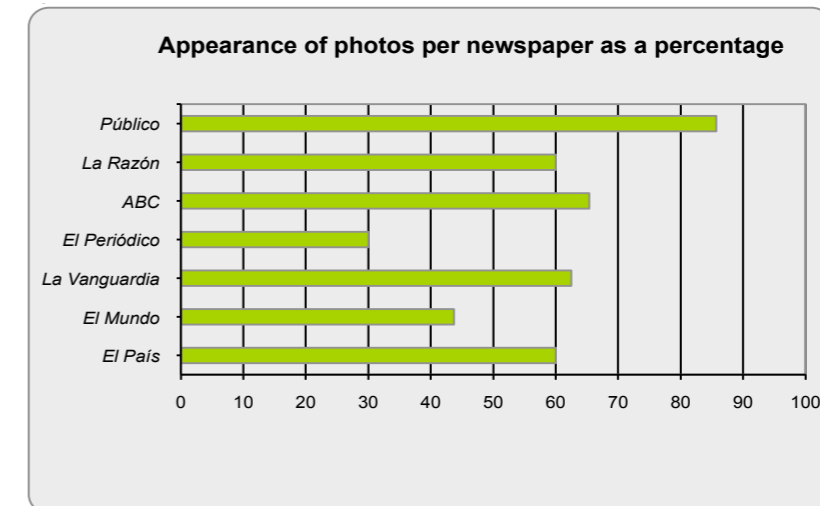
As for the type of media, in publications of a general nature the results range from the 58.5 per cent of the insertions recorded with a photograph in the printed editions of paid-for national daily papers, 59.8 in the case of regional ones and 60 per cent in the case of the free press. If all the entries in printed and digital printed media are taken into account, the percentage is of 59.55%. The proportion of items in which the information goes along with a photograph in the case of the specialised media is higher, with 62.16% in the publications specialising in medicine.



Graph 18

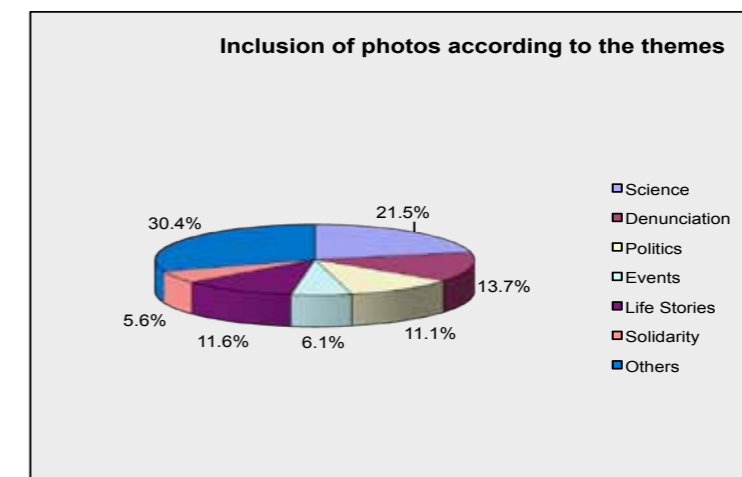
Paid-for national papers reveal disparate patterns as regards the use of photography in pieces on RD. From the highest percentage of *Público* (85.7% of the insertions) to that of *El Periódico* (30%), the other daily papers move from 60 per cent of the information items with a photograph (*El País* in 60% of these, *La Vanguardia* in 62.5 and *Abc* in 65.4). *El Mundo* would be the paper publishing fewest photographs on the issue of RD (43.75%). Including photographs depends, amongst other factors, on the model of newspaper and the general design of the medium, and the choice of journalistic genre. Hence, *El Periódico*, a publication with a large number of photographs, is the one that contributes least as regards the matter of RD, because no report or interview appears between the insertions analysed, as

can be confirmed in the section on Newspaper Genres. On the other hand, a prominent proportion of these interpretative genres is chosen in *Público*, *El País*, *La Vanguardia* and *Abc*.



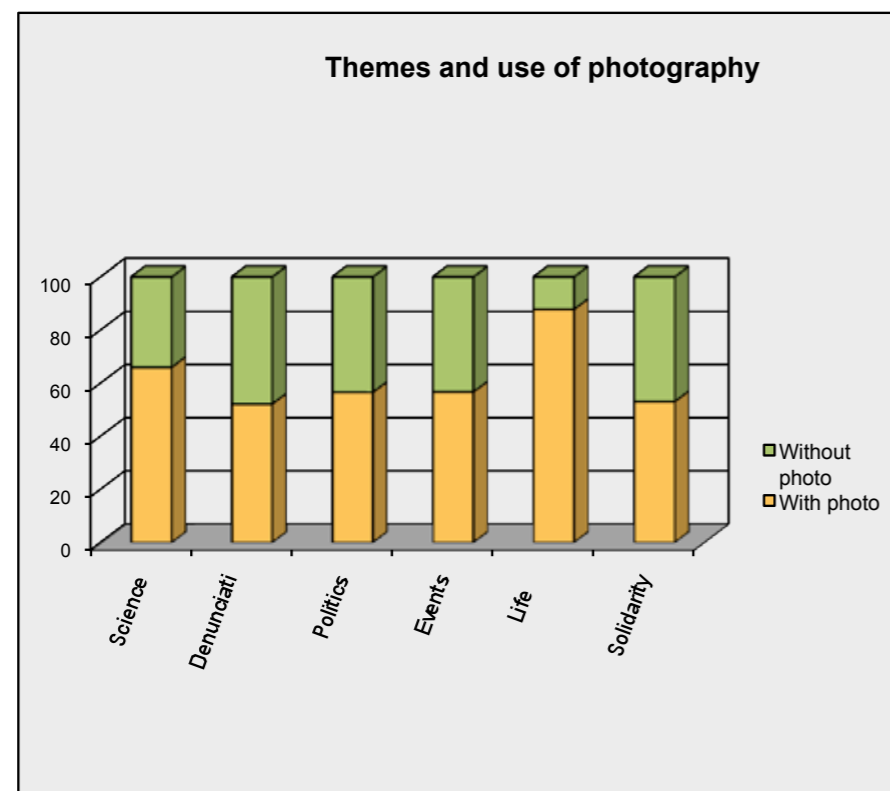
Graph 19

In respect of the total number of news items in which it is known whether photographs are used or not, those dealing with scientific discoveries are the ones showing greatest journalistic value as regards the use of photography. 21.5% of the total number of news items on RD with photographs refer to this issue. The other frame which obtains photographic accompaniment to the greatest extent is that of denunciations or claims (13.7%) followed on one hand by the one focussing on personal testimonies or life stories (11.5%), and on the other by the frame concerning institutional policy (11.1%), in which the pictures of public representatives are of central importance.



Graph 20

The analysis of the use of photography in relation with each of the frames recorded shows that more importance is given in some cases than in others. The case of life stories is prominent, since 88% of the news items on this subject have a photo. The second most highly-valued frame in this respect is that of scientific discoveries, with 66% including a photo. The rest give similar results with percentages indicating that on half of the occasions there is indeed a photo, and in the other half there is not, meaning that other production routines seem to come into play apart from the subject in question in the information. Hence, Denunciation has 52.1% with a photo and 47.9 without one; Institutional policy 56.5 with, 43.5 without, an almost identical proportion to that of Events and Commemorations (56.7 with, as opposed to 43.3% without). Lastly, in the case of information about Solidarity, in 53% of the cases these go with a photograph and in 47 without.



Graph 21

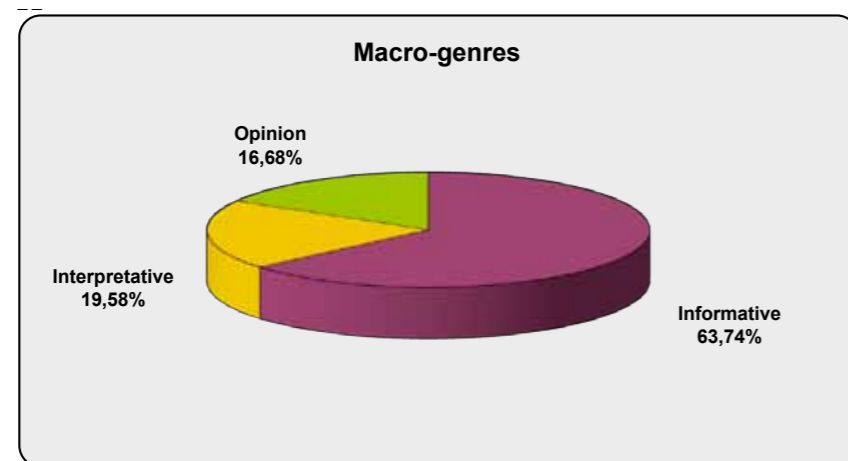
3. JOURNALISTIC GENRES. THE VALUE OF UNIFORMITY IN THE THREE MACRO-GENRES

There are considerable differences between communication theorists in classifying the different forms of writing a journalistic text, but many of them coincide in indicating the journalist's presence in the text as being the main differentiation criterion. Hence, the greater or lesser degree of subjectivity found in the text defines three major groups: information genres, genres for interpretation, and opinion. This piece of research has taken into account news items and news in brief in the information macro-genre; reports and interviews in the interpretative genre; and articles, criticism/reviews, columns and editorials in that of opinion. According to Alex Grijelmo (2003:27-30), a reader accustomed to a newspaper knows how to identify the greater or lesser information presentation being given to a subject, knowing the differences between a front page with a five-column header and an opening on two columns, and is aware of the way opinion articles are typographically laid out.

The existence of genres forms part of that non-verbal language surrounding words and conveying relevant data to readers about the approach to the text that they are reading. The importance of genres, beyond their use and function in editorial offices and journalism faculties, therefore resides in the fact that they may also be useful for the reader. The mindset with which the reader heads into a news item changes a lot from the approach to a report or an opinion article. Readers are on guard when tackling an opinion article: they know that what is being given there are value judgments in line with the specific idiosyncrasy of the person drafting the text. On the other hand the news item constitutes the essence of facts, reproducing data and declarations. The other genres lie somewhere between both of these, all with a different degree of author-involvement.

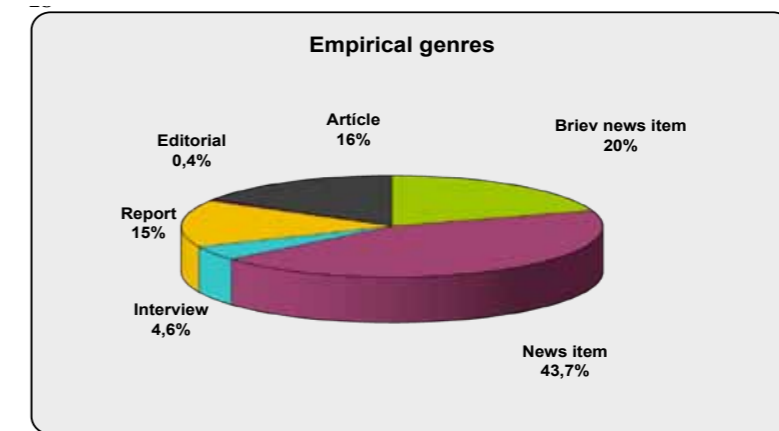
Interpretative genres entail greater preparation by the journalist, get greater space in the newspaper, greater coverage as opposed to succinct information. As a general rule interpretative journalism tends to be considered a form of going more deeply into the information, with precedents and analyses which provide a background situation or attempt to explain situations of current interest, not only to inform about these. Interpretative genres therefore entail greater preparation, dedication and knowledge of the subject being dealt with. Their use underlines the interest that the medium may have for a particular information topic.

Opinion genres, on the other hand, are a rhetorical discursive construction whose main aim is to persuade. As part of these, the editorial takes on particular importance as a text that reveals the ideological approach through valuing and judging a news item considered of particular importance for the medium. The choice of the journalistic genre represents a further item in journalistic valuation and the establishment of the thematic agenda of the medium. That is why the purpose of finding out what journalistic genres are most widely used by reporters writing about RD is to assess the degree of involvement in the preparation of the items and the hierarchy ranking given to the subject by the type of medium in question. The information macro-genre is the one appearing with greatest frequency in the total number of insertions recorded. With 63.8%, this triples interpretation, with 19.6. The difference in respect of the opinion macro-genre is still greater, with 16.68% of the total number of texts analysed.



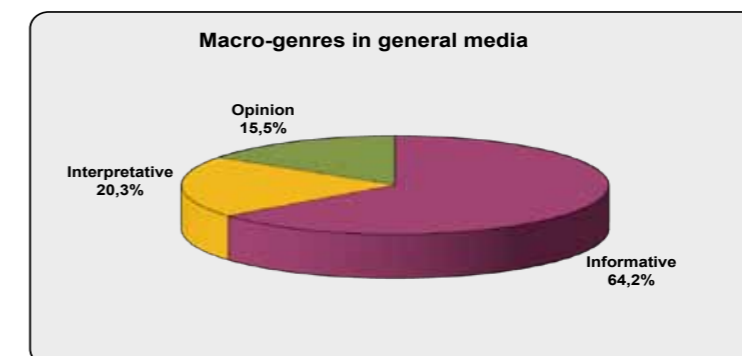
Graph 22

As for the empirical genres, the news item is the genre most widely used by all the media, on 43.8% of the occasions on which they inform about RD. The brief item is the other genre most commonly selected (20%). The amount of reports reaches 15%, while the interview is below five (4.6). Opinion articles signed by contributors represent 16.2. Editorials make up 0.5%. There are in short a lot of brief items, a few reports, extremely few editorials (none in the national dailies with greatest circulation) which shows that the media do not give the information on RD any prominent coverage as regards the choice of journalistic genres. As was stated above, they do not succeed in attaining the media's consideration as an item of priority interest on their agenda.

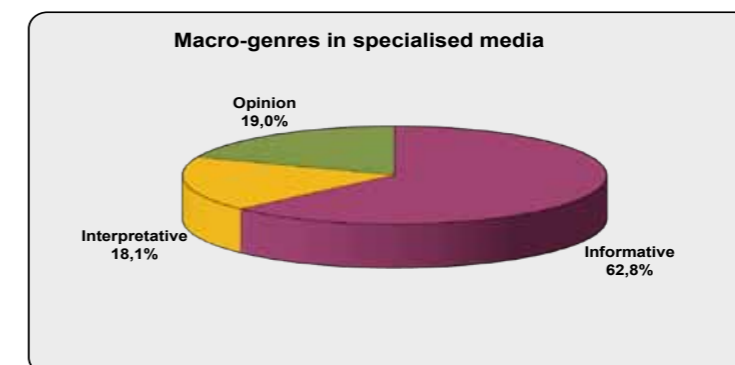


Graph 23

The X^2 test shows that there is a significant association between the type of medium and the journalistic genre: [$X^2(133, N=2443) = 678.343, p<0.0005$]. In the general media, the information and interpretative genres represent 64.2 and 20.3% respectively. Opinion is just 15.5. In the specialised press one can appreciate a greater number of opinion articles by experts, which make up 19% of the total, while the figures for informative (62.8) and interpretative texts (18.1) drop.



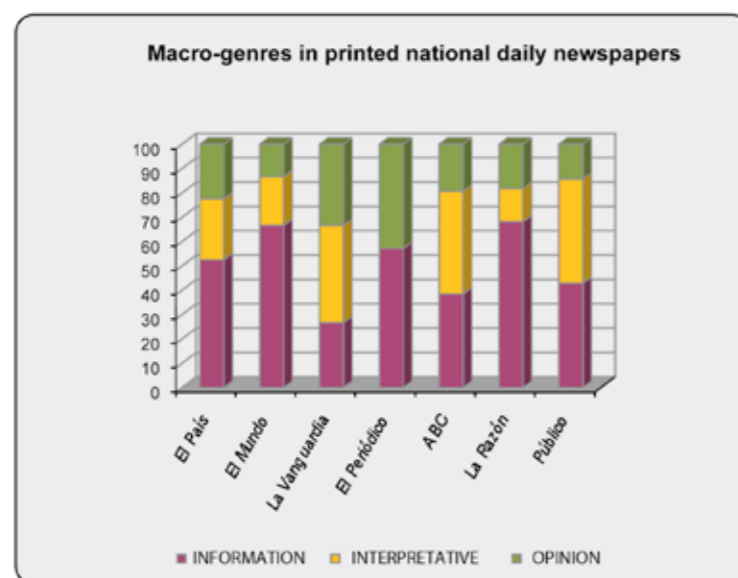
Graph 24



Graph 25

In printed editions of paid-for media the texts are informative in 64.6% of the insertions. La Razón is the daily national paid-for paper with greatest percentage of informative texts (68.2), followed by El Mundo (66.7) and El Periódico (57.1), the one giving most opinion on RD and the only one to publish an editorial on the issue. El País has over 50% of its texts in the informative genre (52.5). On the other hand La Vanguardia is the one with fewest informative genres, with 26.7% while interpretation reaches 40%. Abc and Público are the daily papers with greatest proportion of interpretation on their pages (42.3 and 42.8 respectively).

The data on the free papers (ADN, Qué and 20 Minutos) reveals a greater preference for informative genres, with 79% of their texts in this category, while interpretation and opinion come to 11% each.



Graph 26

After associating the type of medium informing about RD and the genre of journalism used to do this, we will now look more deeply at the intersection between the genre of informative pieces analysed and the frame. To answer the question of whether journalistic genres, understood as forms of encoding information, preferentially use certain informative frames over others in the treatment of RD, the statistical formula describes a significant relationship between both variables: $\chi^2(56, N= 2445)= 361.188, P<, 0003]$. Hence, if we are talking about informative macro-genres, one can see that the brief item gets a higher frequency in the use of the research frame, which is why these short informative items

first of all report news on discoveries, with a score of 33. The second approach used is that of formal events, with a frequency value of 30. The third and fourth places are taken by frames focussing on denunciation stories and solidarity campaigns, with 26 and 24 for frequency respectively. News items also give priority to the discoveries approach, with a frequency value of 108, followed by institutional policy and denunciation, with a score of 68 and 67. The same patterns already described for purely informative discourse are reproduced.

In the opinion macro-genre the highest frequency scores go to research and denunciation (with the same value of 35). Institutional policy and testimonies lag behind with scores of 13 and 20 respectively.

The editorial genre, acting as an institutional judgment and expressed in accordance with the medium's editorial line, gets the greatest frequencies in the denunciation frame. In the letters to the editor, the expositions in the denunciation frame are similarly plentiful, through including forcefully assertive arguments. The frequency value is 12, as compared with a value of 3 in the thematic topic of solidarity or of 1 in institutional policy.

As regards interpretative genres, in the interview type preference is given to demand for recognition, with a frequency value of 11. The people affected demand normalised healthcare and the right to a better quality of life. This is closely followed by the frame of discovery and policy, with a score of 8 for each of the themes.

The report, somewhere between information and interpretation, focuses its interest on the frame of life stories, since the format is seen to be suitable for going more deeply into personal accounts. As reports of human interest, relevance is given to the testimonies of people affected and their relatives. This manages to get a value of 47, as compared with the score of 19 for research or 12 for institutional policy.

After going through the topics and genres it was corroborated that of all the existing topics it is the Dependency Law which fails to obtain significant scores in any of the genres studied. For this reason no relationship is established by the media between this frame and that of low frequency diseases. The prevalence of news items analysed alludes to a portrayal of RD in an eminently informative pattern, as has already been stated, and confirmed by the frequency value of 654 obtained through a count of the figures for the news and brief items. The treatment proper to interpretative journalism reaches values similar

to that of opinion. If the figures obtained in the interview and the report genres are added, a value of 200 is recorded, only a little over the amount of 170 obtained by adding up the articles of opinion, criticism, columns and editorials.

The way news items on RD are narrated and the preferential frame in which these are structured helps to create a particular perception of the theme. Hence, by framing reality on RD in an informative context, this is removed from emotions, from interpretations and opinion discourse. The research and denunciation frame is structured in all the macro-genres on a discourse concentrating almost exclusively on stories talking of discoveries and demands or claims.

3.1. GENRE OF THE ITEM AND MOST FREQUENT TOPICS: AGAIN SOLIDARITY, RESEARCH AND INSTITUTIONAL POLICIES

After the analysis of the link that can be found between press frames and genres, an in-depth look will be taken at topical frames and macro-genres, a nexus in which there is again a clear association between both variables, as shown by the formula: $\chi^2(98, N=2445)=189.170, P<.0009$.

Out of all the most commonly repeated topical frames, the prominent approaches in the informative genre of the brief news item are solidarity, research and institutional policies, obtaining similar values, with 39, 36 and 33 respectively.

The same view is repeated in the news item: the frequency values most widely reproduced are those of the disease itself, with explanations of its diagnosis and traits, research, institutional policies and solidarity. Aspects connected with the economy, integration or isolation, installations, Dependency Law and disability reach only very low figures. The topic of employment is non-existent.

Along with the information macro-genre and the supremacy of this angle, similar treatment is to be found in interpretative discourse. The prevalent frame in both items with a report format and the interview genre is the one in which the disease and its characteristics are associated with institutional policy and research. Furthermore, in reports the information frame of solidarity and economic arguments is seen to reach a high frequency value. We

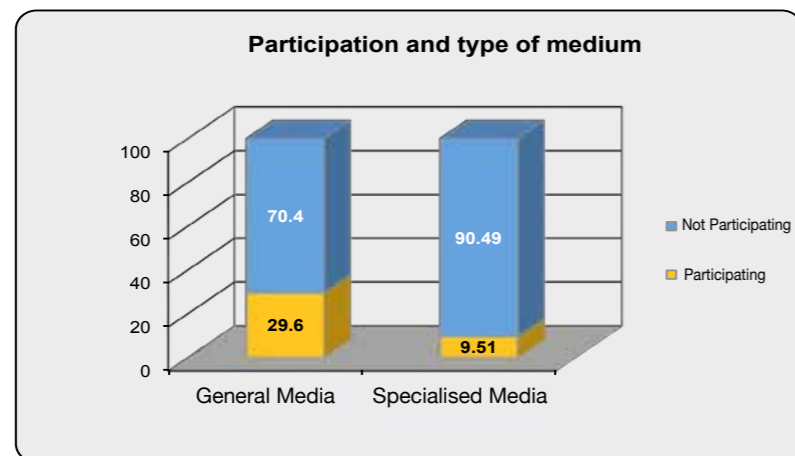
find very scant references to disability, integration, employment, the Dependency Law or alienation, in spite of being journalistic items which lend themselves to going deeper into the causes, effects and details surrounding uncommonly found diseases.

Articles, criticism and columns framed in opinion genres also connect the disease with research and institutional policy frames, as already happened with the other journalistic genres, and also, though to a lesser extent, with the topic of solidarity and the economy. As regards the figures obtained in the other opinion genres (editorials and letters to the editor), there are some differences in spite of involving low values. Solidarity and institutional policy get a higher frequency in letters to the editor, followed by the economic argument, while the most commonly repeated specific frames in the editorial format are research and the economic issue. Again there are few references to frames such as disability, transport, employment, integration, insulation or the Dependency Law, meaning that the same information patterns found in general frames are reproduced in the topics or specific frames.

4. READERS' PARTICIPATION IN ONLINE MEDIA

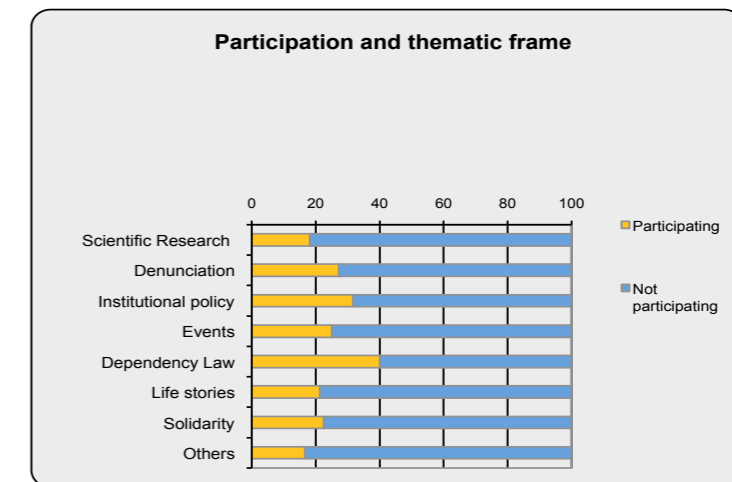
Participation is one of the salient features in the interactive communication of the so-called new media. It brings about a change in the reader's status, as the latter becomes an active user involved in the production of contents. The active role played is sustained by the capacities for communication with the people responsible for the content and with other users. The reader can get involved and have an influence on what is being disseminated, as never before. So far, nonetheless, the reality of the web does not tally with some of the Utopian principles of participation. Although the number of users connecting in better conditions is growing and the uses made of the web have diversified, only a low percentage of Internet users make use of the opportunities to participate and share resources, opinions and contents. In most online communities 90% of the users just have a look without getting involved, 9% contribute something and only 1 per cent really participate (Igarza, 2008:207). In all the insertions on RD recorded in online media, 21.8% make some comment. Considering that the users' participation may depend on the type of medium being consumed, depending on their interest in or knowledge of the matter in question, in this case RD, the statistical test gives a positive result, that is, a high association between participation and the type of medium can indeed be established: $\chi^2(38, N=2445)=610.826, P<0.0002$.

The readers of information on RD in the online versions of all the general media analysed (daily papers and magazines, national and regional, paid for and free) participate on 29.6% of the occasions in which they are given an opportunity to do so. If the digital editions of printed national media are taken separately, nevertheless, the percentage of participation reaches 31.57% in the case of paid for media and 48.2% for the free ones. The level of participation is seen to be directly associated with the audience rates. Hence the percentage of readers making comments in the specialised media drops sharply to 9.51%. Taking into account only the media specialising in medicine, disability or science, the figure drops further, to 8.59% of the readers of these media. The greater the specialisation, the lower the diffusion and the lower the participation.



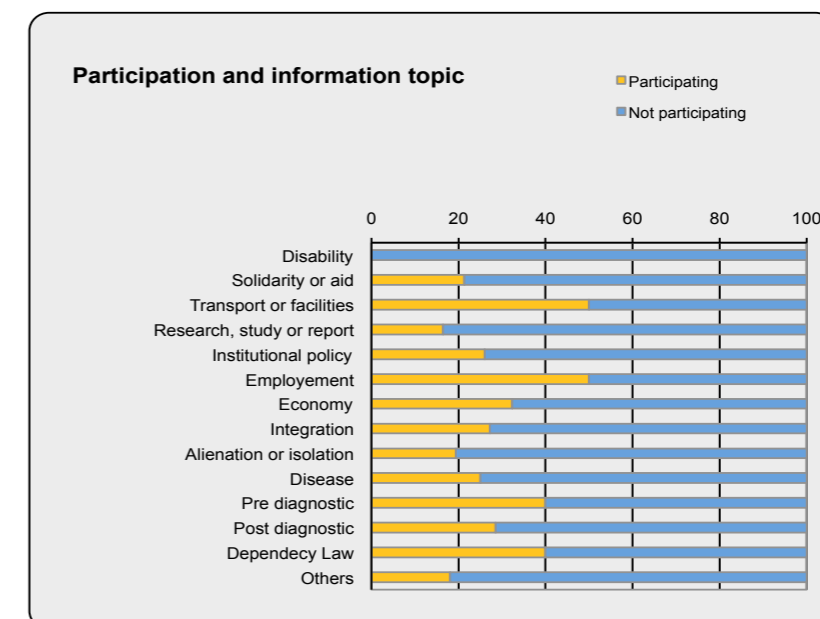
Graph 27

A minor relationship may be established between the participation and the topic of the text in view of the statistic [χ^2 (28, N= 2445) = 53.628, $P < 0.002$], while the dependence between participation and the thematic frame is fairly significant: [χ^2 (16, N= 2445) = 61.913, $P < 0.0002$]. The greatest participation takes place in themes alluding to the Dependency Law and Institutional Policy. In these information items the users comment on the insertions recorded in respectively 40 and 31.8% of the cases. This is followed by Denunciation or Demands for recognition with 27.2% of the information items in which there is participation. The frame which triggers off readers' comments least is that of Scientific Research and discoveries, with 18,2.



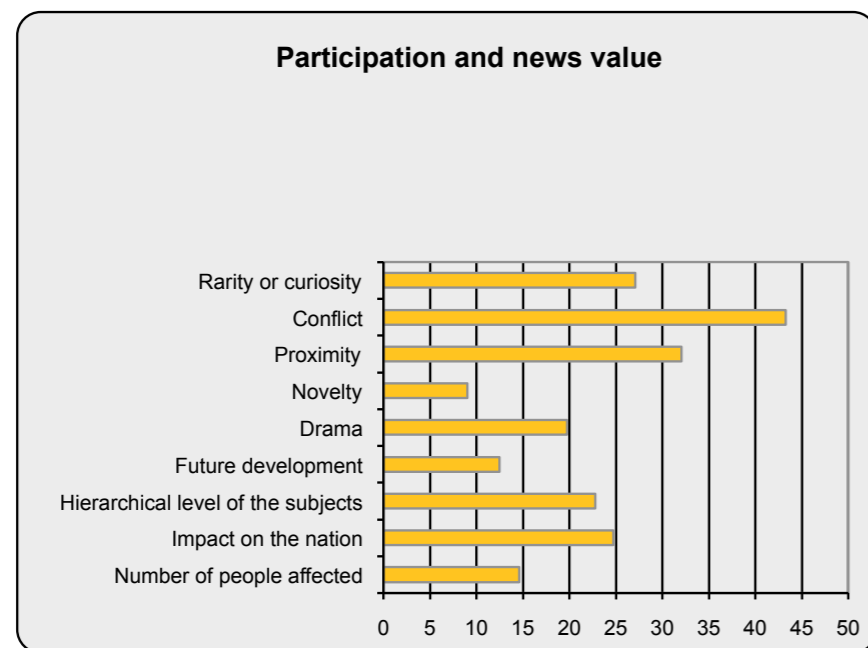
Graph 28

The information topics in which greatest participation is observed are Transport or adapted facilities and Employment. In both cases the user participates in 50% of the items. On the other hand, no-one makes remarks when the item deals with Disability. Over 25% of the participation is for the topics of Integration, Economy, Institutional Policy and the ones referring to Disease and Post-diagnosis. In the thematic field the readers' participation stands out in items dealing with Pre-Diagnosis, reaching 40, the same participation percentage in the items on the Dependency Law.



Graph 29

The significant relationship between readers' participation and news value is very prominent: $\chi^2(18, N=2445) = 113.439, P < 0,0007$. The news value which very particularly arouses readers' participation is conflict: in 43.3% of the items the user comments on the information. This is followed by proximity (32%). Novelty is the news value generating fewest comments from readers (9%).



Graph 30

6.

DIFFERENTIAL VALUES OF RARE DISEASES: DENUNCIATION, DEMAND FOR RECOGNITION AND DRAMA

Anunciación Ramírez e Inmaculada Rius
(Grupo GIDYC, Universidad CEU-Cardenal Herrera)

A major part of this piece of research involved considering the correlation that might be found between the authorship of the news items analysed with a specific thematic-textual frame; that is, with the theme of the news item, the news values that might be found in this and the topics which were referred to above. To what extent could an information agency, an anonymous signature –by our editing team– or the journalist's own direct authorship lead to a different frame? Is the medium aware of this? Is the reporter? In the literature concerning studies of Communication Sciences, it is taken for granted that collecting information is one of the characteristics associated with doing a journalist's work. The image of the active professional journalist, going out on the streets in search of the news of the day - the traditional reporter - has nevertheless been clearly minimised indeed, if not drastically cut down, as the information contents directly supplied by institutional sources and agencies and even public relations services have gained greater influence. Both of these have to a great extent been favoured by the convenience implied from the production standpoint, the minimum effort required for the medium to publish this. It has already been seen in previous chapters how agencies, and very particularly Europa Press, were able to monopolise a very important space among all the media analysed, either as a support or as a source. We have similarly shown how institutional sources became basic suppliers for the specific case of Rare Diseases. This entails the undisputed importance of press offices in a highly significant sense. The same thing occurs with the second of the major sources: experts, particularly when these are research centres. Why should press offices and agencies take on such importance in the specific case of RD? According to professors Armentia and Caminos, news agencies are at the present time seen as irreplaceable sources in the process of producing information (Armentia and Caminos, 2003:127-128). For these authors, the media's subordination to

the information agencies entails the uniformity of the messages; the newsworthiness (the media end up applying the newsworthiness criterion as a condition of the material available); and the information coverage or dependence on the selection of agencies in the choice of news which should be covered in person. But can this be applied to medical information, the sort most dealt with in the field that we are studying in this research? Can it be applied to information on RD? Yes and no, we could reply. Yes, insofar as the news item is connected with the finding, the discovery, progress or scientific improvement concerning the diagnosis, treatment or prevention of these pathologies. Yes again, when the day is the one assigned for the celebration of RD, complying with the newsworthiness characteristic. No, when the most important thing is the convenience of ready-made and supplied information, that is, without either the newsworthiness, or the homogeneity of the messages being of any account as basic criteria.

One of the matters that surprised us most was to see that use of the journalist's signature, most often, or that of the expert, most seldom, did not come to over a third of the total number of 2445 news items which we worked with. On this point Álex Grijelmo assures us that not all the news items published should be signed, adding that the matter of whether the journalist's name is stated or not will depend on how much they took part in drafting the item:

Simple reproductions of communiqués, press conferences, official statistics, announcements of events or reworkings of teletypes (in this last case of course the agency or agencies which have supplied them should be mentioned) should not be signed. But news items with some exclusiveness or staff's own work may indeed be signed. In any event, this will all depend on each newspaper's style guide and above all on the prestige that each professional may wish to give to their own name (2003:140-141).

Grijelmo's assertions in their own right bring up a contradiction which cannot be overlooked, by identifying at the start what the reporter should not do, to end up leaving it to the business criterion and the professional ethics of the person involved. With the exception of the professionals from the media who have been dealing with specialised information on RD and their thematic setting for years, a great majority of them are exposed to a volume of information going right over their heads. The topics, themes and protagonists of these diseases in the Spanish press in the 2009-2010 period were already observed and analysed. It is clear that if said period and sample for research constitute a pattern representing how our printed and digital media cover this information, press releases, press conferences, official statistics, announcements of events or

reworkings of teletypes are, as people say, their everyday fare, while news of some exclusiveness or their own work— to use Grijelmo's terms— constitutes the exception. The information fields that need specialisation, specific treatment, suffer from this phenomenon. One might only think, for example, of an information subject which is included in what is known as specialised journalism, for example science and research; then we go on to a second degree of precision: medical science or medical research, and then we can include a third degree of specificity: Rare Diseases. Now we could ask the question - how many journalists are prepared to inform about RD, with some exclusiveness or their own work? We know that the reader has immediately interpreted the reply to this, perhaps even before we put forward this simple, obvious riddle. Requiring the journalist's training to involve specialisation is a debate that was left behind in the 1990s, when the business demand designed an all-purpose professional profile, quite the opposite to specialisation. The company gives the orders – and do readers demand this? The present years of economic crisis, with the cutbacks in personnel – amongst other very important factors which are not dealt with in this book – have only speeded up the process.

Hence, in spite of the lukewarm advice of Álex Grijelmo, president of the Efe agency, and the quantification of signatures analysed by our research, the practice of not signing what has not been written because it comes from an agency is not strictly implemented. It was already mentioned that news items can multiply in different publications and leap all over the land with an information source –an agency in fact - and a signature that have nothing to do with the area. To go back to Grijelmo, we could deduce that drafting a news item by a professional from the publication reflects the importance that the medium attributes to the subject in the whole daily volume of information, though we should add that this is not always so. Some reporters' practice of attributing themselves agency information may be due to several factors: from the work of a freelance being paid per item, to the clear intention of becoming more strongly established in a journalistic theme, in this case medical-scientific (social) information, or even something as simple the popular adage: minimum effort with greatest returns.

Apart from this, as regards the permanent choice entailed by developing a daily information product from the material available, there is a list of criteria, known as news values, involved to a different extent in the final selection. For José Francisco Serrano, "news values are at the same time qualities of the event which lead it to be considered by the journalist as something singular, and practical rules in the preparation and se-

lection of reality. They have a balancing factor in their acceptance by the public, who assume the professionals' processes with discipline and share them, vouching for their effectiveness in the use and consumption of the medium" (Cantavella and Serrano, 2004:157). Again we have our doubts on this matter, when the subject or the event to be dealt with comes into the category of social journalism, where we do indeed include Rare Diseases. To some extent social events of a certain type are beginning to show that the journalist is sometimes limited with traditional news values. In the case of a news item of gender violence, or emigration, or disability, or patients with RD is there for instance a value category of social conscience, solidarity? Social journalism has in some of its facets that twin-edged blade which recovers the ethical importance of the profession, by helping, or – failing to help – transform a reality which needs the media as social mediators. Obviously, journalism manuals have not yet begun to handle this approach, which is usually (and not always) relegated to the style guides of the media or to the action of the groups involved themselves, drawing up their own recommendations and hoping that the media will take these into account. So, until now, the most outstanding news values are temporality (with its three aspects: novelty, timeliness and immediacy) and proximity (spatial or geographical, emotional and/or thematic). Both are factors which act with greatest intensity in the choice of news items³⁰. It has already been discovered that the first of these – novelty – but above all the second of the ones named here – proximity – was particularly powerful and that the media, above all regional media, very often acquired this as their main value. This has generated a very interesting effect. The associations which represent those affected by Rare Diseases and relatives have over time learned to appreciate these aspects of reporters' production routines. This has gone so far that their communication strategies, through a national federation, include the adaptation of the information note to each of the geographic areas of interest. This was observed in some of the news items analysed in our study. Hence, for example, if the information was about the number of patients suffering from Rare Diseases in Spain, for example, the press note with this information could be converted into as many notes as the number of autonomous communities represented in that federation of associations. The original message could thus be multiplied, in the most optimistic case, into at least 17 variants, for instance, as many as there are autonomous cities and communities in Spain. These would no longer be Spanish patients, but canarios, andaluces, valencianos, gallegos, murcianos... Proximity no doubt works,

³⁰ Other criteria are: exclusivity; interest (public and of the public); the service factor; exceptionality; generality (greater or lesser number of persons affected); circulation, consequences for the public; relevance of the actors; struggle between the parties; future development of the circumstances; models of daily papers; quality of the story; overall balance of the information; and the reciprocal expectations

since this acquires the public's interest immediately and it makes the news multiply as it is disseminated, creating the information echo communication effect, where the sounding board is the medium.

As regards interest (both public interest and the interest of the public) as a news value, RD develop the first meaning –public interest– and stress the medical and scientific importance, as well as its possible successes and shortcomings, also the fact already mentioned that in 80% of the cases RD have a genetic origin. This makes a direct hit on the sore point and brings up relevant questions: the need to provide greater financing for research and to consider health policies which avoid the repercussions that this genetic origin causes in the medium and long term. As for the second meaning –something which may be of interest to the general public– the media's approach sometimes consists in stressing the extraordinariness, the curious aspect of such diseases.

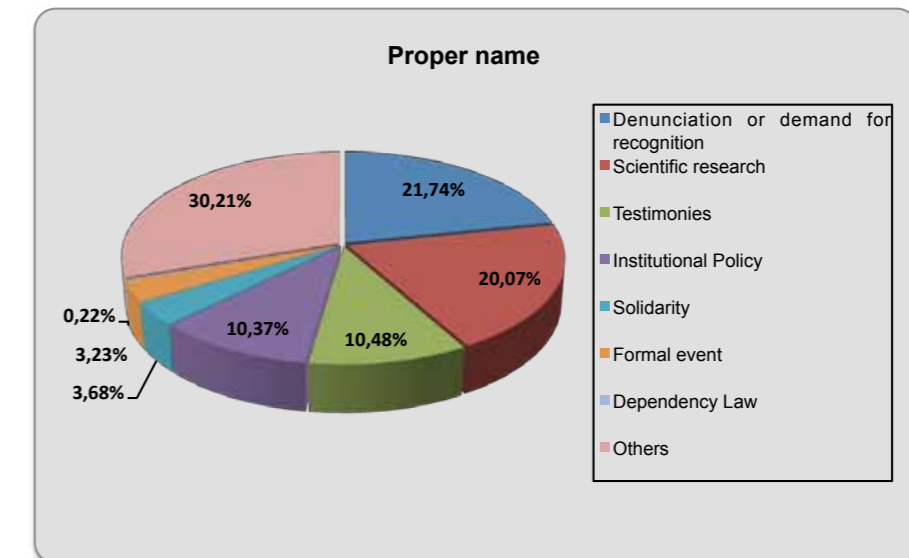
The persons affected by RD furthermore struggle in their media representation – as in their everyday lives – with the information selection criterion known as generality. This factor refers to the larger or smaller number of persons affected and thus to the consequent interest for a larger or smaller number of readers in the case of the press. If RD are low prevalence conditions, the stress should be placed on the fact that this is no reason why they should cease to be relevant - to make this point once again, they are relevant because the percentage of RD with a genetic origin is very high. Their communication strategies need to be based on other selection criteria attracting reporters: the already mentioned proximity, exceptionality, the celebrity status of the people involved, etc. If generality implied a handicap, exceptionality makes up for this: it is the best press value of RD, in short, their very essence, though it sometimes proves a high price to pay, because sensationalism tends to find itself dangerously at ease in the realm of the exceptional. As for the celebrity of the actors in this information, we can similarly see that the groups representing RD patients and their relatives have also noticed its importance. Footballers, television hosts, singers ... are invited to take part in awareness-raising and solidarity activities. The main drawback with all this is making sure that the personality does not devour the subject of the information, which is a fairly complex matter in most cases. The intention is to stress the RD, and the journalist only has eyes for the celebrity. Other interesting actors in information are political representatives. Although the subject will be dealt with more extensively and thoroughly in the second part of this book, we cannot avoid pointing out the odd kind of boxing match fought between two contenders. In one corner, people who are interested in conveying their message about

these pathologies in respect of the improvement, treatment, quality of life of the sick, development and research ... and making all this heard by their political representatives; in the other, these representatives, who very often utter words with more propaganda than reality in them. In any event, the important status of the political actor attracts the press and will thus be chosen as a receiver of the messages claiming attention as a media instrument. Proximity, exceptionality, celebrity of the protagonists... but also demands for recognition, denunciation and what the Anglo Saxons define as news items of human interest, known in Spain as life stories.

1. DENUNCIATION OR DEMAND FOR RECOGNITION AND LIFE STORIES, WITH PROPER NAMES

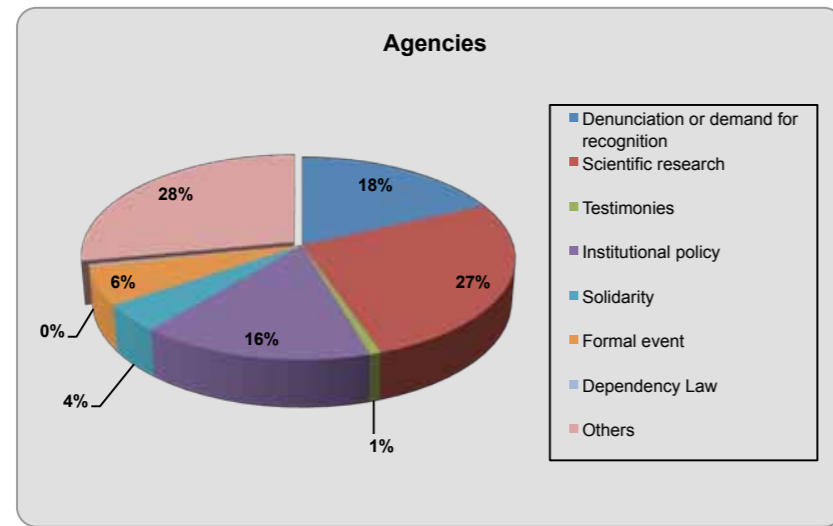
This chapter begins with a discussion of our interest in interrelating diverse hypotheses such as the authorship of the information analysed and the thematic-textual frame, that is, with the theme of the information item, the news values that may arise in this and the topics. The confluence between the variables "Authorship" and "Theme of the text" reflects that there is a significant relation between these: $[X^2(40, N = 2445) = 256,007, P < 0002]$. The news items signed with a proper name make up 36.97 % of the total. This authorship predominates in almost all the thematic categories established for analysis of the news forming the sample of written and digital media studied. The information signed by agencies in the block of news with the theme of Institutional Policy takes second place, with 93 entries as compared with 103; and in the Formal event, Commemoration or Celebration theme, with 29 hits as opposed to 41.

Denunciation or Demand for Recognition is the theme agglutinating the greatest number of entries signed with a proper name (195). This is followed by Scientific Research or Discovery (180); Personal Testimonies and Life Stories (94); and Institutional Policy (93). At a great distance from these come the news items which have a thematic nexus of Solidarity (33); Formal event, Commemoration or Celebration (29); and the Dependency Law, with 2 hits.

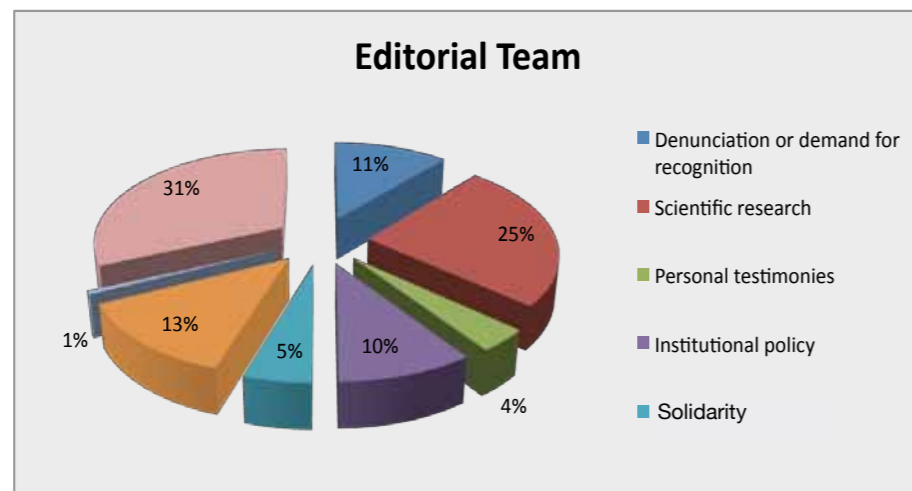


Graph 31

News items signed by agencies make up 27 % of the total sample covered by the study. The importance of their work is connected, as we have already stated, with research, denunciation and politics and official events of all kinds: Scientific Research or Discovery (175); Denunciation or Demand for Recognition (119); Institutional Policy (103). Coming below these values one can find the Formal event, Commemoration or Celebration, with 41; Solidarity (29); Personal Testimonies and Life Stories (5) and the Dependency Law (2). It would seem so far that both agencies and newspaper journalists can be said to specialise in the press field of Rare Diseases, in the scientific and institutional field, but that the differences between them lie in the fact that the agencies add formal events to their field of interest, while journalists stress life stories and testimonies more than these. The most interesting part of it all is the transversal interpretation that can be made of the data. If the source of the information is considered, research centres and individuals connected with relevant social and political institutions could be said to seek either agencies or publications to disseminate their messages. On the other hand, rank and file citizens, people affected, either contact or are contacted by journalists from printed or digital publications to a greater extent.

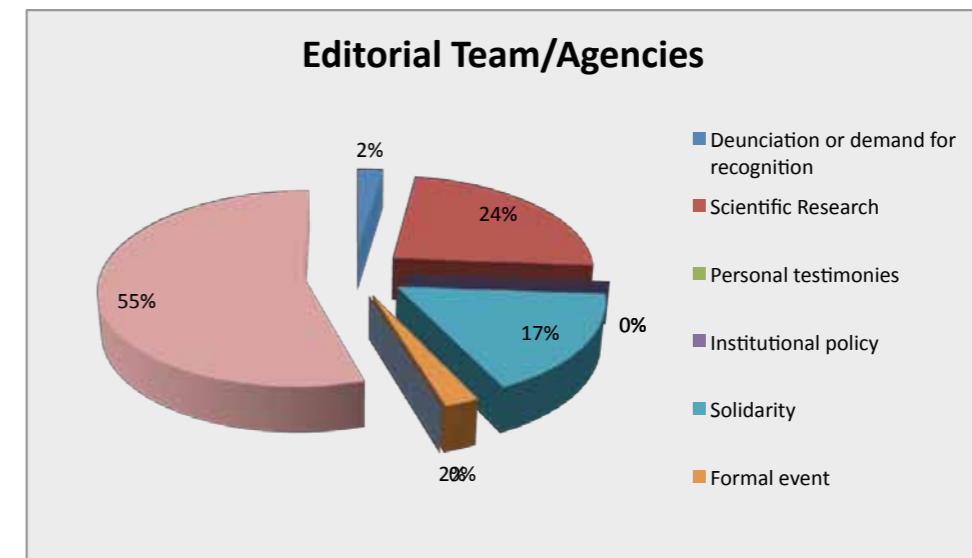


Graph 32



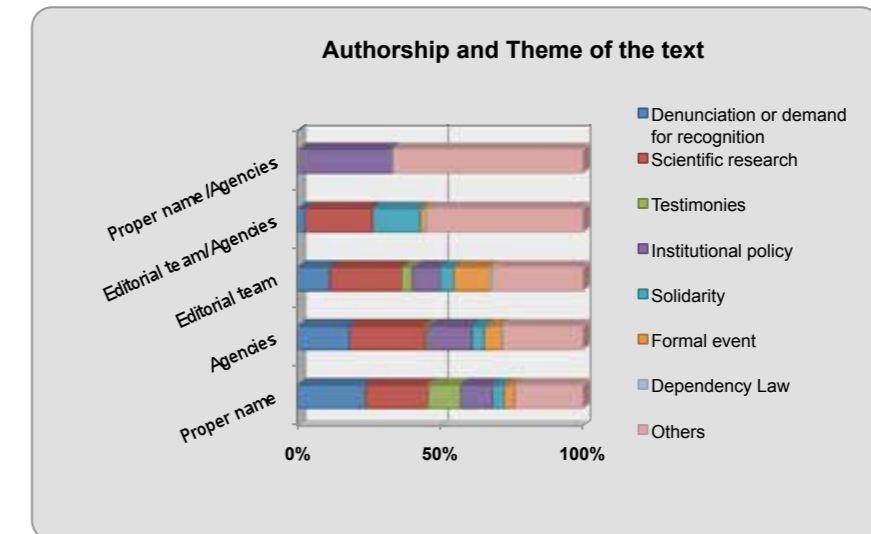
Graph 33

A long way from the previous two, the editorial team is the authorship representing 7.6 % of the total number of information items analysed. The prevalent theme in the information signed by the editorial team is Scientific Research or Discovery, with 46 hits. This is followed by the Formal event, Commemoration or Celebration, with 24; Denunciation or Demand for recognition (21); Institutional Policy (18); Solidarity (9); Personal Testimonies and Life Stories (7); and the Dependency Law (1). With a share of under 2 %, the prevalent themes in information items signed jointly by editorial teams and agencies are Scientific Research or Discovery, with 10 hits, and Solidarity, with 7. Denunciation or Demand for Recognition and Formal Event, Commemoration or Celebration have one hit.



Graph 34

There are only 3 information items signed jointly by proper names/agencies, representing 0.122 % of the total.



Graph 35

These second results, which the graphs help to explain more clearly, display a predisposition to several issues which can be added to the ones listed above:

1. A trend to assign themselves thematic areas, as was seen by the agencies and journalists signing items.

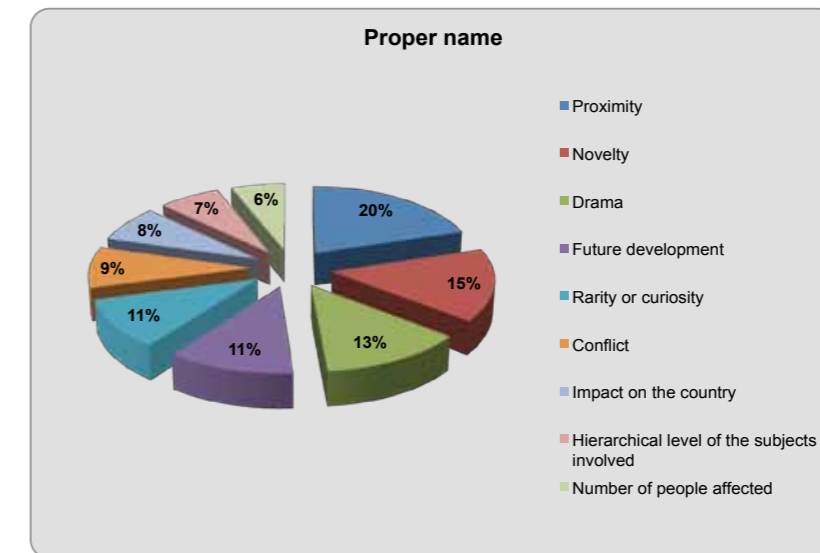
2. A low prevalence of information items with no signature, from our editorial team or editors, or those with co-participation in the authorship (agency and editing office, journalist and agency, etc).
3. A slight predominance of authors signing the news, followed closely by the agencies, from whom they occasionally appropriate these items, as stated above.

2. THE ODD AND THE DRAMATIC ASPECT AS A DIFFERENTIAL VALUE

The intersection between the variables “Authorship” and “News Value” shows that there is also a significant relationship between these: $\chi^2(45, N = 2445) = 209,667, P < 0.0004$. Proximity and novelty, as mentioned, are two values which stay in the top positions on the table in the different authorships established, except for the block of news items signed by editorial staff, in which proximity comes precisely at the bottom of the list. Emphasis should also be given to the significant role of drama in the information items signed with a proper name (only behind proximity and novelty) and that of rarity/oddity or curiosity in texts signed by agencies. In this last case they even come above the proximity value.

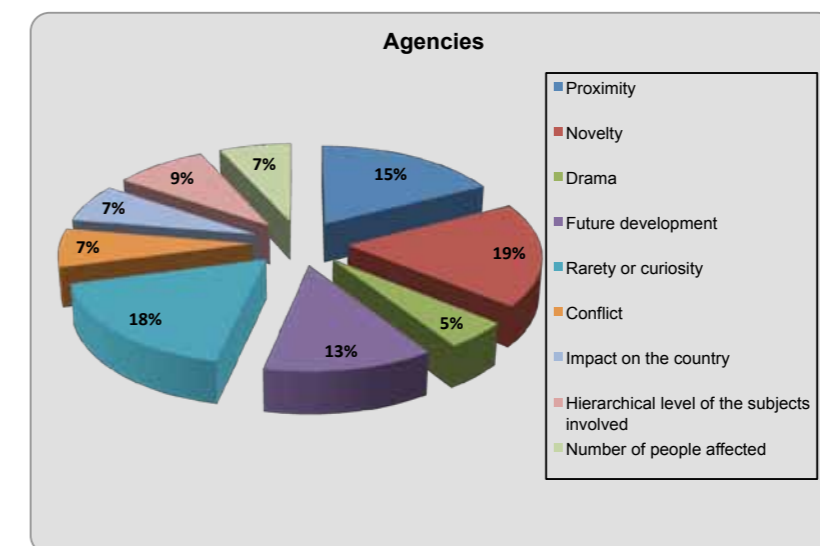
The proper name is the predominating authorship in all the news values established for the examination of the sample, with the sole exception of rarity/oddity or curiosity, a category in which the agencies get a higher number of hits (118).

In the information items signed with a proper name, the prevalent news value is Proximity, with 173 hits. This is followed by Novelty (133); Drama (113); Future Development (99) and Rarity/Oddity or Curiosity (91). Behind these lies Conflict, with 75 hits; Impact on the country, with 66; the Hierarchical Level of the subjects involved (59); and Number of persons affected (51).



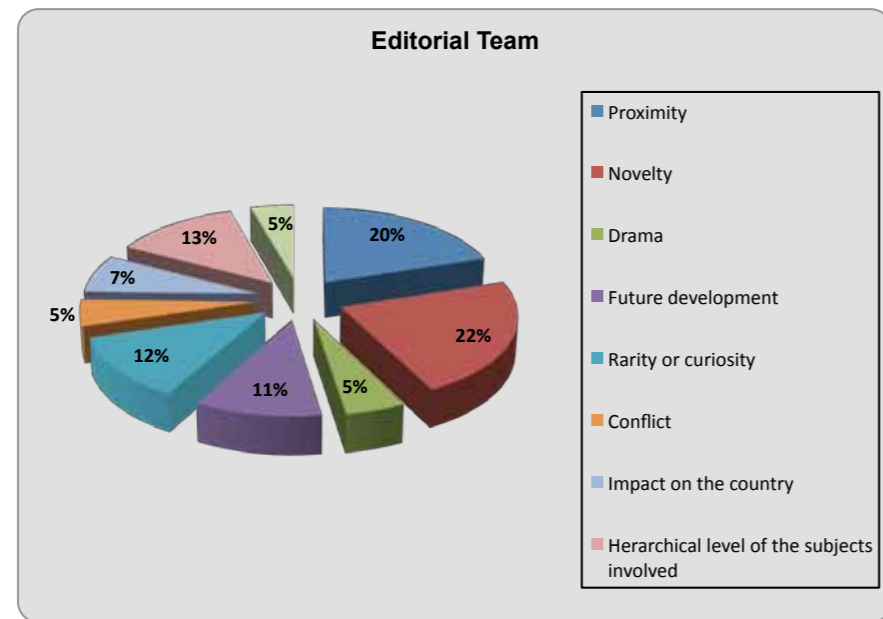
Graph 36

The news value obtaining the greatest number of entries in the information items signed by agencies is Novelty, with 121 records. With 27 % of the total, this constitutes the second predominant authorship in the sample covered by the study. Rarity/oddity or curiosity lies in second place, with 118; Proximity in the third, with 97; and Future development in fourth position, with 82 annotations. Below this one can find the Hierarchical Level of the subjects involved (57); Conflict (47); Impact on the country (46); Number of persons affected (43); and Drama (29).

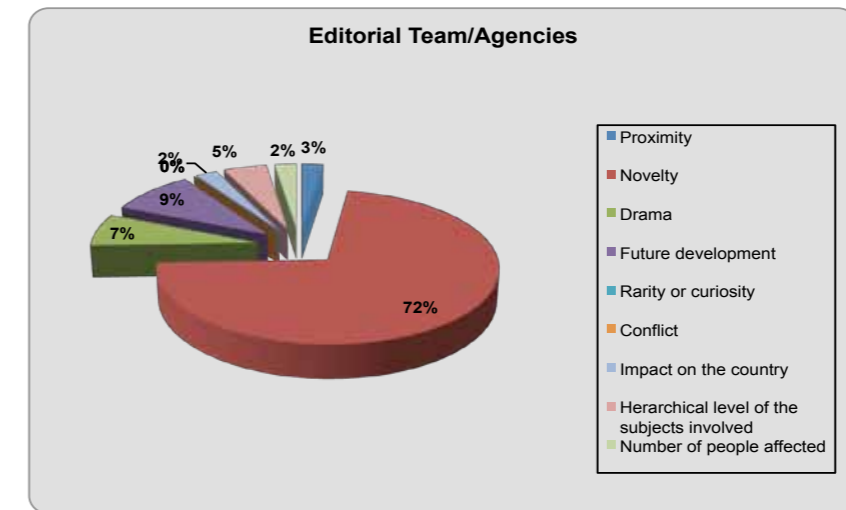


Graph 37

If the data given above is given some consideration, both agencies and newspaper journalists are comparatively seen to view proximity and novelty as a news value in the context of RD. For news items signed by editors of printed and digital media, drama also turns out to be of great importance: sick people, close to you, to the place where you live; and lastly novelty. This may refer both to the unknown aspect of the information and to the (medical –scientific) finding, though here this is taken to involve the second element, since ignorance of RD would be subject to the rarity value. This constitutes the second difference between agency and newspaper journalists of written and digital media, as it is highly important for the former and lies outside the interest of the latter. Another of the questions which calls one’s attention is the lower value for both; at agencies and as regards newspaper journalists, where drama, the life or human interest story is not a top selection value. In the information signed by the editorial team, the prevalent news values are Novelty, with 40 entries, and Proximity, with 36. These are followed by the Hierarchical Level of the subjects involved (23); Rarity/Oddity or curiosity (22); Future Development (19); and Impact on the country (13). The block is closed by Drama and Conflict, with 9 hits each, and Number of persons affected, with 8.



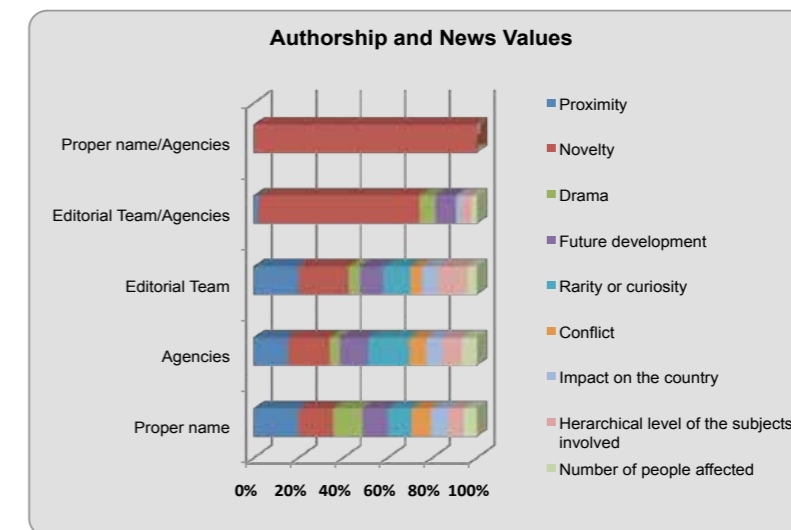
Graph 38



Graph 39

In the group of news items jointly signed by editorial offices and agencies, which represents 1.75 % of the total, the outstanding news value is Novelty, with 31 hits. Very far behind this there is Future Development (4); Drama (3); Hierarchical Level of the subjects involved (2); and Number of persons affected, Impact on the country and Proximity, with one hit each. None of the news items with this authorship has Conflict or Rarity/Oddity or curiosity as news value.

Finally, Novelty is the news value in the three information items jointly signed by proper name and agencies.



Graph 40

3. THE SAME TOPICS IN DIFFERENT PLACES

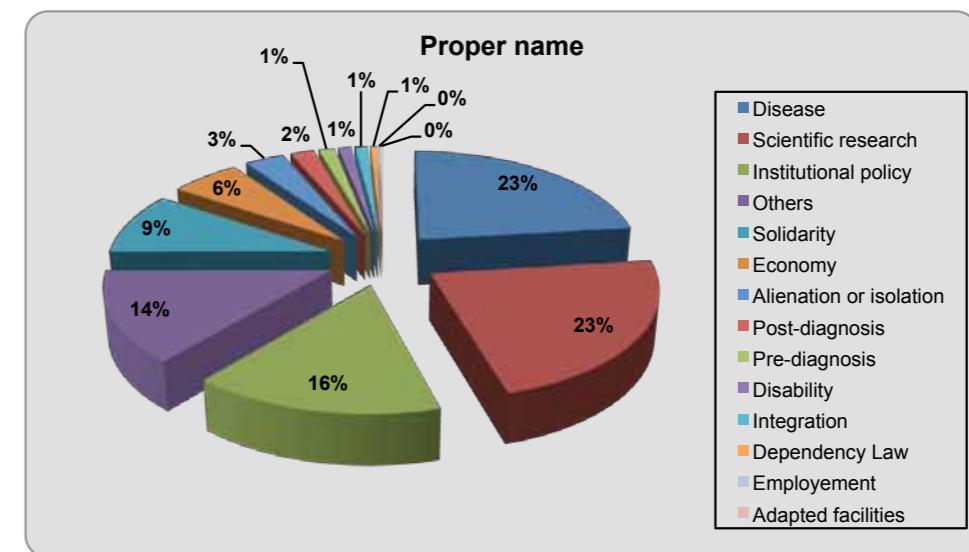
The relationship between the variables “Authorship” and “Topic of the text” shows that there is a significant bond between these: [$\chi^2(70, N = 2445) = 198, 225, P < 0003$].

As a whole, disease, research, either study or report, institutional policy, solidarity or aid, economy and alienation or isolation are the thematic topics which monopolise – with some variations in their order – the top places on the list in practically all the authorships established. In this section the scant presence of the Dependency Law is also evident, as a topic prevalent in only five information items signed with a proper name and in three by agencies. The data will be given straightaway, but some interesting conclusions can already be pointed out. The main thematic niches of Rare Diseases are plain and as expected: disease, research, institutional policy, solidarity and economy. The interesting point is that the information emerging from affected persons, relatives and associations is reaching the media loud and clear, or at least the media have typified information items in thematic groups of interest for these people. The topic of RD is thus quite understandably disease, but in direct connection with research into these pathologies, with a high component of involvement (either real, as propaganda, solidarity or in any other form) of institutional representatives (politicians, associations, sports or of other kinds of bodies,...). The call for solidarity takes fourth position, in this succession of themes where the World RD Day and the association work already noted have a lot to contribute. Economic issues, including a wide range of questions from the request for aid for those affected, demands for budgets for research by experts to requests for specialised institutions, training of doctors, and so on, are connected with all of this.

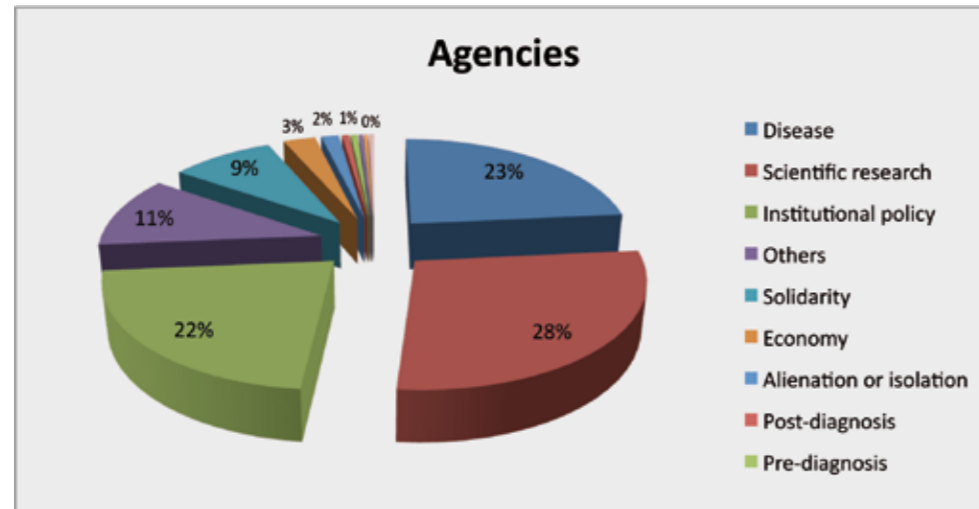
The data itself is now given: proper name is the predominating authorship in almost all the topics of the text established for study in the sample analysed. This is only exceeded by agencies in Institutional Policy, with 140 entries as opposed to 145; and in Transport or Adapted Facilities, with 1 entry as opposed to 3. The topics of the text which are most often repeated in the information items signed with a proper name are Disease (208) and Research, either study or report (203). Institutional Policy already mentioned is the topic stressed in 140 news items; Solidarity or aid agglutinates 85 entries; Economy, 53; and Alienation or Isolation, 30. With under twenty entries there are Post-diagnosis (18); Pre-diagnosis (12); Disability (10); Integration (10); Dependency Law (5); Employment (2); and Transport or Adapted Facilities (1).

The specific topics for which the greatest number of entries are found in the information items signed by agencies are Research, either study or report, with 184 entries; Diseases, with 154; and Institutional Policy, with 145. These are followed by the generic item Others, with 72 hits, and Solidarity or aid, with 58. Some distance from these are Economy (18); Alienation or isolation (10); Post-diagnosis and Pre-diagnosis, with 4 each; Transport or Adapted Facilities (3); and Disability and the Dependency Law, with two entries each.

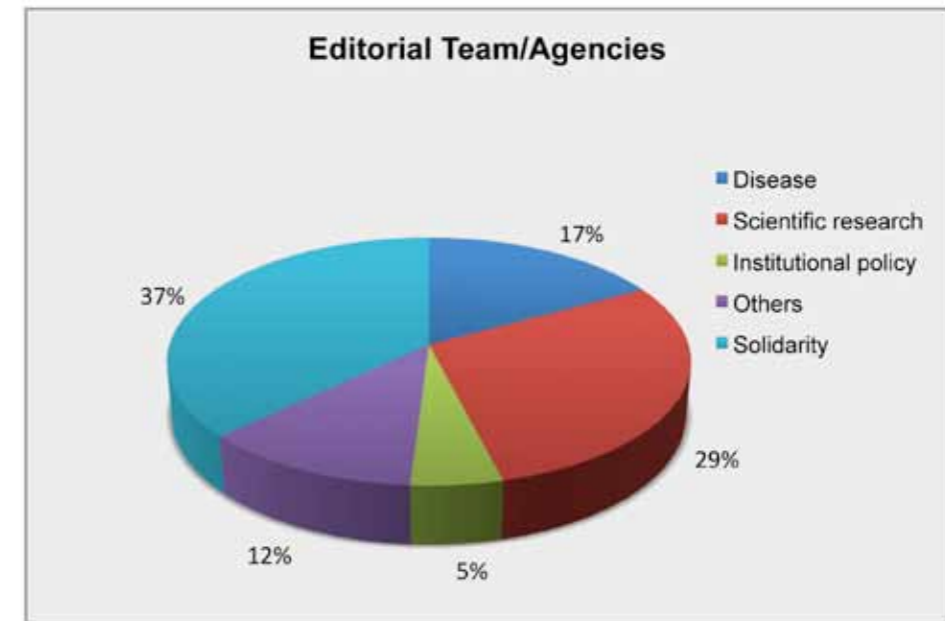
In the block of news items signed by the editorial team, the prevalent specific topics are Research, either study or report, with 51 entries; Institutional Policy, with 40; the generic category Others, with 35; and Diseases and Solidarity or aid, with 23 hits each. A long way off from these are the Economy (6); Alienation or isolation (2); Pre-diagnosis (2); and Transport and adapted facilities, Employment, Integration and Post-diagnosis, with 1 entry each.



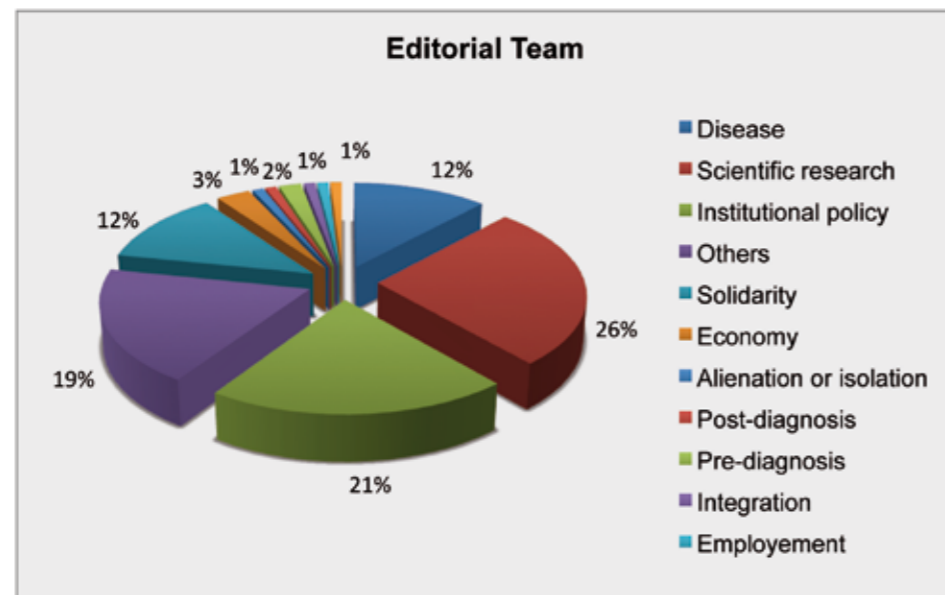
Graph 41



Graph 42

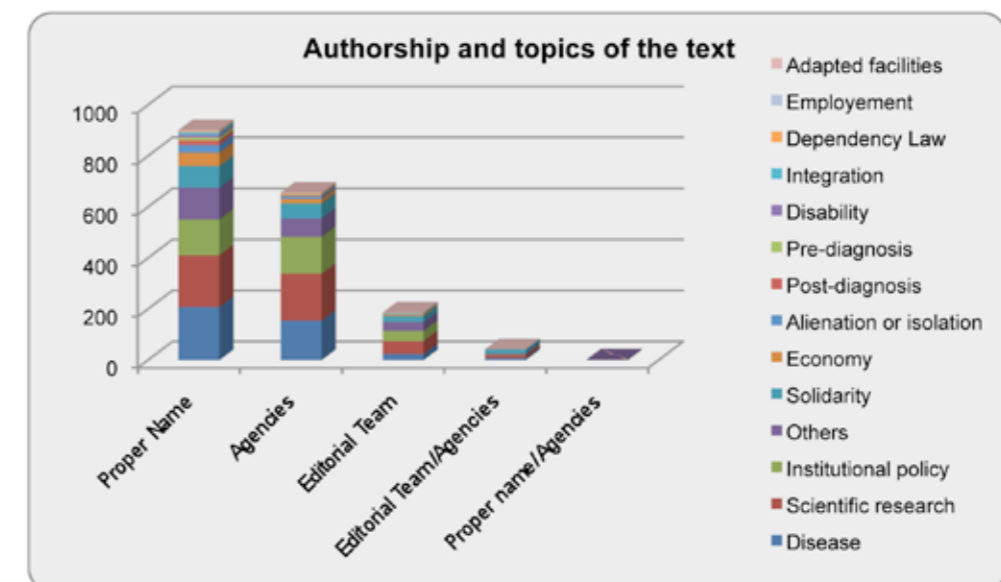


Graph 44



Graph 43

One of the three information items signed jointly by proper name/agencies presents Institutional Policy and 2, the general category Others, as specific topics.



Graph 45

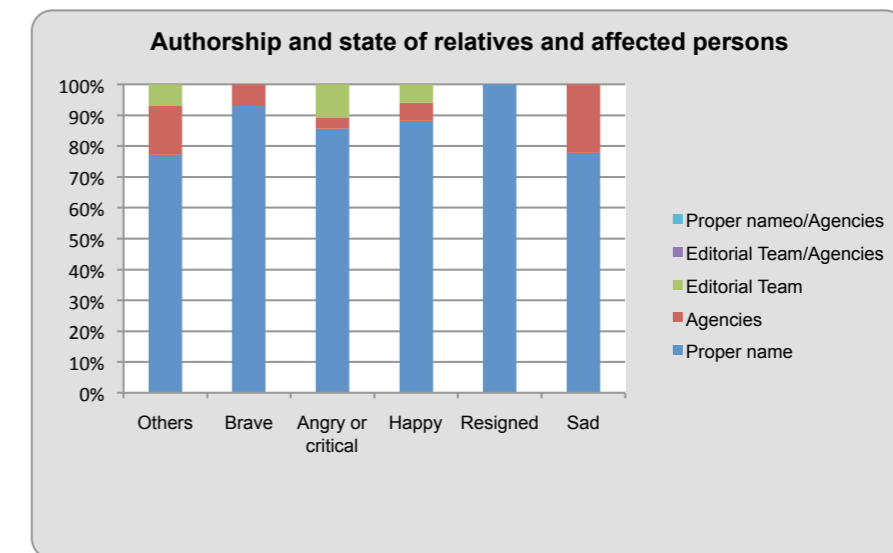
In the news items signed jointly by editorial team/agencies, the predominant specific topic is Solidarity or aid, with 15 entries, followed by Research, either study or report, (12). Behind these come Disease (7) and Institutional Policy (2).

4. RELATIVES: FROM BRAVERY TO ANGER

In Social Journalism, which is understood as preparing news from a standpoint of defending social values in all areas of life, news professionals must break away from what is known as friendly journalism. Their work instead consists of quite the opposite, and involves defining a central social theme to be acted on, and making all current events, wherever they come from, revolve around this (Servimedia, 2007:31). “Another aspect of the matter implies the need to act as a megaphone for the sectors of society in general and of citizens in particular who are seen as journalism as an ally to express issues which are taken into account less often than might be desirable. This includes people with disability, minors, the immigrant population and such values as solidarity, cooperation and peace, amongst others” (Servimedia, 2007:32). In the specific theme of Rare Diseases and their reflection in the media, the relatives of affected persons act as their voices in a good deal of the cases. It was already observed for instance, that people signing letters to the editor, to give one case, were relatives with a single exception. Unlike other groups, the names of associations representing these patients include relatives, in most cases. Patient, relative and disease (RD) are inseparable, particularly when the protagonists are minors, but not only in this case, because children and spouses of those affected also get involved. This is the reason why we were interested in observing the way in which Spanish printed and digital media portrayed these relatives: Did they appear in the news items, in photos? To what extent? Did they interact with the media? How were they depicted? How did they portray themselves? Some of these questions were answered already in earlier chapters. It is now time to make a further query: To what extent does authorship have an influence on the way and the state in which the relatives of people affected by RD are presented? To what extent is this done as a reflection of both the way they face up to the situation and the way their presence is materialised in the news items in which they appear?

The interrelationship between the variables “Authorship” and the state in which the relatives of people affected by RD are presented is highly significant: $[X^2(30, N = 2445) = 104, 265, P < 0003]$. The information items signed with a proper name take first place by far in the count of all the categories established for analysing how the relatives of affected persons are presented in the news items forming the sample. The predominant state in the news items with this authorship is Brave, with 27 entries. This is followed by Angry or Critical, with 24; Happy, with 15; Resigned, with 12; and Sad, with 7. In the information items signed with agencies, the states repeated most often are Sad and Brave, with

2 hits each; Angry or Critical and Happy, both with one entry each. In the news items which have Editorial Team as authors, Angry or Critical gets 3 hits and Happy, 1 out of all the condition categories.



Graph 46

5. ON JOURNALISTIC GENRES AND THEMES

5.1. THE REPORT: THE GENRE FOR LIFE STORIES

The conception of newspaper genres as systems of rules facilitating communication between the emitter and the receiver implies, according to José Ignacio Armentia and José María Caminos, that these are not determined by the themes, but by the type of rules that are used for establishing the relationship with the public (2003:16-17). Is this the case when Rare Diseases make their appearance in Spanish written media?

To answer this question it was decided to observe the existence or non-existence of a connection between the predominating themes in each of the information items analysed and the journalistic genre used by the medium for spreading the message.

The study of the relationship existing between the variables “Genre of the item” and “Theme of the text” shows that a clearly significant bond is established between these: $[X^2$

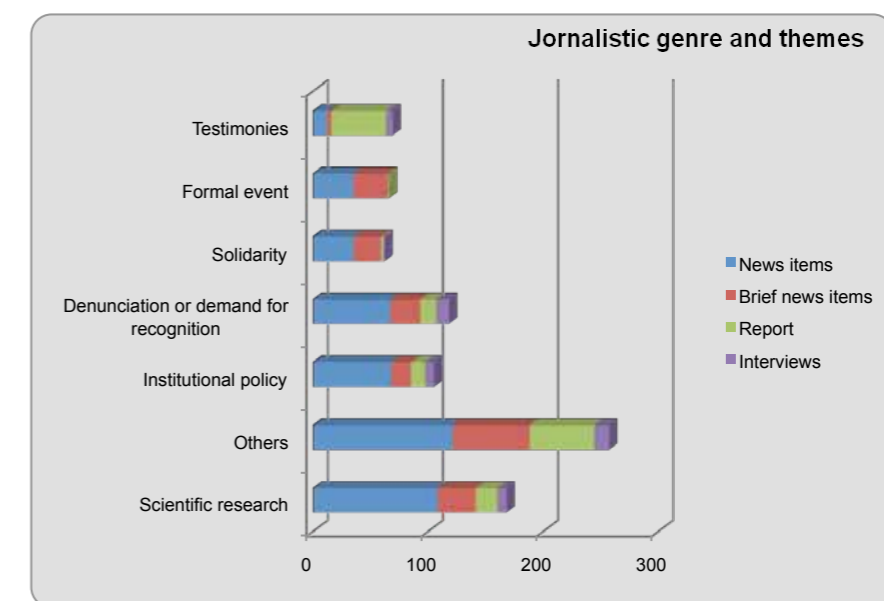
(56, N = 2445) = 361, 188, P<0003]. No further mention will be given to the identification of genres and themes, which was already dealt with in sufficient depth in preceding chapters, and which the graphs shown below give a reminder of. In the relationship established between the genre of the item and the theme of the text of each of the information items analysed, the news item is the predominant genre in almost all the themes which we established, with the sole exception of the Personal Testimonies or Life Stories category, in which the genre par excellence is the report. The data is given below, to then go on to the arguments involved.

Of all the themes, Research or Discovery, with 108 entries, is the one with the greatest number of items covered in the news genre. This is followed by Institutional Policy (68); and Denunciation or Demand for Recognition (67). At some distance from these in this genre there are Solidarity and the Formal event or Celebration, with 35 each; and Personal Testimonies and life stories, with 12. Apart from this, the outstanding theme in the brief items is Scientific Research or Discovery (33); Formal event, Commemoration or Celebration (30); Denunciation or Demand for Recognition (26); and Solidarity (24). Behind this are Institutional Policy, with 17 entries, and Personal Testimonies or Life Stories, with 4. The report is the favourite for the information items which have the thematic nexus of Personal Testimonies or Life Stories, coming to a total of 47. This is quite understandable, through the concept of the report as a journalistic narration of some length, drafted in a highly personal literary style, setting out to explain how certain recent events have developed, although the latter are not news in the strict sense of the word (Martínez Albertos, 1983:314).

Personal Testimonies or Life Stories are followed by Scientific Research or Discovery (19); Denunciation or Demand for Recognition (14); and Institutional Policy (12). Far behind this comes Solidarity, with 2 entries, and Formal event, Commemoration or Celebration, with 1 hit.

It should lastly be stated that the prominent theme in the interviews category is Denunciation or Demand for Recognition (11), followed by Scientific Research or Discovery (8) and Institutional Policy (8). Personal Testimonies or Life Stories are the central theme on 6 occasions and Solidarity, in one of the interviews. The predominance of denunciation or demand for recognition ties in with the forceful sensation of a face to face encounter between the reader and the person involved in the press interview. As professor Begoña Echevarría points out, “the interview creates the sensation of being close to the source,

and seeks to create the feeling of a “live” encounter for the reader. Writing an interview is thus also a matter of construing signs and details, of looking for fragments, of attributing meanings (Echevarría, 2002:6). This feature is also stressed to the same end by José María Sanmartí, for whom the advantage of the interview is “the audience’s possibility of reading, hearing or seeing the information directly from the source. The journalist gets the person interviewed in touch with the audience in a lengthy and sufficiently complete way. It is the person interviewed him or herself who comes forward as the protagonist, while the editor drops into the background, diluting the intermediary role” (2004:355). RD do not have the privilege of the interview on many occasions, as was already seen, so this face-to-face immediacy is lost. In any case, this will not be further analysed now, simply wishing to observe which journalistic genre prefers each of the subjects assigned in the media to these diseases. The following graphs will display this:



Graph 47

Some comments on the data seen so far could now be provided. Research is the most versatile theme, insofar as it fits in each and all of the journalistic genres of our study sample. This is highly positive insofar as scientific research is a journalistic ally for RD, a foot in the door to the media and thus to people who know nothing about these pathologies. The same thing could be said about denunciation or demand for recognition, which

is assigned some space in the following section in a genre which is not very conspicuous for RD - opinion. Another of the prominent issues is the fact that information of all kinds stemming from institutional policy or which has this as its central core is not representative in the brief news items. This to a large extent reveals the work done by press offices in fitting this field to the news genre, in particular, and to interviews in second place. It is even surprising that they should manage to creep just a little into reports, in which life stories, demand for recognition and denunciation or medical research find themselves at ease.

The last surprising piece of data from the study in the hypotheses now being put forward is about Solidarity. This always appears among the least relevant frequency values in each and all of the genres registered, when both the news item or the report or interview would be its natural information niche. Life stories have greater scope in the report than in interviews, and this can also be stressed as positive because the coverage space is greater in the report, often including short interviews and contributions of others involved in RD, thus meaning more complete and detailed information can be given.

5.2. DENUNCIATION OR DEMAND FOR RECOGNITION, A MAIN ELEMENT IN OPINION GENRES

Journalism is a method of successive interpretation of social reality, as Emy Armañanzas and Javier Díaz Noci see it, and for them:

(...) informing is the result of an interpretation process which essentially consists in narrating what has occurred, understanding this, valuing it and expressing it [...]. In the opinion genre, either as a spokesperson of a publication (the editorial) or as a specific author (signed article) the point is to find the meaning of certain facts; the intention is to understand these as in interpretation but, while the latter gives meaning to the news but refrains from saying what is to be done, the function of expressing an opinion or the editorialist role seek to influence the reader with recommendations and advice on the course of action to be taken. (Armañanzas and Díaz, 1996:61).

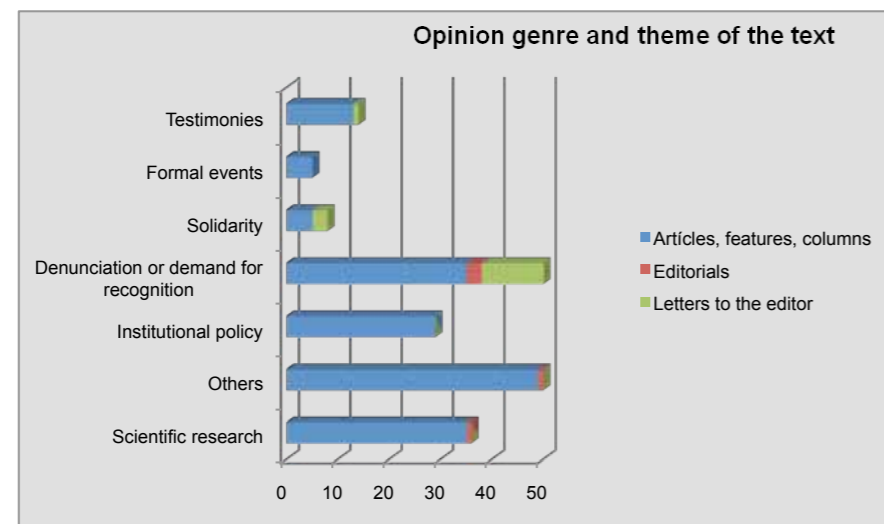
In this respect, Armañanzas and Díaz Noci stress the mobilising intention of editorials and their potential function as unofficial supervisors of what is going on in society. Editorials make judgments, adopting a role of informal guardians of the public conscience. That is, they provide value judgments on what the publication considers is right and what is wrong” (1996:95). It is thus known that media opinion can lead people, have an influence

on their positions, values and attitude. But not everything is selected as a subject of opinion or of the master of all opinion genres: the editorial. For Martínez Albertos, the editorial meant “taking a stance on a subject discussed about which different attitudes and public opinions are expressed”. The least that could be required of this was for it to shed “light and clarity on that stance taken by the newspaper and for the reader to glean without too much effort what position is favoured by the newspaper” (Martínez Albertos, 1983:386). From this point of view, the editorial dimension assigned by the medium to a particular subject is connected with an event of greater or lesser current interest or relevance, understanding the latter to be an underlying issue in social life. The same thing can be said as regards readers’ letters, for although they imply recognising the right to express a particular opinion, it is likewise true that the ones which are finally published are those that survive intense filtration by the medium, as regards different aspects and valuations (Martínez Albertos, 1983:165).

Hence, following the traditional canons of journalism reflected by the no less traditional works of Armañanzas, Noci and Martínez Albertos what chance do Rare Diseases have of becoming the subject of the day’s editorial and how many readers’ letters with RD as their subjects will get through the media’s intensive filtration until they become a published letter to the editor? The question was getting increasingly involved, so it seemed better to ask what subjects connected with these pathologies are the predominant sort in the argumentative and opinion genres.

In our research the themes that stood out in the items considered within the category of articles and columns are Scientific Research or Discovery and Denunciation or Demand for Recognition, with 35 hits each; Institutional Policy (29); and Personal Testimonies or Life Stories (13). Solidarity and Formal event, Commemoration or Celebration are each the thematic cores of 5 articles, chronicles or columns.

The predominant theme in the few editorials found is Denunciation or Demand for Recognition, with 3 hits. With one entry each, Scientific Research or Discovery and Institutional Policy lie behind these. In the same way as for editorials, and even more prominently, the main theme found in the letters to the editor is focussed on Denunciation or Demand for Recognition, as was explained above, with a dozen entries. The hits found in this genre are completed with the 3 for Solidarity and a further one in the section of Personal Testimonies or Life Stories.



Graph 48

Opinion continues to be a peak not conquered by RD in Spanish written media. It similarly reveals the level of importance that these media assign RD among the main news and events of all kind taking place every day. The fact that they do not even manage to get onto the sought-after column on the second page on World RD Day reflects the lack of social awareness of these pathologies. We have come a long way since RD sufferers first got organised in associations and later on took the step towards federated associati-onism, thus acquiring nationwide status for their social representation. This brought up two issues to be solved: the challenges which were arising (social, political, medical ...) and the strategies to attempt to deal with these (social, political, medical...) where the media took on a relevant role. The following phase would thus see their expectations set on gain-ing a foothold in the media and after getting that far, generating attitudes of awareness and solidarity, also political and social. The quantitative results of the research forming part of this book have provided an x-ray of the existing achievements and shortcomings, one of these being the real awareness-raising of the media as opinion genres, an issue not yet resolved.

Even so, we were able to observe that RD made themselves a niche in the press at least as regards news impacts and, as occurs with so many other issues in so-called social jo-urnalism, precisely the press, with all its successes and errors, is possibly the only medium which at least gives them some standing room. New challenges and new strategies are no doubt coming forward in the immediate future panorama of the Rare Diseases in social communication media.

7.

THE DISCURSIVE REPRESENTATION OF RARE DISEASES AND THOSE AFFECTED: NAMES AND FIGURES

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(Grupo ECCO. Universidad de Almería)

1. ON THE TERMS USED

As Francesc Palau has pointed out in some of his public appearances, the term 'rare disea-ses' "was coined twenty-five years ago to agglutinate such uncommonly found diseases as cystic fibrosis, muscular dystrophy, Huntington's disease or the Asperger syndrome" (DIA, 09.03.10). In spite of the time that has gone by, it could be said, as mentioned in Chapter 1, that minority diseases continue to be at least partly a new topic for the media. In any event this term can be seen as becoming well-established in sociomedical information in Spain. Its constant presence in the headlines is good proof of this: «What are rare diseases?» (EIG, 23.01.10); «Three million people suffer from rare diseases in Spain » (AAR, 10.03.10). The debate on whether this term is (the most) appropriate or not continues to come up from time to time. This discussion is even participated in by the journalists who talk about this type of pathologies: "Hugo Díaz is 29 years old and has one of those wrongly called 'rare' diseases" (LNE, 02.03.10). There can be no doubt that these misgivings as regards the term allude in some way to the connotative power of the Spanish adjective 'raro', as we indicated at another point in the research.

Precisely for this reason, what could be called discursive 'distancers' tend to appear, with the function of attenuating the responsibility assumed by the announcer as regards the expression used. In the case of RD, these distancers are built around the following words: 'considered', 'known', 'qualified', 'named', 'classified as' or 'called'. We could look at a few examples: "low-prevalence diseases, better known as rare diseases" (EUP, 01.03.10), "pa-tients affected by one of the diseases considered rare through their low prevalence" (DIM, 15.03.10). "Marisa's disease forms part of the group described as Rare Diseases" (HER, 14.03.10). "Seldom-found diseases, also known as 'rare diseases'" (NME, 13.03.10). The-se distances even appear in headlines: «Zaragoza celebrates a symposium on pathologies

that are considered rare » (COD, 02.03.10). This distancing function is also played by inverted commas when these are placed around the adjective, as was seen in the headline of the daily paper Jaén reproduced a few lines above, or in the following headline: «Alcalá de Henares goes all out to help a girl suffering from a “rare” disease who needs to be operated on in Philadelphia » (QUE, 19.03.10).

To talk and write about RD, there are of course other alternative terms (nouns and adjectives) which prove very interesting and display an also very evocative lexical panorama. Observe the following table, in which we include the main terms identified in our corpus from the lexical base of ‘diseases’:

TERMS, FUNCTIONS AND CONCEPTS				
Basic term	Basic funciones	Reference concepts	Complementary term	Examples in the media
	IDENTIFICACIÓN	RARITY	<i>rare (sense 1)</i>	SUR, 10.03.10
		FREQUENCY	<i>not frequent</i>	ABC, 01.02.10
			<i>not very frequent</i>	PRO, 30.01.10 EUP, 19.02.10
			<i>infrequent</i>	ELP, 16.02.10
			<i>low frequency</i>	PRO, 20.02.10
		INCIDENCE	<i>low incidence</i>	LUK, 27.02.10 ELI, 27.02.10
			<i>with little incidence</i>	El Ideal Gallego
		PREVALENCE	<i>with little prevalence</i>	LNE, 02.03.10
			<i>low prevalence</i>	LAV, 28.02.10
			<i>not very prevalent</i>	DIM, 26.02.10
		MINORITY	<i>minoriti</i>	PRO, 20.02.10 LAV, 28.02.10 PRO, 30.01.10
		OTHERS	<i>not usual</i>	NME, 16.03.10
			<i>un common</i>	GAC, 02.03.10 PRO, 30.01.10
			<i>afecting few people</i>	OCU
			<i>unusual</i>	ECO, 27.02.10

	ACCOUNTABILITY	ATTENTION	<i>neglected</i>	ACS, 12.03.10
			<i>priority</i>	LAV, 28.02.10
		PROTECTION	<i>orphan</i>	ACS, 12.03.10 ACC, 05.02.10
		COVER	<i>with major medical necessities not covered</i>	ACC, 05.02.10 DIM, 09.02.10
			<i>still not covered</i>	RME, 16.01.10
		NECESSITY	<i>needing special medical treatment</i>	GEN, 17.03.10
		KNOWLEDGE	<i>unknow</i>	ARA, 01.03.10
			<i>forgotten</i>	ADN, 18.03.10
			<i>misunderstood</i>	ECO, 27.02.10
	DIAGNOSIS	<i>no diagnosis</i>		
		<i>no name for it yet</i>	ECO, 27.02.10	
		<i>hard to diagnose</i>	LAS, 16.01.10	
		<i>no name</i>	ECO, 27.02.10	
	TREATMENT	<i>incurable</i>	ELM, 01.03.10	
	EVALUATION	STRANGENESS	<i>Rare(≈odd) (sense 2)</i>	ELM, 11.03.10
			<i>unusual</i>	TER, 11.02.10
			<i>appearing in the population in a strange way</i>	ECG
		INTENSITY	<i>devastating</i>	DME, 27.02.10
<i>serious</i>			LAV, 28.02.10	
EVOLUTION		<i>progressive</i>	LVG, 26.01.10	
		<i>degenerative</i>	QUÉ, 28.02.10	
		<i>weakening</i>	NME, 16.03.10	
		<i>limiting</i>	HOY, 14.03.10 QUÉ, 28.02.10	
		<i>irreversible</i>	ABC, 13.03.10	
CHRONICITY		<i>chronic</i>	QUÉ, 28.02.10	
		<i>suffered lifelong</i>	DÍA, 09.03.10	
DEPENDENCY		<i>highly disabling</i>	LAV, 28.02.10	
		<i>very limiting</i>	HOY, 14.03.10	
ACCEPTABILITY		<i>difficult to absorb</i>	HOY, 14.03.10	
“PERSONALITY”	<i>incredible</i>	HOY, 28.02.10		
	<i>cruel</i>	DAV, 18.02.10 ECO, 27.02.10		
	<i>whimsical</i>	ECO, 27.02.10		
	<i>mysterious</i>	ADN, 18.03.10		
	<i>elusive</i>	ADN, 18.03.10		
	<i>appalling</i>	ADN, 18.03.10		

Table 25. Terms, functions and concepts

Identification-based expressions have a lower subjectivity content than responsibility assignment or evaluation. At the same time it should be underscored that, as a general rule, all these terms have a similarly social-communicative consequence: the receivers of these news items will feel that these ‘low-prevalence’, ‘infrequent’, ‘low-incidence’, ‘minority’, etc. diseases form part of a possible but very far-off world (“You always think that one of these rare diseases is something that could happen to someone else, something very remote”, asserts the mother of a girl with neurofibromatosis, Abc, 01.03.10). That is how we interpret the presence of the contrastive conjunction ‘but’ in the following sentence: “low-prevalence, but in many cases devastating diseases” (DME, 27.02.10). The terms which we could describe as more understandable or closer to the reader (‘which affect few people’, ‘uncommon’ or ‘unusual’), actually paradoxically lead to the problem being identified as something if possible more remote. Given that their nature involves precisely that low prevalence, the challenge lies in how to bring in terms which generate greater awareness and also more involvement for reacting and seeking solutions (which partly also entails investments), without this meaning having to go through the compassionate or pitiful look stage. Perhaps the expression ‘genetic lottery’ could have some added value in this respect (Abc, 13.03.10). In this first lexical block the preferential value of the adjective ‘rare’ should also be taken into account. This is an extremely polysemous adjective which very easily loses its quantitative sense, a sense which is not always clear if we bear in mind such assertions as this one, referring to cerebral palsy: “this is an RD, but not extremely so” (ATL, 07.02.10).

Sometimes, if lexical-semantic preferences other than those of ‘rare diseases’ are displayed in journalistic work, it might be worth mentioning the ‘minority diseases’ option, which is more firmly established in Catalan media. Furthermore, although this is in the sphere of audiovisual information, this expression was a preferential option in the *Marató de TV3* shown in December 2009. Although ‘minority’ keeps the sense of affecting few people, it might be thought to form a social-semantic field to which a more positive interpretation could also be given: that of the elite, or groups which deserve special attention or respect, embodied in this case in new specific research and sociomedical healthcare measures. On one occasion, a person uses the expression ‘great minority’ to refer to RD and also to the persons affected, which even brings to mind a famous slogan used for a long time by a television channel (TVE2) to allude to its assumed audience profile (M21, 01.03.10).

In this first block one might also wonder whether terms such as ‘frequency’, ‘incidence’ or ‘prevalence’ are appropriately used or not. The media and their sources seem to use these as if they were all the same thing, but we ought to consider whether they really do have the same meaning. Here are two parts of news items in which the rare nature of a disease does not coincide with its valuation as more or less frequent: “This is the first cause of hereditary mental retardation in the world. But very few people know its name. The Fragile X syndrome, arising through the mutation of a single gene in the X chromosome, is one of the so-called rare diseases, though not for this reason infrequent” (LVG, 18.03.10): “This is a disease [referring to congenital glaucoma] which is seldom found, but not considered to be rare; the incidence is one person affected for every 35,000 born alive” (DIM, 23.03.10). Even when talking of reference centres, this distinction between concepts which are very often used as equivalents is very clear: “Spain already has 100 reference units for seldom-found pathologies and two of these are for rare diseases. The work now entails managing to get the EU to recognise the need for having these units running” (TRI, 26.03.10).

Press sources and journalists themselves become less involved when they use for example, ‘seldom-found diseases’, as when they say, for instance, ‘neglected’, ‘misunderstood’, ‘still not covered’ or ‘orphan diseases’. In the second block (assigning responsibility), part of the emphasis made by lexical options is the absence of something (care, understanding, healthcare coverage, diagnosis or treatment). In Spanish this is expressed by the use of such prefixes as *des-* (‘desatendidas’ = neglected) and in English by *in-/mis-/un-* (‘incurable’, ‘misunderstood’ ‘unknown’), through the negation *not* (‘not covered’) or the adjective *no* (‘no name’, ‘no diagnosis’). Then again, this type of terms is at the same time being used to denounce a problem and to some extent allude, perhaps rather indirectly, to possible responsibilities; this is why the expressions in this block were grouped according to the idea of “assigning responsibility”. There are discursive items which intensify this function, such as for example the use of the temporal adverbs ‘still/yet’ (‘still not covered’, ‘no name for it yet’) or the adjective ‘major’ (‘major medical needs’) which seem to lean more towards the denunciation of a situation than towards its observation. The same thing occurs with adjectives such as ‘orphan’, which has great impact and inevitably refers not only to the lack of protection but also to the need for that lack to be properly met. In fact the complete phrase in which the expression appears on one occasion is as follows: “Orphan diseases not catered for by pharmaceutical research” (ACS, 12.03.10). We should remember that this is the term used for drugs which have a special status and which are specifically

intended for minority diseases: 'orphan drugs'. There does not however seem to be any absolute consensus about the equivalence of 'orphan drugs' and 'rare diseases'. Indeed, rare diseases are sometimes seen included within the orphan category: "The qualifying expression orphan drugs 'covers two major groups of pathologies: the rare ones and the neglected ones" (DIM, 16.03.10). In other texts from our corpus rare and orphan are seen to be considered the same thing: "a large number of rare (orphan) diseases" (NME, 16.03.10).

As regards knowledge of Rare Diseases, along with the term 'unknown', included in the previous table, other terms which contradict or complete this idea are found: 'not unknown' or 'not recognised'. As we are told by Francesc Palau: "Although all of them have been studied by doctors at the university and are not unknown, the truth is that it takes an average of five years to diagnose the disease from when a patient goes to the doctor for the first time" (NDN, 10.03.10). "If there are delays in the diagnosis it is because these diseases are not recognised by medical staff", asserted Palau" (AAR, 10.03.10) (Abc, 10.03.10). Apart from this, it was noticed that RD are sometimes informed about with some ambiguity: "The origin of many of them is unknown, although in ataxia or cystic fibrosis the genetic component has some relevance" (ATL, 11.03.10). It would seem that genetics has very little relevance, and only in very few pathologies, which is not true. It furthermore appears that the unknown origin (not genetic in the system of argument used here) is presented in most cases. It is important to remember that, as they say, a very significant percentage (roughly 80% of the cases) of these pathologies have a genetic origin. Readers will feel the problem to be even more remote with this type of approach.

Special mention should perhaps be given to the term 'incurable diseases', above all if this is associated with another term, implicitly present in the debate on rare diseases: "uncured diseases": "The official figures state that from 6% to 8% of the world population are affected by a rare disease, with around three million people in Spain suffering from one of the 5000 to 7000 different existing pathologies of this type (mostly neurodegenerative: many of them incurable)" (ELM, 01.03.10). Terms which include the adjective 'difficult' can be seen as attenuators of responsibility ('difficult to diagnose', 'difficult to treat'), as they allude to the fact that it is not all a matter of wishing to act on this type of diseases, but that the difficulty that these tend to involve from the biomedical and biotechnological standpoint also needs to be taken into account. Difficulty also

marks the terms used for the complicated acceptance of the disease by relatives and people affected ('difficult to absorb'). On some occasions the adjective 'complex' was found being used to allude to RDs in general (DIM, 26.02.10).

In view of the lack of curative treatment and the sad prospect of observing the progress of the disease in some cases, the qualification of some rare diseases as 'chronic' is not only not bad news, but actually also an important objective, as opposed to what it might seem. That is, those who have a rare disease want their pathology to become chronic, because that might mean some stability; one might remember what once happened with AIDS, for example.

There are hardly any adjectives which we could call "positive"; but, as we have seen, on some occasions we find 'priority', alluding to the normative and legislative changes that are taking place at the present time, both in Europe and in the United States, to turn this type of pathologies into a focus of attention for research and for sociomedical management.

Finally the third block, the one on valuation, is intended to generate a more emotive approach by the reader: emotion which may entail greater empathy for this type of pathologies and those affected, or also greater distancing from these same pathologies and those affected. In Spain, the use of the adjective 'raro/a' in contexts in which it might be associated with strangeness undisputedly distances readers from the problems of those affected, though it may clearly help to call their attention. "The propagation of certain rare diseases has led them to lose their qualifier as rare, as has occurred with AIDS or multiple sclerosis" (LVA, 18.01.10). Here the basic aspect leading one to think of associations added to the mere quantitative sense is the word 'propagation', which partly refers to the idea of contagion. In Spanish putting the adjective in front of the noun focuses on the semantic value of rarity: 'raras enfermedades' (ELM, 11.03.10). The expression 'which appear among the population strangely', seems even more distancing because, when the reader is not well informed about this type of pathologies, their appearance may be associated with personal, social or family conducts which may lie beyond what is "normal". The same thing can be said of the term 'enfermedades insólitas' (unusual diseases). If the Diccionario de la Real Academia Española is consulted, the definition of "insólito-ta" that can be found is: "Rare, strange, unusual".

The set of terms connected with intensity, evolution, chronicity, dependency or acceptability could really be less specifically applicable to rare diseases, insofar as they could be expressions also appearing in other types of prevalent diseases: ‘devastating’, ‘serious’, ‘progressive’, ‘degenerative’, ‘terminal’, ‘irreversible’, ‘chronic’, ‘suffered lifelong’, ‘disabling’, ‘very limiting’ or ‘difficult to absorb’. However, this “shared lexical world” for minority and non-minority diseases is established from the idea that we are talking about important pathologies, with a great impact on people’s health; this is indeed the reason why in certain enumeration contexts, rare diseases and cancer, for example, are seen in the same list, for example when referring to investments in research (DIS, 27.02.10; YAH, 19.03.10; XXI, 19.03.10; TEL, 19.03.10; LAV, 25.03.10; ADN, 29.03.10).

Sometimes there is a prior personalisation of the disease, which is described as ‘appalling’, ‘cruel’, ‘elusive’, ‘incredible’ or as ‘whimsical’. This strategy and the use of this type of adjectives do indeed partly turn one’s attention towards the responsibilities that were mentioned above, and also intensify the communicative impact, a preferential objective of journalistic narrations on health and disease on many occasions. At this point one must be aware of the denominative differences when talking about RD in the plural, or when terms are put forward to define or describe some of these in particular. The above adjectives were used to allude to Duchenne Muscular Dystrophy (ADN, 18.03.10); ‘incredible’ is the adjective proposed to define visual agnosia (HOY, 28.02.10). In respect of Huntington’s disease, we could for example see the following definition: “Huntington’s disease, (also known as Huntington’s chorea, and formerly known as Saint Vitus’ dance or Saint Vitus’ disease) is a hereditary neurodegenerative disease (triggered off by a genetic mutation) which gradually destroys specific regions of the brain known as basal ganglia (nuclei) and inevitably leads to death” (NME, 26.02.10). Up to four different terms are used, although the ones which call our attention most are the third and fourth (Saint Vitus’ dance or disease). This is not only through their being easily understandable terms that are easy to remember, but also because they clearly express how a term for a low-prevalence disease ends up forming part of a language’s expressive resources; these two formulas are indeed used as clichés and stereotyped expressions with some regularity in everyday speech, though without knowing that they refer to this disease. Even in medical information media such as *Diario Médico*, the expression is used in headlines («The instability of ‘Saint Vitus’ Dance’») and alludes to its origin: “The pilgrimage to the chapel of Saint Vitus, in Ulm (Germany), during the Middle Ages gave Huntington’s disease (HD) the nickname of Saint Vitus’ dance” (DIM, 27.01.10).

We find a number of expressions in our corpus alluding to different degrees of rarity within rare diseases. Paroxysmal nocturnal hemoglobinuria (PNH), for example, is described as an ‘Ultra-Rare disease’ (ACC, 16.03.10; NME, 18.03.10). People also talk of ‘rare even among the rare’ to describe for example Opitz C disease (LAR, 10.01.10), or «The rarest of all diseases » (ELM, 01.03.10), to talk, amongst others, of Apert syndrome; or of ‘extremely unknown’ to inform about congenital insensitivity to pain, Moebius syndrome, Proteus syndrome or Wolfman Syndrome (GAC, 02.03.10). At the other end of the scale, there are times when some diseases (the least rare) are occasionally included in list contexts where they share space with more frequent diseases; the news item entitled «Infanta Cristina Hospital is to have a specific outpatients’ department for dealing with diseases such as Parkinson’s» starts like this: “Parkinson, walking disorders, dystonias, choreas, nervous tics, myoclonias, ataxias and trembling are pathologies increasingly found in our society” (HOY, 14.03.10). Sometimes even, rare diseases are identified (the ones least seldom-found among rare diseases indeed) among common ailments: “The ones common to the general population such as Down syndrome or cystic fibrosis are also found” (LAO, 30.01.10).

Of course, the most commonplace situation is to mention the name of the disease directly: «Epigenetics defines which twin develops lupus» (DIM, 04.01.10), « 32 mutations causing Usher syndrome discovered» (DIM, 11.03.10); though mistakes may be made when using these terms: “Huntington” (NME, 26.02.10), “Narcolepsia” (HER, 14.03.10), “Glucogénesis” (Abc, 13.03.10), “Fiedreich” (RIO, 11.02.10).

To end with, it could be mentioned that in the corpus studied the lexical system reproduced and analysed in the above paragraphs was also seen to extend partly to other lexical bases such as ‘ailments’, ‘pathologies’, ‘illnesses’, ‘complaints’, ‘conditions’, ‘processes’, ‘disorders’, ‘anomalies’ or ‘syndromes’.

2. ON NUMBERS, PERCENTAGES AND STATISTICS

As was already mentioned, figures have preferential value in the treatment of rare diseases. The shortage of data available about these pathologies has always been a problem for preparing press communication. This data is also a regular object of interest for media professionals, especially when dealing with subjects connected with medical and scientific

aspects. That is why the importance of the Estudio sobre situación de Necesidades Socio-sanitarias de las Personas con Enfermedades Raras en España (ENSERio study) drawn up by FEDER needs to be stressed. It contains figures on the delay in diagnosis and its consequences, the perception of the fitness of the treatment received, medical services giving medical treatment to those affected, travel outside the province to be given diagnostic or therapeutic care and number of kilometres, etc..

The press considered this Study to be a tool of great value and it is frequently mentioned in our corpus. What type of data is preferentially given? Here are some fragments of this:

Nº.	FRAGMENTS (F.)	MEDIA
1	"In this respect the data from the ENSERio study, carried out by the FEDER and by Obra Social Caja Madrid, reveals that it takes people with RD on average 5 years to obtain a diagnosis, 76 per cent feel discriminated through their disease, and 36 per cent of those affected consider the cover given by healthcare products to be 'little or none'".	(YAH, 01.03.10) (LAV, 28.02.10)
2	"According to the last study made by FEDER up to 82.74% of the families affected by this type of diseases have had to travel outside their own province several times to be able to gain access to treatment, and 17.26 could not travel even though they would have needed to. 76% of those affected furthermore felt discriminated through their disease".	(DSC, 27.02.10)
3	"76 per cent (two million people) of those affected felt discriminated through their disease".	(MTV, 27.02.10)
4	"76% of patients with rare diseases have at some time felt discriminated through their disease, according to FEDER".	(EUP, 12.03.10) (YAH, 12.03.10) (XXI, 13.03.10)
5	"Rare diseases take on average 5 years to be diagnosed"	(NDN, 10.03.10)
6	"Patients with rare diseases will on average take five years to be diagnosed"	(ELM, 10.02.10)
7	"Care for the sick person represents up to 20% of the family income"	(LVA, 18.01.10)
8	"There is often no cure for these and around 30 % of the children die before reaching five years of age"	(ELP, 09.03.10).

9	"The aim is clear: 'we want everyone to know of the reality of these diseases, which cause the death of 35% of the children under one year of age', explains Salud Jurado, FEDER delegate in Andalusia".	(DSC, 11.03.10).
10	"Rare diseases are attributed 35% of the deaths before one year of age, 10% from 1 to 5 years and 12% from 5 to 15".	(Sport, 30.01.10)

Table 26. Figures from the Enserio study in the media. Some examples

Sometimes the data is given with no explicit reference to the title of the Study, as occurs in most of the fragments reproduced in the previous table. In other cases, the study is indeed mentioned as source of the data reproduced. One way or another, it is important to emphasise that FEDER is identified as a reliable source, and the reliability lies not only in the data being reproduced, but also in the fact of this data becoming headline news. Even when these headlines fail to indicate the source, it could be interpreted that these numbers are grasped and accepted by the journalist.

As regards the figures reproduced most, the ten extracts above may act as an indicator of the great interest aroused by the five-year average delay in diagnosis and the fact that over three quarters of the participants in the survey felt discriminated on some occasion through their illness. The percentage of families having to leave their province or the expense for the family meant by care for the affected person also arouse particular press interest. The information with greatest impact is perhaps the sort alluding to the number of children who die before reaching one year of age as a result of these pathologies: around 35%. As can furthermore be appreciated in extract 9, the spokespersons also sometimes stress this figure when they want to convey the personal, social and family significance of rare diseases clearly and quickly. The impact is of course greater through being a detail affecting a particularly sensitive group - children. The fact that sports dailies (f.10) also reflect this data has added value, no doubt, even though it is only through their great circulation.

Aside from this data from ENSERio, the leading figure is the three million calculated when an attempt is made to estimate the number of people affected by a rare disease in Spain: «Three million people suffer from rare diseases in Spain» (AAR, 10.03.10); «Three million Spanish people suffer from rare diseases» (SUR, 10.03.10). It has been thanks to the FEDER that the three million message has been put across (above all through its World Rare Disease Day campaigns) and through being an explicit source for the media in this

aspect too: “According to data from the FEDER, there are three million people affected by rare diseases in Spain” (YAH, 11.02.10). The use of the generic term ‘millions’ intensifies the image of the possible number of sufferers for the reader: “the millions of people affected by a rare disease in Spain” (ELM, 01.03.10). This discursive technique retains its significance, though perhaps to a lesser extent, when this is extrapolated to those affected worldwide: “Given that rare diseases form a very heterogeneous family affecting millions of people all over the world” (DSE, 11.03.10). This figure of three million is not, however, always the one chosen to inform about the number of people affected in the country; attenuators of the three million can be found and a figure of two million can even be found as reference datum: “Because there are known to be over two million sick people in Spain, 100,000 in Castile-La Mancha” (VER, 25.03.10); «The roughly three million people with a rare disease in Spain are asking the Health Service for more reference centres» (ADN, 01.03.10). Some headlines, like this one from ADN reproduced above, use the figure of three million as if all of them were identified and as if all of them were lobbying at the same time, which is clearly not true, but in any event it gives a new dimensions and weight to the patients’ discourse. Likewise, intensifiers of the three million by means of structures of the ‘more than/over’ type can also be found: “Over 3 million Spaniards suffer from some RD. Roughly 8% of the Spanish population” (ACC, 26.02.10).

The most attention-grabbing case is nevertheless the fact that the estimation can rise to 5 million people, with argument structures like this one: “Over 3 million Spaniards suffer from some RD. Roughly 8% of the Spanish population, although if the people who are not diagnosed are taken into account the figure soars to 5 million” (ACC, 26.02.10) (DIS, 0.03.10). And of course, there is the one that hints that the number could rise to 15 million: “In Spain, over 3 million people are diagnosed as having one of the over 7000 low-prevalence diseases known up to now. These diagnosis figures would however be multiplied by five if they were properly diagnosed and if there were greater knowledge of these diseases by the medical staff and the people, as experts state” (ELI, 27.02.10). This is further proof of the confused information to be found when rare diseases are being discussed.

These estimations have also been converted for the population of regions, provinces or cities, thus complying with the function of bringing news closer to home, or localisation, particularly necessary for local and regional media. Here are some examples: «There are estimated to be about 15,000 people affected by RD in Lugo» (headline) (PRO,

30.01.10); “As for Galicia, they affect over 100,000 persons, 15,000 of these estimated to be in Lugo” (PRO, 30.01.10); “There are known to be over two million sufferers in Spain, 100,000 in Castile-La Mancha” (VER, 25.03.10); «80,000 Asturians suffer from one of the over 7000 rare diseases » (LVA, 18.01.10); “One of every 12 Asturians suffers from a seldom-found pathology” (LVA, 18.01.10). This localisation occasionally leads to some rather unfortunate headlines: «4,000 inhabitants of Aragon are neuromuscular» (EPA, 31.01.10), in which the people’s identity is reduced to the identity of the diseases and where it would also prove easy to remind readers that all human beings are actually neuromuscular!

Sometimes even the media themselves question this transfer of regional estimations: “From 80,000 to 100,000 Murcians suffer from some rare disease, according to certain calculations, which cannot in any event be proven because there are no records” (VER, 14.01.10). These doubts may even lead to affirming that it is impossible to find out the prevalence of these pathologies, not taking into consideration the fact that this prevalence is indeed known in some cases (many of them): “In spite of all these estimations, neither the number of sick people of this type in the world, nor the prevalence of each pathology are known for sure” (COR, 14.02.10). The reference to families proves very interesting for establishing a figure for those affected in the case of Andalusia: «Rare diseases affect 400,000 families in Andalusia » (DSC, 12.03.10).

It should also be pointed out that cases of manifest errors have been found when a figure clearly under the real one is given in Galicia or the Canary Islands for example: «Around 2,500 Galicians suffer from complaints not commonly found » (ECG, 30.01.10); «Around 3,000 people in Galicia suffer from some RD » (LOG, 29.01.10). “Hyperoxaluria, cat cry syndrome or leukodystrophy are some of the over 5,000 rare diseases (RD) existing in the world and which are suffered by around one thousand inhabitants of the Canary Islands” (LOT, 27.02.10).

The number of people affected is not always given in absolute terms, and provided instead in percentages or frequencies of appearance: “diseases affecting 2 out of every 10,000 inhabitants” (DSC, 18.02.10). Mistakes can also be found in this information option. “This is a common experience shared by people suffering from one of these pathologies with an unpronounceable name, affecting two or three of every 100,000 inhabitants” (ELM, 01.03.10); “Rare diseases are the ones affecting five of every 100,000 inhabitants” (DID, 11.01.10).

'Low' prevalence is not however the same thing as 'negligible' (*ínfimo*) presence; the adjective *ínfimo* in Spanish has connotations beyond the merely quantitative aspect: "The prevalence of each of these is negligible (*ínfimo*), but if all these pathologies are added up the number of sick persons is more than significant all over the world" (COR, 14.02.10). The third sense of *ínfimo* proposed by the twenty-first edition of the Spanish Academy's Dictionary is given as: "A term for the most vile and despicable in any field".

Another controversial issue connected with figures is the one referring to the number of minority diseases identified. There is obviously no unanimous figure and that press information only reproduces these doubts. They thus talk of five thousand, six thousand, seven thousand, nine thousand and even ten thousand, as seen in the following examples: "There are from five to seven thousand different types" (ECG, 07.02.10); "According to the PP, there are over 7000" (JAE, 10.02.10); "9000 pathologies" (TEL, 10.02.10); "Over 5500 RD have been identified" (ACC, 06.02.10); "scientists engaged in the over 5000 rare diseases calculated to exist" (ELM, 01.03.10); "This disease, one of the 6000 known rare diseases" (YAH, 02.03.10); "In the coming years, family sequencing could help more people suffering from one of the 10,000 rare genetic diseases, which represent 5% of all known ailments" (PUB, 11.03.10). Observe that in this last case the figure would be even greater if the rare diseases that do not have a genetic origin are added.

8.

NOTES ON POLITICAL DISCOURSE ON RARE DISEASES

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At another point in this study an archetypal argument commonly found in politicians' words on RD was mentioned: "We have done things, and are continuing to do things, but we recognise that there are still things to be done". Here is an example that we found in our corpus: "The minister stressed the budget and coordination efforts made so far by her department. She acknowledged the need to raise the funding for resources and the commitment to innovation" (DIM, 11.03.10). Another recurrent model is the one alluding to wishing to do (stating for example that RD are a management priority) and to actually doing. This is found in: "The Castile-La Mancha Health Minister has referred to seldom-found pathologies as one of the priorities of his department and stressed that the regional government is working on opening a support unit 'intended to give professional help to people suffering from these diseases'" (DIM, 26.03.10).

Two aspects prove particularly worthy of mention as regards one main issue in political discourse - the specific time when commitments are materialised. The first is connected with the presence or absence of items marking the times for action in a definite or indefinite sense. In this regard one must acknowledge the peace of mind provided by the fact of not taking on commitments on action with rare diseases accompanied by well-defined deadlines: "The regional Minister of Health and Social Welfare repeated his commitment to go on promoting projects and future action" (EUP, 19.02.10). It should be pointed out that these deadlines are precisely the ones which will be insisted on most vigorously by those affected, relatives and patients' associations. The verb used for reporting on future action in rare diseases sometimes marks more or less favourable treatment by the media of political-healthcare management. Compare the use of the verb 'manage' and the phrase 'looking into opening' in the following extracts: «The Generalitat (autonomous community authority) is managing the opening of the first independent unit in the country for dealing with rare diseases after the success of the pilot experiment applied at Alicante Hospital» [Sub-heading] (LPO, 08.02.10); «The Generalitat is looking into opening an RD unit» [Headline]

(LPO, 07.02.10). It is clear that ‘managing’ conveys the idea that this unit is already under way, whereas ‘looking into opening’ leads one to infer more remote execution deadlines.

The second question is about the degree of symmetry or asymmetry that can be detected when comparing the saying and the doing of politicians with direct or indirect responsibilities in the healthcare domain and consequently in the field of rare diseases. One must firstly analyse whether what was previously said matches what was later done. If this were the case there would be the greatest degree of symmetry or semiotic correspondence. There would otherwise be an asymmetrical relationship between saying and doing: for example, having said something that would later be done, but not having done this after the time set (or simply after a reasonable time in relation with the complexity of the management proposed) had gone by. A headline like «Rare disease census to be drawn up in six months» (LAP, 09.02.10), might make one wonder whether that deadline has been complied with. That is, was there really an RD census in August 2010? This is outside our corpus, but it would obviously be useful to look at the news items on RD published over those weeks to find out if the completion of the census was confirmed or not. In this other example, the paper is clearly denouncing the lack of any specific time element in the political commitment: «Castile-La Mancha is to have its register of rare diseases, though Lamata does not give any details as to when this will be set up» (DIM, 26.03.10). The newspaper La Tribuna in Albacete (25.03.10), nevertheless prefers this other headline: «The Authority is going to set up a rare disease unit and register». In the body of the text it states: “It was in fact announced that the creation of new reference units will start to be defined in the coming months”. The vague ‘in the coming months’ is completed with the progressive structure ‘start to be defined’, from which one can infer that no new reference units will be created in the coming months, but instead that their establishment will start to be defined. This same piece of information appears with a more specific angle (though still vague) in other news items and it talks for example of the end of the year as time limit: “What is more, before the end of the year, Castile-La Mancha will have a Technical Support Unit, to advise and help relatives and professionals, and a census of the sick” (VER, 25.03.10).

Here is another example, in which the appearance on up to two occasions of the adverb ‘probably’ or the nouns ‘model’ and (design) ‘phase’ appear, completely relativising the time scale of the proposed measure: “The model is still in the design phase and will probably not be launched until this summer, but is based on having a case manager in each healthcare area. This person, probably part of the internal medicine services of major hospitals, will receive the consultation referred by general doctors when the primary centre

comes up against a possible rare disease” (LAV, 02.03.10). Well, is this post active now, in summer 2010? In any event, their backs had been covered with the attenuators indicated above. At a time when not only national, but also regional Plans for RD are being drawn up, such follow-up work by media professionals would prove particularly useful. If the following extract is read, referring to the Andalusia Integral RD Plan, one would think that everything in it was already under way: “In Andalusia there has been a plan for Rare Diseases since 2008. The Andalusian Administration’s intention is to raise awareness as to rare diseases, improve sufferers’ access to aid, promote professionals’ training and foster research. There has been an Andalusian register of rare diseases since November”. (COR, 14.02.10). The fact of the plans being approved may mean a lot in the sphere of saying, but little if this is not combined with specific measures.

Special mention should be given to the fact of saying, only saying, without establishing any connection with a future action. Sometimes the unwilling promoters of this communication pattern may be the people affected themselves or their organisations, given that sometimes what they are asking for is understanding, recognition of their serious problems, of their weary trail through the healthcare system, of social lack of understanding. This type of talk facilitates counter-discourse in which those affected are told that they have the absolute support of the (local, regional or national) administration or of the institutions, who can imagine their misery, and that urgent measures need to be taken to solve their problems and avoid society’s lack of comprehension. If this kind of message is analysed, the conclusion reached will be that there is some emotional proximity, which is naturally highly important, but which establishes hardly any specific commitment: “After stressing that the Chamber of Deputies – as the Senate did in the last edition – is thus renewing its ‘permanent proximity and sensitivity’ to the Spanish people’s most pressing problems, Doña Elena reaffirmed her solidarity with the sick people and their families” (YAH, 19.02.10). [The President of the Xunta (Galician Autonomous Community Authority), Núñez Feijoo] “alluded to the efforts made by relatives of the chronically sick, although every day they win a battle over the difficulties. He promised all of them that his government would ‘rise to the occasion’” (LVG). What exactly does ‘rise to the occasion’ mean? The paternalistic interpretation of the function that has to be played by political leaders in respect not only of people affected by RD and their families, but also of the representatives of associations, fits in this same knowledge and communication framework. We could look at the use of the expression ‘give shelter’ (cobijar) referring to José Bono and what the president of the Chamber of Deputies does, and consider the expression ‘wandering around lost’ or ‘without sticking their neck out’ in the following extract: “Over three million Spaniards wandering around lost without anyone

sticking their neck out are given shelter by José Bono” (GAM, 25.01.10). “To shelter” - *co-bijar* - also means “succouring people, giving them affection and protection” according to the Spanish Academy Dictionary.

Likewise, the appropriation made of the most emblematic expressions of the patients’ and patients’ associations’ discourse by political managers may have something to do with a personal commitment to the problems of those affected, but it is also an indicator of how simple it becomes to take over the patients’ words in their claims and demands. One example can be seen in the repeated phrase ‘painful pilgrimage’, used for instance by one of the officials from the Health Delegation of the Andalusia Authority in Cordova (COR, 14.02.10). Compassionate discourse towards people with rare diseases is based on the same type of idea. Along with the appropriation of expressions from others’ words to attenuate their lobbying value, the use of positive and very abstract terms such as “hope” should be mentioned: “This will mean –continued Arnáiz [PSOE Burgos] – that a hopeful future is provided for patients and their families” (COP, 12.03.10). The same thing happens when the exchange of messages is established on the utmost possible level for getting improvements for people with RD: the integral, global or multidisciplinary approach, without of course clearing up what ‘integral’, ‘global’ or ‘multidisciplinary’ mean; the intention is thus made to come forward as an achievement: “...entails global action on this type of diseases and the participation of the agents involved” (LAV, 28.02.10); ‘integral care’ (EUP, 21.03.10, Abc, 21.03.10); “Need for integral care” (PRO, 30.01.10).

What is more, the support given by politicians for forming associations of patients with RD does not imply any backing for the claims and demands made by these associations, although it may be seen as if setting up associations facilitates immediate agreement by the parties (tending to be called ‘collaboration’) and problem-solving: “The regional Minister of Health and Social Welfare, Fernando Lamata, today endorsed the unity of the different associations in Castile-La Mancha connected with rare diseases as a tool for more effective cooperation with a view to meeting demands and necessities” (EUP, 19.02.10). Another point to be taken into account is that simplifying the number of possible interlocutors is an important step for political-healthcare managers insofar as interlocution (talk between them) becomes clearer.

There are also news items in which it represents what politicians do, when it is just a matter of doing. This can for example involve the representatives of rare disease sufferers being received by political figures, without these encounters resulting in any statement and even

less, any commitment, or managing to have them attend certain events. The fact of receiving anyway tends to be construed as a gesture of proximity, of interest and in the best case, of implicit support for the claims of those affected, stressing the word implicit. “In the morning Mayor Juan Carlos Aparicio is receiving the associations of people affected by rare diseases” (COP, 26.02.10); “The act will be attended by the top echelons of Public Administration” (DIS, 18.02.10).

As is quite understandable, there are similarly references to what is not done by politicians. This denunciation becomes even more intense if the claimant’s discourse is alluding to something more akin to a wish not to do, that is, to the lack of any will to take action in the RD field: “It was in 1997 when mother and daughter, tired of not getting any replies from politicians, got under way a project which even today has not been materialised” (LPO, 07.02.10). Here too one can appreciate the importance of time: thirteen years without any response, if what is said here is accepted.

When political discourse on rare diseases is discussed one is really talking about different processes of representing responsibilities. If what is said is good, the usual thing would be to accept responsibility for what is done. If what is said is not good, the strategy would instead be intended to assign responsibility or to extend this. This is done by including more responsible parties: “What is more, ‘we have the institutional loyalty of the autonomous communities and the cooperation of FEDER, which will enable us to create further reference units covering more pathologies’, concluded Jiménez” (DIM, 11.03.10); or they transfer this responsibility to higher decision-making levels (Europe, for example): “Lamata and Martínez Olmos undertook to improve coordination not only on the nationwide but also the European level” (VER, 25.03.10). Naturally, improving coordination on a European scale will not depend on the Regional Minister or General Secretary for Health, not even on the Minister, as many other factors will also have to be involved. This is thus a case of a mortgaged commitment.

Comparison is also a very useful tool for bolstering one’s own image and assuaging any possible negative responsibilities. The minister is said to have: “also extolled the fact that ‘Spain is at the head of the European Union in catering for rare diseases insofar as the national strategy was passed in 2009 here, when 2013 was the deadline set by the Union’” (DIM, 11.03.10). It catches one’s eye that the word ‘extol’ should be used, as it seems to be hiding a criticism of any positive self-assessment of the management work done by the minister. In the Spanish Academy’s Dictionary, the word originally used for extol - ‘ensalzar’ - is said to mean: “To uplift, exalt. To praise, commend”.

It hardly needs mentioning that the analysis will be quite a different matter when the politicians taking part in the social debate on rare diseases are in the opposition. On these occasions, they tend to draw much closer to assertive patients, and come forward as self-proclaimed mediators between those affected and the people with governing responsibility: “As *Diariomedico.com* informed, Tarruella mentioned that ‘he is not aware of any steps having been taken beyond presenting the strategy’ and that he gets many complaints from sick persons and their relatives because ‘access to treatment and innovative drugs can vary depending on the autonomous community in which the patient resides’” (DIM, 11.03.10). This mediation work can lead to acting as a genuine co-claimant, assuming not only the contents, but also the forceful, assertive approach. This occurs for example when «CiU asks the Health Service to guarantee access to drugs for patients with rare diseases » (SOD, 15.03.10): along with ‘asks’, the article also uses terms such as ‘demands’, ‘proposes’ and ‘suggests’.

Occasionally some item connected with urgency is tagged on to the verb ‘ask for’ in order to make the request more of a demand, the highest possible degree of assertiveness or co-assertiveness; it may be the word ‘priority’ or the adjective ‘urgent’: «CiU asks the minister for priority for rare diseases » (DIM, 11.03.10); “urgent question” [from Conxita Tarruella] (DIM, 18.03.10). CiU has precisely been one of the political parties to assume clearest prominence in the corpus now being analysed, through its Member of Parliament Tarruella. Its work in demanding recognition is even seen as a ‘struggle’ in some press headlines, something which brings to mind even greater closeness in affinity to the patients: «CiU fights for rare diseases » (SEG, 16.03.10).

The Popular Party has also taken on an increasingly prominent role, through Dolores Pan, for example. It is at this point where the gap between doing and saying becomes clearest in the case of RD. The matter revealing this gap is precisely the non-compliance of some of the proposals made by the Senate some years ago. This non-compliance concerns getting specific bodies under way or providing budgets and assigning a specific time schedule. In the development of the news item entitled «The forgotten» (DIM, 15.03.10), one can read: “Dolores Pan, spokeswoman for Health of the Popular Party in the Senate, has reminded this newspaper of the commission on rare diseases created in the upper house, ‘at which all the groups agreed to create a specific state body, as well as a national plan with strategic memory and application schedule, that is, something much more specific than the strategy that was passed in June last year’ (...). These questions ‘were not taken into account as much as those affected and their relatives require, and they continue

to see that the administrations only remember them on the world RD day’, concluded Pan” (DIM, 15.03.10). This can be seen to be a very categorical tone close to the claims of those affected and their relatives, who are specifically mentioned.

A further gap between saying and doing can be seen, not between what is proposed by the Senate in the Report of the study committee commissioned with analysing the particular situation of the patients and what is established in the RD strategy, but between what is stated in the text of the Strategy and its real application. At this point, it may be of interest to point out that it is the whole Parliament which often comes forward as the lobbyist: « Parliament is asking for financing and a plan against rare diseases » (ELM, 16.03.10) (ELM, 16.03.10). « Parliament is asking the Government to finance products and surgery treatment that are ‘absolutely essential’ for patients with rare diseases » (DIS, 17.03.10). « Parliament is asking for the rare disease strategy to be applied» (DIM, 18.03.10). « Parliament is asking for real application of the RD strategy» (DIM, 18.03.10). If all these headlines are analysed, they will nevertheless be seen to allude to the request for a plan, when that plan already exists; that financing is being requested for ‘absolutely essential’, products and surgery, while it is known that not all the social and sociomedical agents coincide as to what ‘essential’ means. In fact, this has been one of the grounds for greatest confrontation between those affected, relatives and associations, on one side, and administrations, on the other, in the last few years. Insinuation is also a very useful technique in these headlines, given that asking for the strategy to be applied insinuates that this is not being done. Finally, the adjective ‘real’ implies a manifest denunciation in the last headline. Other pieces of information have a different profile, through offering an over-optimistic version, by depicting an improvement (which is at most going to be requested) as something already agreed (as if it were already a reality).

The discourse found is indeed also very different depending on which type of administration is proffering this. Special mention should be given to councils. Municipal policy’s approach is in theory closer to citizens’ sociomedical problems and this can also be seen in the sphere of rare diseases. This closeness can be materialised in support for patients’ demands and their awareness-raising campaigns. One very special case might be that of the Murcia town of Totana. There councillor Juan Carrión acts as promoter of activities at the Council, but also as spokesperson of the *Federación Española de Enfermedades Raras*, and furthermore as the relative of a little girl affected by a minority pathology. This triple status, and very particularly, belonging to the group of those affected and relatives, doubtlessly generates greater capacity for political action and thus for gaining support: “Similarly,

Carrión Tudela has announced that both municipal departments will be presenting a motion to the Plenary Session of the Council for the institution to support the commemoration of this World Rare Disease Day by participating in the acts to be held as well as backing the claims to be presented through the awareness-raising campaign” (TOT, 19.01.10).

Another interesting example which comes up in the corpus is that of Alcalá la Real, where the approval of a manifesto of support was requested, through the Popular Party, for the celebration of the World Rare Disease Day. Observe that the petition seeks unanimity: “This request has given rise to a motion which, after including the amendments of the PSOE, the PP and Esquerra Republicana-Izquierda Unida-Iniciativa por Cataluña-Verdes, was backed by all the groups and urges the government to truly apply the strategy” (COF, 22.03.10). One should take note of the importance of the adverb ‘truly’. The allusion to the truth in one of its lexical-semantic forms makes one of the most severe criticisms on the gap between saying and doing, a point which was discussed above.

Another key concept is ‘unanimity’, since in such a sensitive field it is hard to find someone failing to express their support, regardless of the political ideology that they may defend. One should of course at this point again remember how easy it is to find solidarity with a discourse involving general and more abstract support, in which hardly any specific actions are being requested. In any event, there are again some possible nuances in this matter; for example, the ones stemming from the use of the verb ‘to ask’ or the verb ‘to demand’. In the news item entitled «PP interested by rare diseases », it reads: “For the celebration of the World Rare Disease Day next 28th February, the Popular Party of Alcalá la Real has put a proposal to the plenary session of the Council for the joint approval of a manifesto in support of those affected by one of the approximately 7000 diseases grouped in this category, in order to be read and passed at the ordinary plenary session” (IDE, 11.02.10). It is rather strange that the headline should foster greater distancing and greater interpretative ambiguity, resulting from the appearance of the word “interested”. In this other heading of the newspaper Jaén, nevertheless, the word used is ‘request’, whereas in the later development of the information they talk of ‘demands’: «The PP is requesting more support for people with rare diseases and their families» “Alcalá’s Popular Party is demanding greater support for the group of people with rare diseases and their families” (JAE, 10.02.10).

9.

THE DISCURSIVE TREATMENT OF RESEARCH AND RESEARCHERS IN THE FIELD OF RARE DISEASES

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Research obviously has a central role in social discussion on Rare Diseases proves. Patients and associations clamour for further progress and more resources to encourage scientific activities. On one hand, they are well aware of the shortage of treatments for minority diseases and on the other, research is what best expresses the idea of ‘future with hope’ for those affected and for their relatives.

Two types of contradictory evaluation discourse thus coincide in research: negative evaluation, which denounces the shortage of treatments and investments in RD and which can be materialised in such headlines as «The diseases that no-one researches into» (VER, 14.01.10); and positive valuation, since research is precisely where a path towards a solution for a good deal of the problems stemming from the fact of having an RD can be found.

Apart from these guidelines the following sections can be established in the discourse on research appearing in the media: (1) salient features characterising research into RD: coordination, applicability; (2) appraisal of research and researchers; (3) information and scientific dissemination; and (4) arguments and counter-arguments on research.

1. SALIENT FEATURES OF RESEARCH INTO RD

The peculiarity of minority diseases makes researchers and doctors, like those suffering from them, issue public statements insisting that cooperation, joining forces is necessary. As was stated elsewhere, Doctor Palau proposes tackling these diseases from a multidisciplinary, ecological standpoint, which takes into account the relation of the

individual with the environment and social aspects. When this researcher was interviewed, the headline expressly reflected this impression: “The answer to the set of low-prevalence diseases involves coordination”, (EDC, DCA, 3.12.2009). When he mentions the contribution of the CIBERER, Palau values it from this angle and considers this to be “a model of cooperative research with nothing comparable to it in Europe or anywhere else in the world”.

The importance of cooperation leads to researchers’ statements in the press emphasising the need for seeking mechanisms, initiatives which even enable dividing up the work, coordinating the information or data compiled. Armando Giner considers that it would be useful for molecular biology laboratories to join forces so that each one could handle particular tests as a reference centre in order to take advantage of the resources available. As this specialist himself points out, this sometimes comes into contradiction with the structures established by the autonomous community system (HER, 25.02.10).

Along with the need to coordinate scientific activities, research into RD appears to be marked by another basic trait in the press: it must have a practical nature (applicability). Research, it is often stressed, must produce results, and must have a clinical application. The declarations of the CIBERER’s scientific director insist on this point time and time again. All the projects includes the objective of “the research being free-flowing and more transferable to clinical practice” (DIM, 26.02.10); “our aim is to improve knowledge on these (diseases) resulting in an improvement in patients’ quality of life, in both the diagnostic and the therapeutic senses” (DIM, 15.02.10); “the objective of the CIBERER is to perform quality research into rare diseases which is then passed on to the patient” (NME, 01.03.10).

The search for therapies for RD provides an emblematic example of what is known as ‘translational research’. In this context, the adjective ‘transnational’ becomes very commonplace in the corpus analysed. It is said of the CITRE that “it will concentrate its work on translational research” (DIS, 27.02.10); it is no coincidence that its name should already contain this idea: Celgene Institute of Translational Research Europe (PMF, 26.02.10). Expressions simplifying its meaning are used along with this term in order to get through to the average reader. One can thus find such phrases as ‘conveying laboratory progress to patients’ (PMF, 26.02.10), ‘giving the patients the benefit of scientific discoveries as soon as possible’ (PMF, 26.02.10; DIA, 26.02.10) or ‘transferring laboratory results to the patient’s bedside’ (NME, 01.02.10).

To conclude this section, we would like to emphasise certain contradictions which are somewhat accentuated precisely in the field of communication. Scientific work requires a coordination of efforts beyond national frontiers, but that requirement sometimes comes into contradiction with other more local-level political structures.

The interpretation and impact that these subjects have mean that there is a paradox between the demands of science on one hand and the practice and approach of the media, on the other. Science seeks universal responses and promotes cooperation between researchers from different countries. The headlines leave no doubt about this: «Seville is to be the venue for development of pluripotential adult stem cells», XXI, 17.02.10, from EUP); or «The strange disease of the Costa da Morte», a variant of ataxia, in which the focus pinpoints the origin of the cases found (ELP, 17.12.09). There is thus a contradiction between the scientific objectives and the readers’ interests which requires some reflection so as to avoid any errors or lax approaches.

2. APPRAISAL OF RESEARCH AND RESEARCHERS

The importance of the work done by researchers is something unanimously acknowledged by all sectors. Patients have no doubts about that. The progress made in genetics mean that the risks of undergoing a rare disease can be foreseen, and for many of the people affected, going to a research centre or participating in some clinical test or drug being experimented with means their sole hope.

The highly positive representation of research that we find in the press is also connected with the feeling of fascination aroused by the bio-technological area at the present time, which is shared by communication professionals and media. The Medical Genome project, directed by doctor Antiñolo and closely related with RD, is thus presented in the press, as was already affirmed in a previous chapter, as “the greatest step forward in genetic research since the complete sequencing of the genome in 2001” (COR, 14.02.10). The researchers in turn constantly assert this point in their declarations that the media hasten to reproduce: the work done with adult stem cells and gene therapy provides

“the greatest benefits for patients”; “has enabled us to develop cell therapies adapted to them, and thanks to genetics we are starting to learn the causes and processes of these diseases and to develop new therapies” (XGA, 07.12.09).

For all these reasons, it is understandable that one should find key words which are often used in press information to express or consolidate that feeling and which are connected with ‘the pioneer element’, ‘the new thing’, ‘the first’, ‘the exemplary quality’, ‘leadership’, etc.. It goes without saying that it is easy to find an indirect reference to competitiveness and comparison behind these expressions; in fact, sometimes the terms of the comparison are clearly expressed (between countries, between continents, between hospitals, regions or companies, etc.), and that research in the field of genetics tends to be particularly prominent in the hyper-positive representation of research into RD. Here are some examples:

(MTV, 27.02.10).	“In spite of having much lower investment than the United States, Europe is today the leader in the field of research into gene therapy of monogenic diseases”
(DIM, 13.01.10)	“In the curative plane, many specialists have their sights set on gene therapy, which will probably be the most effective option in the future”
(LAV, 02.03.10)	“Europe is now at the head of this research and Spanish teams, many of them in the front line”.
(LUK, 27.02.10)	“The CSIC is the first Spanish public body to get the designation of an orphan drug”
(LNE, 28.03.10)	“Ignacio Blanco, ‘Asturian of the month’ of February through his pioneering research into fibromyalgia”
(MTV, 27.02.10)	“Similarly Doctor Lluís Montoliú presented a new system for development of universal genetic diagnosis of albinism, which his research group is carrying out in cooperation with the Asociación de ayuda a personas con Albinismo (ALBA)”
(PMF, 26.02.10)	“In this respect, CITRE represents the culmination of the paradigmatic change brought in by the Andalusia Authority some years ago by promoting high-level biomedical research as the top priority”
(DIA, 26.02.10)	“Seville is to be the venue for a ground-breaking centre for research into cancer and rare diseases ”
(PEX, 19.02.10)	“The region stands ‘in the European avant-garde as regards the early detection, care and research into these diseases”
(HER, 08.03.10)	“Aragon is a worldwide reference in the study of the diagnosis and treatment of these pathologies”

(LAP, 30.01.10)	“Pioneering initiative in the Archipelago”
(PUB, 11.03.10)	“Two studies published today have opened up the age of the <i>familioma</i> ”
(PMF, 26.02.01)	“”CITRE represents the start of a new era for medical research in Spain. A new paradigm which will speed up finding solutions for treatment of rare diseases, cancer, inflammatory diseases and advanced therapies, including cell therapy and regenerative medicine. In short - a model of unity, cooperation, communication and progress’, stated Sol J. Barer, Chairman & CEO Celgene Corporation”

Table 27. Portrayal of research into RD

One can understandably also find examples in which the effort entailed by researching precisely into RD is assessed: “It is a sign that science is not forgetting these low- prevalence, complex and sometimes devastating pathologies” (DIM, 26.02.10).

Along with the positive valuations there are critical testimonies. In these cases one should nevertheless stress the fact that people prefer to talk in general terms about research or about shortcomings, weaknesses or failures of science, and not so much of scientists and researchers: “When science does not manage to explain what is failing in human machinery, the sick have to face up to a long trail through medical institutions, an economic overload, a feeling of isolation, exclusion and an insult to fairness” (ECO, 27.02.10).

Some of these criticisms can be found in the discourse of patients and associations. They are the ones most interested in fostering projects and actively cooperating in initiatives seeking resources for research. For this reason, they never stop saying that this research needs to be fostered, that it is insufficient. In this respect we need to understand the statements in which they declare that ‘they feel abandoned’ by research: as a denunciation of a situation and as a way to claim further aid for scientific work. («Three families marked by their genes», ELM, 01.06.09).

The most significant aspect can perhaps be found in the arguments that are put forward to justify the lack of research into RD. This involves a clear argument about their complexity and purportedly unapproachable aspect, materialised in the discourse in very different ways and with similarly diverse degrees of explicitness. Here are some examples of possible dissuasion strategies in respect of research into RD: “one of those realms where reality comes up against desires and necessity”. (DIM, 12.03.10). “Rare diseases

[...] are complicated and unprofitable” (ELP, 02.03.10); “a wide range of rare diseases” (HER, 14.03.10); “a group that is very difficult to cater for” (ELP, 16.02.10); “complex and heterogeneous mosaic of the roughly 9000 pathologies” (GAC, 02.03.10); “‘it would be impossible’ to look for all of them” (PUB, 04.03.10); “in each of these there are multiple variants” (HER, 08.03.10); “There are almost as many forms of the pathology as there are of those affected” (LAR, 21.02.10).

In the media, this complexity is seldom interpreted as a challenge for research in the sphere of health or as something that can be got to grips with. One of these exceptions can be found in a contribution by Rafael Artuch, a biochemist at the Hospital Sant Joan de Déu, published in *Abc* with the title «The solution is in our own hands » (13.03.10). In the body of the text it states the following: “The way to solve these problems is in our own hands. We can follow the example of other countries and perform serious and well-organised work, abandoning vain and suspicious rivalries”.

The challenge meant by researching into RD may sometimes be put forward as an ‘adventure’, which implies a risk, as we can see in the following examples: «A three-year adventure to bring about a revolution in diagnosis» (HIN, 01.02.10); “The Regional Health Ministry’s commitment for the coming five years” (DIM, 09.02.10).

Although one can find direct criticism of ‘the scientists’³¹, researchers are generally described with a positive profile, as already mentioned. Certain images tend to be found in this area. Their achievements in some cases are seen as ‘miracles’ (SUR, 26.03.10; LID, 26.03.10), and they themselves come forward, in some press narrations from our corpus, as ‘an invisible army’, ‘guardian angels’ or as ‘ants in white lab. coats’. Articles tend to stress the silent work that they do, their tendency not to be seen in the media and for their research not to arouse the pharmaceutical industry’s interest in this case (ELM, 01.03.10). The power of the metaphors that were noticed in stories on minority disease thus extends to researchers, represented as fighters in that same battle.

Through the high value given to research, one should stress other roles played by scientists. In the corpus analysed it was seen that scientists appear in the press, more often than initially imagined, assuming functions supposedly pertaining to other actors. A significant one of these is the role of making society aware and sensitive to the situation

³¹ Sub-heading: “The aim of those affected is to struggle so as not to be forgotten by scientists” (ATL, 28.02.10).

of those affected and their relatives: “Throughout this programme [of conferences], six prominent international scientists explain the present situation of rare diseases, with the aim of raising awareness and making public opinion sensitive to the scale of this problem” (EUP, 15.03.10). It has been shown that researchers also use formulas for bringing this type of pathologies closer to society, either by generalising their presence, or reminding us of the fact that we are all possible people affected or relatives of sufferers, as can be seen from the examples given in the following table:

(SUR,10.03.10) (DÍA, 10.03.10)	“The Scientific Director of the Centre for Biomedical Network Research on Rare Diseases, Francesc Palau, yesterday affirmed that around three million people in Spain suffer from a rare disease, but that these ‘affect us all, more than one might think, because many of them are genetic’”
(ELP, 09.03.10)	“‘Although these are called rare, there are thousands of them, so someone close to us is likely to be affected by one’, asserted the director of CIC Biogune, José María Mato, at the presentation, to give an idea of the significance of the problem”
(LOT, 01.03.10)	“So [Eduardo Salido] explains that everyone has ‘a mutated gene among the almost 30,000 in our bodies, but since we have two copies of each of these, most of the population do not have any symptoms of these genetic diseases”

Table 28. *Discourses for making RD more accessible to society by people linked to research on RDR*

The proximity of researchers and the mutual benefit generated by contact between them and patients thus finds a place in the media. This is shown in the following example: “Many scientists working in this field are in close contact with associations of affected people and a good deal of their research work would not be possible without the cooperation of patients, willing to donate their samples to science and try out experimental drugs which may benefit others in the future” (ELM, 01.03.10). It should not be forgotten that the success of some research lies precisely in this kind of cooperation, sometimes represented by more emotional expressions, such as ‘lending a hand’ (EDV, 28.02.10), ‘strengthening bonds’ (GAC, 27.02.10) or ‘being closer to the patients’ (GAC, 01.03.10): “Cooperation between basic, clinical researchers and patients’ associations has enabled the achievement of an orphan drug being designated by the European Medicines Agency

(EMEA), as explained by Carmelo Bernabeu and Luisa Botella, researchers of the CSIC and of the Ciberer” (ELM, 01.03.10). Over the months analysed they also regularly allude to the value of associations (or of families) as groups able to collect money for research (Fondo Biorret, MTV, 27.02.10; Fondo Juanma, PUB, 04.03.10; Proyecto de Neurofibromatosis, YOD, 09.01.10, etc.); as organisers of congresses with a research profile (LAR, 10.01.10); as subjects involved in clinical trials (COR, 14.02.10), or as victims of cutbacks in research through the economic crisis (PRO, 30.01.10).

It is also worthwhile considering a few lines on how the significance of research, almost always overvalued in headlines, is portrayed: «Researchers are confident in gene therapies for solving rare diseases » (ECO, 26.02.10). In the development of this news item we can see that in his/her declarations, the witness acting as a source talks of both curing and palliating. Quite aside from this, when informing about RD it would be important to set what “effectiveness” means properly, since containing the development of one of these pathologies with a degenerative profile (‘checking the disease’) may be very clear proof of effectiveness, not actually what is being insinuated: “Unfortunately, the existing drug for Pompe’s disease is not effective in all cases. It is above all in newborn children, but in older children and adults it checks the progress of the disease and does not revert it” (PUB, 04.03.10).

We would lastly like to make some brief remarks on the CIBERER in this section. Over the years it has been running, this Institution has undisputedly become a reference for research into RD in Spain, although some means of communication do not seem to understand its structure clearly and use certain distancing qualifiers, such as ‘sort of’: “Ciberer (a sort of agglutinating body set up in November 2006 [...])” (ELM, 01.03.10). Still, when RD research groups in Spain are being discussed, a mention of this is usually found: “This research group belongs to the Centre for Biomedical Network Research on Rare Diseases (CIBERER)” (ADN, 18.03.10). It also tends to be given the same value adjectives as research into RD in general, as referred to above: ‘pioneering’, ‘first’, ‘innovative’, etc. See the following example: “The Centre for Biomedical Network Research on Rare Diseases (CIBERER) is a pioneer in Europe and has few references in the international scenario as a model of institution in a consortium structure. It is promoted by the Ministry of Science and Innovation through the Instituto de Salud Carlos III, and made up of 30 main concerns (public but also from the private sphere) researching into rare diseases. The CIBERER manages, coordinates efforts and generates synergies between 61 research groups and over 700 scientists and re-

searchers” (NME, 02.03.10). Some specific projects, such as the CIBERER Biobank, have also come into the news over these months (DIS, 01.03.10). Greater balance between the institution itself as a trademark and its main spokespersons still needs to be ensured.

3. INFORMATION AND SCIENTIFIC DISSEMINATION

The texts of the EU or the National Strategy itself constantly point out the need to establish cooperation mechanisms. Researchers state this in their declarations to the press when commenting on their work and appraising the relationship with rare disease sufferers and associations. Patients and researchers are groups needing to face up to the problems entailed by RD together. One might nonetheless think that scientists and patients sometimes form two different worlds, precisely through the language used.

If people affected sometimes talk of the impression that it makes on them to be given a diagnosis that they can hardly understand, this problem is even greater when the results of a piece of research are explained. Information about research is often passed on in the media in excessively technical language. Lack of understanding is particularly important when the news item stems from the publication of a scientific article, as occurs in « E3 ubiquitin ligase APC-Cdh1 activates the glycolysis of the cell process », (DIM, 24.12.09). Here we undoubtedly come up against the journalist’s difficulty understanding a piece of research work. This is why a number of resources attempting to palliate the difficulty are often found.

To define what the disease is, the doctor or researcher’s words are reproduced literally instead of seeking a way to put the information across more accessibly: “Considered as one of the rare diseases [leukodystrophy], it is - according to the Head of Neurology of the Hospital Universitario de La Candelaria, Fernando Montón – ‘a neurological illness with alterations in the myelin sheaths which, through not forming properly, end up in this type of pathologies’” (Abc, 01.06.09).

It is especially surprising to see the use of this language so riddled with technical terms by the patients or on the pages of the association, in which they should always bear in mind accessibility for different types of readers, as they attempt to do in Orphanet. It is even very noticeable that when cooperation between patients and researchers is discussed,

this leads to an inevitable contagion of scientific terms in the associations themselves: “the patients are major catalysts of the research” (EUP, 26.02.10).

The use of a type of language that is so hard to understand means that press articles are quick to incorporate any fragments in which common terms come up, or in which there is an image, a metaphor, that enables a foothold for understanding to be gained. With the title «Genome. A compass for health» the project directed by doctor Antiñolo is reported on (DSE, 28.12.09). The text shows us that they are trying to build a pattern for the human genome, “as if this were some kind of compass for the health”, to detect the mutations which give rise to major diseases. The comparisons used by the researcher easily open up a way to understanding the text: we are told that we do not know much about the variations in the genome - “we only know a few pieces which are like the pixels of a photograph”; the challenge now is to get a quality photograph”.

The appearance of a colloquial image or a comparison could always be said to be picked up by the media, which always need this kind of approximators. One good example is in the comparison established by Doctor Pineda between the way the MECP2 gene acts in Rett syndrome and the way an orchestra works (INT, November, 2009).

The failure to use more down-to-earth language that can sometimes be found turns out to be even more appreciable in the field of RD because, as specialised doctors recognise, we are talking of “well-educated patients”, concerned with finding solutions and particularly interested in learning about the latest progress (VER, «The ‘glass girl’ is now 27 years of age», 07.02.10). In this respect we could stress the sub-heading “Doctors, researchers and relatives”, stressing the close relationship between them for dealing with hereditary hemorrhagic telangiectasia («Sierrallana is the only hospital in Spain where they cater for the RD “HHT” », EDM, 17.06.09).

Communicating the results of a piece of research is a particularly complex matter. The information required is generally not given and items which are decisive for its valuation are often concealed. The press article says something about the procedure or the characteristics of an experiment, without the reader having the elements needed or the ability to define the value of the results or the appropriateness of the conditions. In this situation the article has other functions, aside from the information that it transmits. It generates inferences: in some cases it provides a tranquillising, soporific effect; the impenetrable language puts across the idea that things are moving, that it is all a matter of time, a highly

qualified world. On the other hand the reader’s inferences arise from the fact of the information provided not being what they are looking for: the effectiveness or the application of this ‘discovery’. That is why they will infer aspects not actually meant to be there and deduce that stressing this news item means there is a therapy.

In this section the language used proves highly significant. The precision found when describing the experiment is turned into vague text suggesting expectations for the reader that are hard to verify.

As regards the use of IPS cells, we are told, for example, that “this has great potential value and the application of its results is expected to be able to give a response to people’s health needs in the medium term”. The vagueness forces qualifications to be made in the same piece of news: Cibelli pointed out that ‘it is still too soon to talk of results in patients’, ‘in an initial stage we will have to make these cells safe and in a later stage make them effective’ (XXI, 17.02.10).

The fascination generated by areas such as biotechnology was mentioned above. The fact that researchers are seen informing about the progress made and seldom about the setbacks has a lot to do with this. It is therefore not surprising that the information focusing on researchers in the field of RD should sometimes prove excessively optimistic. A few examples may illustrate this point. «Geneticist Robert Desnick is making known the keys for treating hereditary rare diseases at the Fundación BBVA in Bilbao» –it states in a free general paper (20M, 15.03.10). Should we glean from this that they are going to treat all hereditary RD? Obviously not! This is an optimism which is also appreciated on such occasions as when the birth of a healthy child is enabled through the use of the preimplantation diagnosis. In this example it is important to observe whether or not the indefinite article ‘a’ is used with ‘dystrophy’, since interpreting the success as it should really be understood partly depends on this (they are talking about a type of dystrophy and not dystrophy in general): «First Spanish baby born free of muscular dystrophy after an embryonic diagnosis » (LVG, 26.03.10) « First Spanish baby born free of a hereditary muscular dystrophy of the face and arm » (GEN, 25.03.10) « First baby born free of muscular dystrophy in the face» (LRA, 26.03.10) « First baby born free of muscular dystrophy after a genetic diagnosis» (SUR, 26.03.10) « First baby in Spain born free of muscular dystrophy » (HOY, 26.03.10).

These are statements which doubtlessly give rise to great expectations. The journalist’s work consists in making known the importance of some studies, even before starting,

but responsibility must also be assumed for analysing what has happened during their development and whether the goals have been attained,

Among so many exultant declarations our attention is called by the caution with which some researchers from the Hospital 12 de Octubre, specialising in RD, deal with the matter, and the fact of having found a niche in the media. The team “attempts to make steps forward which later on, sometimes up to ten years later on, will be applied to these patients” –states the reporter –; “Sometimes all our work only represents a tiny step in diagnosing a strange pathology better, but that is the direction to head in” (ADN, 08.06.10, Raúl Rejón).

As one can see, informing about research into RD is a challenge through the dissemination effort that this entails, particularly in the general press. Some of the basic concepts tending to appear in stories about these pathologies which ought to be emphasised are the ones that comment on the search for and (in the best cases) discovery of treatments. Some examples connected with the stages of clinical trials, orphan drugs or the so-called compassionate use of drugs allow one to see how complex these matters are. When reading the assertion that “today there are clinical trials of pharmacological therapy for the first of these” (MTV, 27.02.10), referring to a mutation of Rett syndrome, a basic question comes up in order to understand the real significance of the information: What stage is the trial in? The same thing occurs with the following example: “The ELA network is furthermore working on several lines of research, an important part of which are four clinical trials” (EUP, 28.02.10). It is most vital important for the media to get used to incorporating this type of data and to explaining it. One example of appropriate information can be found in the following text: “Marcela del Río (Ciemat) is leading a trial seeking an alternative source of collagen VII in transplanting allogenic fibroblasts for patients with dystrophic epidermolysis bullosa. The product is already an orphan drug and the second stage of a test is being completed, promoted by Celerix, and whose main author is Juan Carlos López, a surgeon at Hospital La Paz, de Madrid” (DME, 27.02.10).

The importance involved by the time factor in the discourse on RD is of course applicable to research. In the field of gene therapy or the approval of new techniques for diagnosis and treatment, there are people such as Félix Notario (Asociación Nacional de Pediatría), who say that “it is going to be a long time before we see any results” (VER, 24.03.10) or those who decide to give a deadline for getting treatments under way. This is the case of Francisco Errasti (director general of the CIMA), who, in a virtual chat with the readers of

the Diario de Navarra, says, about sclerodermia: “if things go on as they have been doing up to now, it will be available to the patients in two years” (DNA, 27.03.10).

If putting across scientific information entails major problems, it is also true that some publications find suitable solutions. As has already been stated, our impression of the treatment of RD in the press analysed is that this information can be improved on, but at the same time be considered positive. In this respect mention is deserved by the sections designed in publications such as La Razón, El Mundo or Diario Médico to put across the main concepts and references to the reader: symptomatology, diagnosis, reference centres and addresses of associations, amongst other aspects.

4. ARGUMENTS AND COUNTER-ARGUMENTS ON RESEARCH

Research has been shown to involve a discourse with arguments and counter-arguments in which there is a fairly intense, but not always highly explicit, debate as to whether a lot of money ought to be invested in research into such low-prevalence diseases. The counter-argument is clearly seen to be very well established in our corpus. At different points it is emphasised that this research also makes great contributions to people affected by more frequent diseases. This is also an affirmation occasionally appearing in the discourse of the researchers themselves, with the added prestige value that this entails: “What is discovered in one of these pathologies may be of key significance for understanding and treating other more common diseases” (EDV, 28.02.10); “apart from managing to solve the sociomedical problems generated by these disorders, extremely specific findings in certain rare diseases are sometimes applicable to more common problems” (Abc, 13.03.10). Readers are thus informed that the scientific analysis of the Sotos syndrome “could lead to new treatments for both ailments and early diagnosis methods for tumours” (PUB, 19.12.09). This point of view is upheld by Juan Pie “helping these patients means supporting a more extensive population group” (DIM, 06.11.09, about the Cornelia de Lange syndrome). As doctor Nurden makes very clear in her research into the anomalous operation of platelets, “Rare Diseases help us to understand other diseases” (the prevalent ones) (ELP, 24.11.09).

The press never ceases to find other arguments of great value for supporting research into RD. The knowledge that is being gained is coming in a field which nowadays arouses such great expectations. Amongst others, Juan A. Bueren (CIEMAT) puts this very clearly:

“RD are the diseases that conceptually will teach us more about how to carry out gene therapy and in which this will be most likely to result in clinical benefits” (DIM, 26.02.10). The rationale for the Genome project directed by doctor Antiñolo lies in the fact of a good deal of rare diseases apparently being connected with the behaviour of a single gene. Studying these is therefore possible and much more practical from the present state of our knowledge, unlike the situation occurring with other more complex diseases, in which other genes or even environmental factors are involved.

Another argument, as already stated, is the one referring to the impossibility of researching into each of the Rare Diseases identified. The counter-argument has consisted in pointing out the importance of transversality: the existing drugs for prevalent pathologies may be of some value for the less frequent ones, in the same way as the progress made in certain RD has repercussions on other, also minority, diseases. The following news, about Hereditary Hemorrhagic Telangiectasia, was thus published: ‘When raloxifene [a drug which is used to prevent osteoporosis] was administered to menopausal women who also had HHT, doctor Roberto Zarrabeitia (from the Hospital de Sierrallana, in Cantabria) discovered that this improved bleeding’. The next step was to pass on this discovery to the laboratory in order to find out the mechanisms by means of which this occurred, a project financed by the Fundación Ramón Areces” (ELM, 01.03.10).

Issues linked with investments sometimes lead to confused approaches from the journalists themselves. One of the information articles reads as follows: “Manuel Posada, a doctor from the Instituto de Investigación de Enfermedades Raras (RD), demolishes the cliché that sufficient money is not allocated to these low-prevalence diseases. ‘In actual fact this is a much more complex problem, where research will never be enough because we will never manage to get as far as the last nook and cranny to be discovered’” (ECO, 27.02.10). Doctor Posada does not therefore refute the idea that little money is assigned, but only says that, however much is assigned, it will always be too little, in view of the complexity of these diseases. In any event RD and the costs stemming from their diagnosis or treatment, (when there is one) form a topic often associated with the economic problems of our public health system: “the endless haemorrhage which health expense, and particularly pharmaceutical costs, have become” [...] “What can we say about rare or non-diagnosed diseases” (Abc, 23.03.10). In the present economic crisis situation, there are not many people who have dared to stress the consequences that such a state of affairs may have for RD. The following headline was published, referring to Francesc Palau,: “Expert warns of the economic crisis possibly slowing up inertia in the fight against

rare diseases » (ADN, 07.01.10). It is brave to say so, and also brave to place this information in a headline.

The present direction being taken by the economy means that any evaluation of scientific activities always goes along with the recognition of the companies that back these. Administrative and political authorities are aware of the prestige that research has in our society and the support provided and the progress that has been made are reflected. The investments of the Celgene company in Andalusia, partly assigned to RD, are welcomed as such by president Griñán, as a way to support “a model of development” creating “wealth, employment and welfare” and research into health as “a sign of identity in Andalusia” (DSE, 26.02.10).

Readers are thus utterly bewildered by figures and statements far beyond their own experience and that need to be examined in greater detail. When enormous investments, or purchasing equipment is being talked about, one must ask about the scope of these statements; whether these sums are sufficient to undertake top-level research, whether the human resources necessary are also available and whether there is the backing to ensure that this means more than just a promise. Another point to be stressed along with this question is the fact that there is some confusion about the role and the support that this research needs. All the applause for the companies contributing to the economic development of a region should not blind us into forgetting that researchers do not work with credits, but with subsidies, since their aim goes beyond marketing a product. The remarks made by Margarita Salas at the start of the debate on the cutbacks in budgets intended for research are very meaningful in this respect (ELP, 04 and 07.10.2009).

Pharmaceutical companies understandably have their own specific influence in the discourse on research and infrequently found diseases. Some important mentions have indeed already been made, for example, of Celgene and its CITRE. Another company often mentioned is GSK and its new unit: «GSK creates a new specialised unit to research into and develop treatments for RD » (ACS, 06.02.10, MTV, 10.02.10, DIS, 08.02.10, EUP, 05.02.10), «GSK will fight RD with a new specialised division » (EGL, 08.02.10). There are media who prefer to use the verb ‘create’, more objective than the alternative of ‘combat/fight’, which furthermore links up much better with the metaphorical framework of the battle, so commonly found in the narrations of patients with RD and their families. Genzyme furthermore appears in the year studied in this research through its indirect important role in the film *Medidas Extraordinarias* (PRS, 27.02.10; XLS, 28.02.10) or through the

problems manufacturing some of its drugs for rare diseases (ECO, 23.03.10), although its commitment to creating jobs of work partly connected with its research projects also had repercussions (PMF, 30.01.10). The development of new drugs or new services for selection of embryos is the basis for several mentions of Novartis (RME, 16.01.10), Neurosearch (NME, 26.02.10) or Sistemas Genómicos Canarias (Abc, 30.01.10). This last news item is in fact the one in which RD are referred to as being a hotchpotch.

Other companies have steered their role further towards awareness-raising and information about ER. This happened for instance with Shire (EUP, 01.03.10) or Merck (DIS, 02.03.10). There are also more general references to the responsibility which has to be assumed by companies through their lack of involvement in research into RD: “But that name [orphan drugs] also stems from the fact that the bulk of the pharmaceutical industry has traditionally not had any interest in diseases which do not make their research profitable, through being so uncommon, which is why the importance of public involvement is so great” (LOT, 27.02.10); “The possibility of suffering from Niemann Pick is one in a million. ‘That is why the pharmaceutical industry is not interested in this’ says the secretary of the Foundation ” (HOY, 117.02.10)

10.

AN ANALYSIS OF MULTIMODAL DISCOURSE: PHOTOGRAPHS IN INFORMATION ON RARE DISEASES

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Images involve a particularly complex language. They represent a deliberate selection of reality, taking one part and silencing the other parts. Their role is not passive but active. They very often imply a comment, an evaluation, an interpretative approach rather than simple representation. One vital characteristic also comes into play: the language of the picture, the photo, is not often consciously perceived. On one hand, it is aimed at the emotions and persuades more effectively; on the other it reaches people in an overall sense often without them being aware of the inferences, and the details that are unconsciously being taken in. One should finally bear in mind that very frequently the headline and the photograph selected are the only parts that reach the reader.

Photographs illustrating articles concerning RD are not alien to these considerations. They may mostly seem neutral, not very expressive, more objective; they are apparently items simply adjoined to the text and represent the people attending an event, the people interviewed, the people affected by a disease or a number of diseases. This is not quite so, nevertheless: they mark preferences, and highlight or play down particular aspects. An example might help to appreciate this better. Earlier on, in the discussion of loudspeakers and projectors, it was mentioned that well-known personalities boost the information's power, but at the same time displace the attention, pushing the real actors into the background. Photography stresses this same situation. The photos used to illustrate the presence of the FEDER at Parliament in February 2010 clearly reveal the point we wish to make. The centre of attention is the Speaker of the Congress, the Infanta, the Health Minister, with the president of the association or the people affected who took part in the event hardly being seen. The photos depict the event, which boils down to the presence of people with some public relevance, overshadowing the reason why they were actually taking part in this.

Other factors that need to be taken into account are involved in the analysis of pictures. Anyone looking at these does so in accordance with assumptions and an established tradi-

tion. In the case of RD, along with the subjects of the news – patients, doctors, politicians, directors of associations – there are the hackneyed images in which the centre of interest is taken by a close-up of an affected organ, of some genetic material under the microscope or of some scientific instrument. These are photographs used above all to go with the news items connected with research or scientific progress. They do not however have any direct connection with RD and their problems, merely putting across general connotations as to the meaning of health and the role of medicine.

The predominating pictures of interest to us head in quite a different direction. The ones standing out most are photos in which those affected and their family settings are shown. Close-up and medium-range shots are prevalent, allowing the reader to infer a number of psychological traits. It is not a matter of chance or something that ought to be seen as a simple graphic testimony, merely vouching for what happened.

There is a clear line of argument in the discourse surrounding RD: patients have to go through a personal struggle, and have to compensate for the scant aid that they are given with their own hard work. They often feel discriminated by the negligible results and initiatives obtained by research. The ignorance of their pathologies, even in healthcare spheres, makes them feel that they are up against an indifferent and sometimes hostile society. Photos provide specific value as opposed to this invisibility. They make them visible, revealing people who are demanding their right to be able to have the same trust in the healthcare system as the readers have when they seek a solution for their own problems. The implicit associations that these pictures have for anyone familiar with RD and their problems are obvious. Some specific examples will help to appreciate this.



Photo 1

The article on RD from La Verdad de Murcia, entitled «Orphan diseases» (LAV, 28.11.09) and subtitled “Over one hundred families with “rare” pathologies get together in Totana” (Text: J.P.Parra; photo: Paco Alonso) is illustrated with a photo (picture 1) and the following caption: “Andrea García hugs her son Eloy, who is 16 years of age, and suffers from Fragile X syndrome, at their home in Totana”.

Nothing in this photo would seem to be stressing any particular significance. Its importance nevertheless becomes clear as soon as one sees that the illustration, with a long horizontal format, takes up 50% of the space reserved for the news and is placed in a preferential position, over the text. In spite of its apparent simplicity, the image undoubtedly shores up the impressions that the article wishes to convey to the reader through Andrea. The text reminds the reader of the impression that is made by coming up against a diagnosis, an ‘incomprehensible’ term, the lack of healthcare staff’s knowledge that can be found. As opposed to this, it stresses Andrea’s attitude and her willingness to take advantage of that negative experience: “wanting to help others in the same situation”.

The picture shows the mother hugging her son, in a close to medium-range shot. The focus emphasises the faces, with a slightly blurred background. The camera position used gives a low-angle shot underscoring the importance of the subjects. Eloy’s leaning body leads us to the left, to fix our gaze on the place where both of them merge. It locates both their heads in the main position, while the mother’s arm, firmly around her son, stresses Andrea’s strength of mind, that energy which even encourages her to help others.

The picture is very thought-provoking: the isolation of the two subjects, clearly focussed, with their eyes closed, their solitude in respect of the public sphere. The scenario is also significant: the home, the private realm as a refuge away from public incomprehension. In this respect, the photo coincides with the denunciation made in this article: “the laboratories are not doing any research and help is needed”, the struggle “against society’s ignorance”, the problems finding a suitable school ... All those who experience the everyday reality of RD will without a shadow of a doubt recognise something close to their own experience: the mother, the family setting, the only haven in the sea of hostility or general indifference.

The picture’s own values –immediacy, emotion as opposed to rationality, abstraction - are reinforced to convey the essential part of the message better: the strength and ability to act generated by feelings, as opposed to the indifference of the outside world.

With the text “Alex is not a rare creature, he just has a rare disease”, the newspaper El Mundo (19.11.2009) published a good piece of work in which it tells the situation of Susanna Blasco and her son Alex after the publication of the book *Enfermedades raras. Manual de humanidad*. Right from the headlines the text underlines the misunderstandings that can stem from the Spanish adjective ‘raro’ and insists on the role of FEDER, Orphanet and CIBERER in transmitting the right information. The photo humanises and confirms the importance of the title. The smile, playing with the baby’s hands, as well as the scenario chosen, all stress the predominance of feelings, “normality” over and above the condition of being ill.



Photo 2

In other cases the picture acts as a counter-argument to what is hinted at in the text. One example of this is taken from the newspaper El Correo Español (Álava, 28.02.10). The headline asks «How much is a life worth?». Once more, regardless of their technical quality, the medium range photos of those affected and others involved, with the face in the foreground, prompt a clear response from the reader.



Photo 3

Along with these photos, which almost always stress the presence of a carer, the importance of the family as a support to make up for insufficient aid, there is another type of picture. These are group photos or close-ups of those affected. An example of this can be found in *Huelva Información, Europa Sur de Algeciras*, talking about pulmonary hypertension. Three photos of a large close-up in the Testimonies section depict the faces of people affected and the president of the Foundation in line with the functions described. Pride of place is nevertheless given to one, the group shot, with the following caption: “Relatives and people affected by pulmonary hypertension”. The use of a photograph depicting an everyday sight, the presence of men and women of different ages, the informality, the smiling faces and the large group all remind us of the presence that these diseases can have in everyday life, the fact that they involve not only the people directly affected. This also reminds us of one essential theme: the importance of fighting as a group, of it being people who are making the efforts and not institutions. The same kind of sensations are conveyed by another photograph of the same kind. This one shows a meeting of the glycogenosis association: the group photograph brings the subjects closer and reinforces the idea of seeking the visibility and humanity that the associations are clamouring for.



Photo 4

The disease and its consequences do not occupy the centre of the picture in any of the photos mentioned, where the reader can above all see some very normal people, in emotional, everyday stances. There is however another type of photos that can be found, for example, one of Noelia, in the article entitled «Coming out of obscurity», published in Hoy (Diario de Extremadura) or Ideal (text by M^a José Carrero; photo: Fernando Gómez;

18/10/2009). A vertical shot takes up the centre of the page. Noelia, who works in the CREER in Burgos, is seen moving along in a wheel chair accompanied by her mother. This also shows Noelia's short stature, suffering as the text says from "a genetic malformation" - "diastrophic nanism", and uses her mother as a contrasting feature. Revealing the consequences of the disease has a specific function in this case. Placing Noelia in her wheelchair in the centre of the photo, in a long vertical format in a full-length shot, while the figure of her mother is slightly cut off at the side, clearly marks the consequences of her disease and indicates who the subject is. The figure also stands out through the light shining on her hair. This up-front presence of Noelia coincides with the heading: «Coming out of obscurity». The picture taken in movement, the gap between her and her mother, the personality seen in the face, the youthful design on the tee-shirt, the conversation they are having without looking at the camera lens all reveal other values indicated by the article. It plainly sums up their effort to gain the utmost personal self-sufficiency, their ongoing struggle to break down social barriers, the prejudices of those who look at her in the street; ultimately her ability to go through with her studies and lead a professional life.



Photo 5

The photos already mentioned represent a successful selection of items included in the frame to reinforce a particular message, but with a sensation of objectivity in these: the photographer seems to have merely been depicting reality in them. In other cases one can see the intention to manipulate the items seen through the lens. They reveal the deliberate aim of commenting on, judging and evaluating the news item. One example is in

the text published by Hoy and Ideal («I only know my father by his eyes », (Text by Zuriñe Ortiz; photo José Ramón Ladra, 28/2/2010). This tells of the experience of a teacher, Esther, with visual agnosia, which prevents her from identifying people, objects or places. Again a large-sized photograph accompanies the text, with Esther walking through the streets of Cuenca guiding herself with her stick. The frame and angle used give rise to very specific feelings for readers. The shot from above makes the subject shrink. The sensation of solitude is accentuated by the walls around her, the lack of any people around, placing the figure in the lower part of the page. The depth of field marked by the central line of the empty street forces the viewer to take a long visual path which makes Esther's figure smaller. This same sensation of disquiet and insecurity is accentuated by means of the angle used. This is also a photo which helps us put ourselves in the position of the person affected to some extent, since the way the reader looks is similarly upset by such a photo:



Photo 6

An appraisal of the image put across by Javier Botet in the media proves highly peculiar. The length of his arms, legs or fingers due to his Marfan syndrome give him an unusual look. The strange thing here does not become discrimination, quite the opposite. The context sometimes induces a very different reading from the usual one. In the show-business society these malformations become something eye-catching, and give him a chance to work in films playing certain roles. In the photograph accompanying the report «Born to be Frankenstein» (El Mundo, 17.03.10), the anomalies are exaggerated and the disease is voluntarily shown as something positive to a certain extent, while the subject's face and informal pose help to steer us away from any negative considerations.



Photo 7

The importance of the context in which the photo is set can also be seen in the reports in which RD are placed in a different section. This is the case of a news item connected with the death of someone affected by the Prader Willi syndrome, a serious illness which does not often get proper treatment in the press. The text was brought out with the title «A disabled person chokes to death at Virgen de la Luz occupational centre» and the subtitle “The deceased collapsed in a corridor after eating a piece of cake which got stuck in his throat and choked him” (30.01.10). The news thus comes into the category of accident reports and the photo accompanying it is of the members of staff carrying the body out on a stretcher, It is therefore not surprising that the news should be given the following comment in the association’s blog: “A sad piece of news, difficult to cope with like this: a 32-year old man died in an occupational centre in Alicante, apparently through choking”.



Photo 8

There are also sensationalist pictures to be found in the RD field. This occurred with the repeated news on the death of Shiloh Pepin, “the mermaid girl”: the same photo showing her legs joined together and lying in a posture similar to the one made popular in the mermaid myth. There is nothing to justify its insertion, since the text merely states the name, the age, the congenital problems and only on one occasion refers to the girl’s hobbies and personal friendliness.



Photo 9

Though it is not common, photos having little to do with the text can also be found, in which the picture loses that indicial value generally associated with the written press. There is an example in the news item «‘familioma’, a new front against rare diseases » (PUB, 11.03.10). The article contains touches that at times seem rather frivolous, and mentions certain pieces of work in which the genome of a family has been analysed to observe the differences and their repercussions in the appearance of certain diseases. To illustrate this they chose a photo, probably from an advertisement, of the healthcare services: a doctor, the parents and a child playing with a phonendoscope, with everyone smiling at her. The over-bright lighting, the warm colours (white, yellow) vouch for the propaganda purposes of the image, which has nothing to do with the text.



Photo 10

The illustrations chosen for the news item «2500 Cordovans suffer from some serious rare disease » (COR, 14.02.10) and the report «A few in distress...» (QUO, 01.12.09) seem rather inappropriate. In the first, two faces projecting from a hand and a fist, one about to punch the other, go with a list of the characteristics of these diseases. Again, the connotations brought to mind by the adjective 'raras' (rare/odd) would seem to be the only justification for this picture.



Photo 11

In the second report the intention is clearly to surprise the reader with an unpleasant image which has no direct relationship with hereditary sensorial neuropathy, a condition which involves insensitivity to pain:



Photo 12

The same thing could be said about resorting to images from House. The eccentricity and aggressiveness of the star of the series are projected over the name of the RD. This usage sometimes requires a degree of caution, although it is true that patients' reactions may head the other way. The need to overcome the ignorance as regards these diseases may make their constant mentions in television series such as House or Bones even be perceived as something positive, in spite of the situation that they describe or the traits of the characters related with these pathologies. Here is a photo illustrating the news item «The

rare (\approx odd) ones from the waiting room raise their voice » (Diario de Pontevedra, 20.02.10). We should also remember the risks created by the metonymy leading to represent these patients as rare (\approx odd):



Photo 13

Other examples of inappropriate treatment are to be found on the Internet. The search for archive images to cover the news item frequently generates mistakes. The delivery of sunscreens for certain RD by a laboratory is illustrated by the images normally used in advertising for sun tan creams (photo 14).



Cremas solares para enfermedades raras

Photo 14

Internet nevertheless doubtlessly provides great possibilities in this field. Through not being limited by the space available, associations take great advantage of this medium. It is worth mentioning the fine range of photography used in the news of Murcia's D'Genes association for example, which can be seen in www.dgenes.es.

CONCLUSIONS AND PROPOSALS FOR ACTION

Grupo GIDYC (Universidad CEU-Cardenal Herrera)
Grupo ECCO (Universidad de Almería)

1. CONCLUSIONS

- (a) A total number of 2445 pieces of information, published over 365 days (June 2009-May 2010), were analysed. This meant that up to 5.8 news items on RD a day were published on average, which initially represents good news.
- (b) General publications are the ones most interested in incorporating RD in their information. Then the interest of the digital press, far greater than the printed media's, should be underlined.
- (c) As regards the positioning on the page, the results tend to even out. The preference of the editors for locating this type of news on an even or odd page is practically the same. Items tended to be placed on the upper half of the pages on both even and odd pages. They did not open the section. They were shown on a single page, in one column, and in news item format.
- (d) Opinion is scant, from both the emitter and the receiver of the information. This may reflect low interest from the standpoint of social awareness-raising.
- (e) There is no special concern for extending the information, either in space (by columns or pages), or by giving this a top information preference (presentation on the cover/front page).
- (f) As for the sources, institutional and political ones took the first place in relevance, in front of people affected and their relatives or associations. They also came ahead of medical experts, researchers and geneticists, who were cited as source in third place. Greater reference to the Centre for Biomedical Network Research on Rare Diseases

was missed. Although the CIBERER has constantly been providing material for the media, they seldom cited it directly. This pattern changed when the scientific director of the Centre was part of the news.

- (g) People with RD were not called a single term (the sick, patients, boys/girls and lastly those affected). This was understood as an effort being made by the reporters to concentrate more on the pathology than on the people that had this, which does not mean that the patients were forgotten. Likewise, their status as the sick affected by a seldom-found disease distanced them from conceptual categories such as that of dependent or disabled. The relatives appeared in the media as angry, critical but brave. On a second level they were seen to be happy and resigned, and lastly, sad.
- (h) The experts frame differentiated doctors – recognised but not at the same level – from researchers or geneticists. The researcher had greater value in information items, which portrayed them as hard-working, providers of a possible cure or geniuses and wise. This fits in well with the idea of collective hope, focussing on scientific findings and progress, amongst other items of media interest. A direct connection was observed between this point and the prominence in information, broken down by autonomous communities. It can furthermore be asserted that, for politicians, science at times became another area in which to seek the centre stage.
- (i) To go on with political figures, Trinidad Jiménez, the Minister of Health during our research, was at the top of the list. The others came far behind. This was not only through being the minister, but due to holding this post at the time covered by the analysis. Only one other person from the Government got onto the list: Cristina Garmendía, as the head of the Ministry of Science and Innovation. Her appearance in the media in the sample was to a large extent linked with budget cutbacks. The representatives of the opposition or other significant parties had practically no weight in the press in this field.
- (j) Andalusia, Galicia, the Murcia Region and Castile and Leon stand out over other regional units such as Catalonia, Madrid or the Valencian Community. The most recurrent thematic domain is scientific research and discovery, as the favourite theme. On the other hand, the most outlying content, least dealt with and least used as a news value, was the Dependency Law.

- (k) News articles on seldom-found pathologies are based on words more than on images and when the latter are used, the photograph is the main resource, over and above infographics or graphics. People are preferable to buildings, parts of the human body or the diseases in question. The most representative groups are researchers and/or geneticists, institutional representatives, child patients, adult patients, doctors, relatives of those affected, social personalities or celebrities; associations and/or foundations and lastly, professional carers and/or healthcare staff.

2. DECALOGUE AND PROPOSALS FOR ACTION ON TREATMENT OF RARE DISEASES IN THE MEDIA

- (I) *The growing interest in RD that has been displayed by the Spanish media must be consolidated.*

RD constitute a social and healthcare challenge through their sheer complexity. Over the last few years, the media have helped to raise society's awareness, by making known their existence and the needs of the people affected by them. They have been a vital tool enabling those affected and relatives to learn of other people with RD and find information about their pathologies. There must be no going back from this point and progress must be made to consolidate the media's interest and improve the quality of information.

- (II) *We have to move on to a new phase in information on RD: the number of hits must go along with an improvement in the qualitative aspects of the news.*

The media's discourse is too repetitive, sometimes merely reproducing the press notes from organisations or institutions parrot-fashion. This presence in the media is not sufficient if progress is not also made in the construction of appropriate information (definitions, figures, importance of research into RD ...). All the parties with anything to do with the field will have to get involved in this task.

- (III) *Authorised sources have to be used properly, also including researchers and associations of patients with RD.*

The development of the Internet is giving people access to some very reliable databases to seek information about RD (diagnoses, possible treatments, reference centres, reference specialists, etc.). Researchers should be added to the authorised sources, as experts, but also associations of patients and relatives of patients with RD. The point should also be made that the fact of affected people often having communication limitations does not imply that they cannot communicate, even though this is in some alternative way.

(IV) RD have to be made part of the media's annual agenda in a more balanced way.

The work done by all the actors involved in the month of February to deal with the information on this type of minority pathologies is highly important. The International Day has doubtlessly become a very important tool in this respect. The time has however come to ask for this information effort not to eclipse RD for the rest of the year.

(V) It is becoming necessary to promote training of media professionals in the specific sphere of Rare Diseases.

The portrayal of RD implies a mastery of terms and concepts particularly alien to the general public and even to journalists themselves. The very names of the diseases may be difficult to remember and reproduce. The same thing may occur with the information generated in the sphere of genetics, so closely connected with RD. Working procedures in the area of human genetics are undeniably matters not tending to be treated in any depth and the way they are conveyed to readers is confused on too many occasions. Designing joint activities intended to improve journalists' training would be a highly appropriate initiative. These activities should involve doctors, researchers and research centres, politicians and people affected. In the specific case of research, the CIBERER could help to find the right information register.

(VI) A sensationalist or compassionate slant on people with RD should not be presented. Patients with RD are not odd.

Sensationalist news items hurt the dignity of people with RD. Sensationalism must be left behind in order to handle the information available, and it would be advisable to normalise both the expression *Enfermedades Raras* - 'Rare Diseases' and the people who suffer from RD. Focussing on the rare (= odd) side (when the term in fact refers to prevalence) may end up in designing messages in which those affected by RD are also portrayed as

rare/odd, dangerous (contagious), etc.. This could also be said for the information providing an interpretation which wrenches compassion from readers and fosters the supposed resignation of RD sufferers or their relatives.

(VII) The media should check to see if what is said by people with political responsibilities in the health sphere matches with what is really done.

General declarations about RD are no use at all if they are not accompanied by specific and time-related commitments for action. Media professionals should make a follow-up of the promises made or the objectives set in the medium or long term.

(VIII) The representation of people with social or institutional relevance supporting RD sufferers should not cover up the most important matter: the defence of patients' and relatives' rights, and getting under way measures to ensure a better diagnosis, medical research or better therapies.

The media should learn to give proper value to the information that they provide on people acting as loudspeakers for those affected and their associations.

(IX) The media should remember that they also play a role as agents, denouncing any incorrect action in the social, healthcare or education sphere.

Ignorance and lack of information lead to a large number of problems connected with diagnosis, treatment or sociomedical care for people with RD. The media are very often the only channel for identifying these problems, informing society of them and bringing about solutions.

(X) Press portrayal of conflict and cooperation between patients and professionals or public administrations should help to generate joint areas of reflection, identifying examples of good and bad practice.

Information on RD should be a field for joint work by healthcare professionals, managers, researchers and groups of patients to analyse the grounds for certain disputes. These grounds very often have a lot to do with a lack of information (as regards patients or those affected). Another important matter is the presence of news items in which some model of cooperation can be appreciated, in spite of the different interests found in each of the groups involved. (Researchers and patients could be a good example in this respect).

BIBLIOGRAPHIC REFERENCES

ALBRECHT, T. AND D. GOLDSMITH (2003): «Social support, social networks, and health», in T. Thompson, A. Dorsey, K. Miller and R. Parrot (eds.), Handbook of health communication, Lawrence Erlbaum, Mahwah, pp.263-284.

ALONSO, M. (1995): Fotoperiodismo: formas y códigos, Síntesis, Madrid, 1995.

ÁLVAREZ, À. AND A. RAMÍREZ (2010): «Estudio de la representación de los deportistas paralímpicos de Pekín 2008 en los espacios deportivos especializados de la radio española: impacto y discurso», Minutes of the congress entitled Comunicación y desarrollo en la era digital, II Congreso Internacional de la Asociación Española de la Investigación en Comunicación, (AE-IC), Málaga, 3rd, 4th and 5th February 2010.

ARMAÑANZAS, E. AND J. DÍAZ (1996): Géneros de Opinión, Servicio Editorial Universidad del País Vasco, Bilbao.

ARMENTIA, J. I. AND J.M. CAMINOS (2003): Fundamentos de periodismo impreso, Ariel, Barcelona, 2003.

ARNO, A. (2009): Alarming reports, Berghahn Books, Herndon.

AVELLANEDA, A. ET AL. (2006): «Necesidades de formación en enfermedades raras para atención primaria», Atención Primaria, 38 (6), pp.345-348.

AVELLANEDA, A. ET AL. (2007): «Enfermedades Raras: enfermedades crónicas que requieren un nuevo enfoque sociosanitario», Anuario del sistema sanitario de Navarra, Pamplona, 2007.

AYMÉ, S. AND J. SCHMIDTKE (2007): «Networking for rare diseases: a necessity for Europe», Bundesgesundheitsbl-Gesundheitsforsch-Gesundheitsschutz, 12, pp.1477-1483.

AYMÉ, S., A. KOLE AND S. GRAFT (2008): «Empowerment of patients: lessons from the rare diseases community», The Lancet, 371, pp. 2048-2051.

BAÑÓN, A.M. (2002): Discurso e inmigración. Propuestas para el análisis de un debate social, Murcia, Universidad.

BAÑÓN, A.M. (2007a): «Las enfermedades raras y su representación discursiva. Propuestas para un análisis crítico», Discurso & Sociedad, 1 (2), 2007, pp. 188-229.

BAÑÓN, A.M. (2007b): «Discourse and Rare Diseases: Proposal for a Critical Analysis in the Spanish Context», *Birkbeck Studies in Applied Linguistics*, 2, 2007, pp. 159-178.

BAÑÓN, A.M. (2010): «Comunicación destructiva y agresividad verbal. Notas sobre el discurso en torno a las enfermedades raras en Internet», *Discurso & Sociedad*, 4(3). In the press.

BENAVIDES, J. AND J. GARCÍA (1991): «Estudios de contenidos de publicidad: mundos marginales y publicidad». *La imagen de las personas con deficiencias y el papel de los medios de comunicación*, Real Patronato sobre Discapacidad, Madrid.

BORRAT, H. (1989): «El periódico, actor del sistema político», *Anàlisi*, 12, pp.67-80.

BRYANT, J. AND D. MIRON (2004): «Theory and research in mass communication», *Journal of Communication*, 54, pp.662-704.

BUCCHI, M. (2009): *Beyond technocracy. Science, politics and citizens*, London, Springer.

CAIRNCROSS, F. (1997): *The death of distance. How communications revolution will change our lives*, Harvard Business School Press, London.

CANTAVELLA, J. AND J. F. SERRANO (coords.) (2004): *Redacción para periodistas: informar e interpretar*, Ariel Comunicación, Barcelona.

CEA, M^a.A. (2004): *La activación de la xenofobia en España. ¿Qué miden las encuestas?*, CIS-Siglo XXI, Madrid.

CHENG, L., J.J. IGARTUA, E. PALACIONES, T. ACOSTA, J.A. OTERO AND J. FRUTOS (2009): «Aversión vs Aceptación, dos caras de la misma moneda: un estudio empírico de encuadres noticiosos sobre la inmigración en la prensa regional de Castilla y León». *Zer*, 14 (26), pp.35-57.

DAINA, E. (1994): «Rare diseases and orphan drugs», *The Lancet*, 343, pp.1560-1561.

DE VREESE, C., J. METER AND SEMETKO, H.A. (2001): «Framing Politics at the Launch of the Euro: A Cross-National Comparative Study of Frames in the News», *Political Communication*, 18, pp.107-122.

DEL RÍO, P. (1998): *Los procesos de representación sobre problemas sociales en los medios de comunicación. Real Patronato de Prevención y Atención a Personas con Minusvalía*, Madrid.

DEL RÍO, P. (1986) *La imagen de las personas con deficiencias y el papel de los medios de comunicación. Real Patronato de Prevención y de atención a Personas con Minusvalía*, Madrid.

DÍAZ, A. L. (2007): «La representación de la discapacidad en los medios de comunicación. Como lograr una presencia más adecuada», *Comunicación y Ciudadanía*, 1, pp.289-306.

ECHEVARRÍA, B. (2002): *Las W's de la entrevista*. Universidad Cardenal Herrera-CEU. Fundación Universitaria San Pablo-CEU, Valencia.

EGEA, C. AND A. SARABIA, (2004): «Visión y modelos conceptuales de la discapacidad», *Polibea*, 73, pp.1-20.

ENTMAN, R.M. (1993): «Framing: Toward Clarification of a Fractured Paradigm», *Journal of Communication*, 43, pp.51-58.

EUROPEAN COMMISSION (2008): *Consulta pública. Las enfermedades raras; un desafío: para Europa*, Dirección General de Salud y Protección de los Consumidores.

FEDERACIÓN ESPAÑOLA DE ENFERMEDADES RARAS / INTERSOCIAL (2009): *Estudio sobre la situación de Necesidades Sociosanitarias de las personas con Enfermedades Raras en España*, Caja Madrid, Madrid.

FIELD, A. (2000): *Discovering statistics using SPSS for Windows*, Sage, Londres.

FIELDING, M. (2006): *Effective communication in organizations. Preparing messages that communicate*, Juta & Co., Cape Town.

FORNIELES, J., A.M. BAÑÓN AND S. REQUENA (eds.) (2011): *Lenguaje, discurso y salud*, Arcibel, Seville.

GAITÁN, J.A. AND J.L. PIÑUEL (1998): *Técnicas de investigación en comunicación social. Elaboración y registro de datos*, Síntesis, Madrid.

GARCÍA, J.E. AND E. GARCÍA (2005): «Enfermedades raras en el cine», *Revista de Medicina y Cine*, 1, pp.93-94.

GARCÍA-RIBES, M. ET AL. (2006): «Nuevos retos: el médico de familia ante las 'enfermedades raras'», *Atención Primaria*, 37 (7), pp.369-370.

GIMÉNEZ, P. (2006): «Un nueva visión del proceso comunicativo: La teoría del Enfoque (framing)». *Comunicación y Hombre*, 2, pp.55-66.

GLUECKAUF, R. AND M. LUSTRIA (2009): «E-health self-care interventions for person with chronic illnesses: Review and future Directions», in J. Parker and E. Thorson (eds.), *Communications in the new media landscape*, Springer Publishing, New York, pp.151-173.

- GONZÁLEZ, E. AND BERNABEU, N. (2008): El periódico, Ministry of Education, Madrid.
- GONZÁLEZ, J., R. ALEIXANDRE AND J.C. VALDERRAMA (2006): «Análisis bibliométrico sobre enfermedades raras en España: adecuar la metodología al objetivo de estudio», *Medicina Clínica*, 126 (12), pp.477-479.
- GRIJELMO, Á. (2003): El estilo del periodista, Taurus, Madrid, (11th ed).
- GRIGGS, R. ET AL. (2009): «Clinical research for rare disease: Opportunities, challenges, and solutions», *Molecular Genetics and Metabolism*, 96, pp.20-26.
- GUBERN, R. (1992): La mirada opulenta. Exploración de la iconosfera contemporánea, GG Mass Media, Barcelona.
- HERTOG, J. AND D. MCLEOD (2001): Framing Public Life: Perspectives on Media and Our Understanding of the Social World, A. E. Grant, Mahwah, New Jersey.
- IGARZUA, R. (2008): Nuevos medios. Estrategias de convergencia, La Crujía, Buenos Aires.
- IGARTUA, J.J. ET AL. (2007): «El tratamiento informativo de la inmigración en los medios de comunicación españoles. Un análisis de contenido desde la Teoría del Framing», *Estudios sobre el Mensaje Periodístico*, 13, pp.91-110.
- IGARTUA, J.J., C. MUÑIZ AND L. CHENG (2005): «La inmigración en la prensa española. Aportaciones empíricas y metodológicas desde la teoría de encuadre noticioso», *Migraciones*, 17, pp.143-181.
- INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES (2001): Exploring challenges, progress, and new models for engaging the public in the clinical research enterprise, The National Academics Press, Washington.
- IYENGARD, S. (1987): News that matters. Television and American Opinion, University of Chicago Press, Chicago.
- KAMARCK, E. (2005): «The Internet», in S. Restivo (ed.), *Science, Technology and Society: An Encyclopedia*, Oxford, Oxford University Press, pp.225-230.
- KASPERSON, R. AND J. KASPERSON (2005): «Considerations and principles for risk communication for industrial accidents», in R. Kasperson and J. Kasperson (eds.), *The social contours of risk. Vol. I. Publics, risk communication & the social amplification of risk*, Earthscan, London, pp.68-93.
- LOMBARD, M., J. SNYDER-DUCH AND C. CAMPANELLA (2002): «Content Analysis in Mass Communication. Assessment and Reporting and Intercoder Reliability», *Human Communication Research*. 28, 4, pp.587-604.

- LÓPEZ, M. (1995): Cómo se fabrican las noticias, Paidós, Barcelona.
- MAHER, T. M. (2001): «Framing: an emerging paradigm or a phase of agenda setting?», in S. Reese, O. Gandy and A. Grant (eds.), *Framing public life. Perspective on media and our understanding of the social world*, Lawrence Erlbaum Associates, Mahwah, NJ.
- MANFREDI, J. L. (2000): Manual de producción periodística, MAD, Seville.
- MARTIN, J. R. (2004): «Positive Discourse Analysis: Solidarity and Change», *Revista Canaria de Estudios Ingleses*, 49, pp.179-200.
- MARTÍNEZ ALBERTOS, J. L. (1983): Curso general de redacción periodística, Editorial Mitre, Barcelona.
- MARTINI, S. (2000): Periodismo, noticia y noticiabilidad, Grupo Editorial Norma. Buenos Aires.
- MATTHES, J. AND M. KOHRING (2008): «The content analysis of media frames: toward improving reliability and validity», *Journal of Communication*, 58 (2), pp.258-279.
- MAZUR, D.J. (2003): *New medical conversation: Media, patients, doctors, and the ethics of scientific communication*, Oxford, Rowman & Littlefield Publishers.
- MCCOMBS, M. (1997): «News frontiers in agenda setting: agendas of attributes and frames», *Mass Communication Review*, 24 (1&2), pp.32-52.
- MCNAMARA, J. (2010): *The 21st century media (r)evolution. Emergent communication practices*, Peter Lang, New York.
- MERCADO, M^a.T., S. SÁNCHEZ AND S. GUARDIOLA (2010): «Los Juegos Paralímpicos en la televisión española: análisis del tratamiento y discurso sobre la discapacidad». Minutes of II Congreso Asociación Española de la Investigación en Comunicación (AE-IC). 3, 4 and 5th February 2010, Malaga.
- NACCARATO A., AND K. A. NEUNDORF (1998): «Content Analysis as a Predictive Methodology: Recall, Readership and Evaluations of Business-to-Business Print Advertising», *Journal of Advertising Research*, 38 (3), pp.19-33.
- NAVARRO, C., ET AL. (2004): «La imagen de la discapacidad en la prensa de Castilla y León». Colección de documentos de acción social serie personas con discapacidad. Castile and Leon Authority.
- ORTIZ, R. ET AL. (2009): «Ataxia de Friedreich», *Atención Primaria*, 41 (6), pp.339-341.
- PALAU, F. (2010): «Enfermedades raras, un paradigma emergente en la medicina del siglo XXI», *Medicina Clínica*, 134 (4), pp.161-168.

PLAZA, S. (2009): «Nuevos enfoques para el mejor conocimiento de las enfermedades raras», *Medicina Clínica*, 133 (5), pp.193-195.

POSADA, M. AND M. GARCÍA RIBES (2010): «Concepto, epidemiología, situación actual y perspectivas futuras», *Atención Primaria*, 42 (3), pp.169-172.

PRAT, R. AND E. DOVAL (2003): «Construcción y análisis de escalas», in J. P. Lévy and J. Varela (eds), *Análisis multivariable para las ciencias sociales*, Pearson-Prentice Hall, Madrid, pp. 43-89.

PRICE, V., D. TEWKSBURY AND E. POWERS (1997): «Switching Trains of Thought. The Impact of News Frames on Reader's Cognitive Responses», *Communication Research*, 24.5, pp.481-506.

PUTNAM, R. AND L. FELDSTEIN (2003): *Better together. Restoring the American community*, Simon & Schuster, New York.

REESE, S.D. O.H. GANDY AND A.E. GRANT (eds.) (2001): *Framing Public Life. Perspectives on Media and Our Understanding of the Social World*, Erlbaum, New Jersey.

REESE, S.D. (2007): «The framing project: a bridging model for media research revisited», *Journal of Communication*, 57, pp.148-154.

REMUZZI, G. AND S. GARATTINI (2008): «Rare diseases: what's next?», *The Lancet*, 371, pp.1978-1979.

REQUENA, S. (in the press): «El síndrome de Moebius. Propuestas para su estudio lingüístico-comunicativo», in J. Fornieles, A.M. Bañón and S. Requena (eds.), *Lenguaje, discurso y salud*, Arcibel, Seville.

RIUS, I. AND J.A. SOLVES (2010a): «Discapacidad y comunicación: periodismo especializado para públicos diversos», *Comunicación y Hombre*, 6, pp.165-175.

RODRÍGUEZ-BAILÓN, R. AND M.S. PALACIOS (2006): «Cognición social: la forma in que pensamos sobre los demás», in A. Gómez, E. Gaviria and I. Fernández (Coord.), *Psicología social*, Editorial Sanz y Torres, Madrid, pp.83-135.

SÁDABA, M.T. (2001): «Origen, aplicación y límites de la "teoría del encuadre" (Framing) en comunicación», *Comunicación y sociedad*, XIV, 14 (2), pp.143-173.

SÁNCHEZ, S. (2010): «Metacobertura del día mundial de las enfermedades raras: análisis de nuevos encuadres noticiosos in the press». XII Congreso de la Sociedad Española de Periodística (SEP). Valencia, 21st and 22nd May 2010.

SCHALKEN, C.A. (1998): «Internet as a new public sphere for democracy?», in I.Th. Snellen (ed.), *Public administration in an information age. A handbook*, IPS Press, Amsterdam, pp.159-174.

SCHEUFELE, D. (1999): «Agenda Setting, Priming, and Framing Revisited: Another Look at Cognitive Effects of Political Communication», *Mass Communication and Society*, 3 (2-3), pp.297-316.

SANMARTÍ, J. M. (2004): «Más allá de la noticia: el periodismo interpretativo», in J. Cantavella and J. F. Serrano (coords.), *Redacción para periodistas: informar e interpretar*, Ariel Comunicación, Barcelona, pp.333-359.

SCHIEPPATI, A. ET AL. (2008): «Why rare diseases are an important medical and social issue», *The Lancet*, 371, pp.2039-2041.

SEALE, C. (2002): *Media & Health*, Sage, London.

SEMETKO, H.A. AND P.M. VALKENBURG (2006): «Framing European Politics: Analysis of Press and TV News», *Journal of communication*, 50 (1), pp.93-109.

SENIOR, T. AND A. KNIGHT (2008): «Rare diseases: a role for primary care», *The Lancet*, 372, p.890.

SERVIMEDIA S.A. (2007): *Periodismo social. El compromiso de la información*, Madrid, 2007.

SILBER, D. (2004): «The case for e-health», in I. Iakovidis, P. Wilson and J. C. Healy (eds.), *E-health. Current situation and examples of implemented and beneficial e-health applications*, IOS Press, Amsterdam, pp. 3-27.

SOLVES, J.A., A. CASTAÑOS, A. MUÑOZ AND M^a.T. MERCADO (2008): «Tratamiento de la discapacidad en la televisión pública valenciana (TVV)», in E. MORENO, E., et al. (ed.), *Los desafíos de la Televisión Pública en Europa*. Pamplona, EUNSA, Pamplona.

STAINTON, T. (2008): «Reason, grace and charity: Augustine and the impact of church doctrine on the construction of intellectual disability», *Disability and Society*, 23 (5), pp.485-496.

STEVENS, J. (1992): *Applied Multivariate Statistics for the Sciences*, Hillsdale, NJ, Lawrence Erlbaum Associates (2nd ed.).

TACQ, J. (1997): *Multivariate Analysis Techniques in Social Science Research, From Problem to Analysis*, Sage, Londres.

TANKARD, J. ET AL. (1991): «Media Frames: Approaches to Conceptualization and Measurement», *Comunicación presentada in Education in Journalism and Mass Communication Convention, Communication Theory and Methodology Division*, 7th to 10th August, Boston.

TEWKSBURY, D. AND D.A. SCHEUFELE (2007): «Special Issue on Framing, Agenda Setting, & Priming: Agendas for Theory and Research», *Journal of Communication*, 57, pp.1-18.

TONES, K. AND S. TILFORD (2001): Health promotion. Effectiveness, efficiency and equity, Nelson Thornes, Cheltenham.

TORRES, R. AND J. GARCÍA (2004): «Experiencia en enfermedades raras: el síndrome de Lesch-Nyhan», *Medicina Clínica*, 122 (9), pp.60-61.

TREICHLER, P. (1987): «AIDS, homophobia and biomedical discourse: an epidemic of signification», *Cultural Studies*, 1 (3) pp.263-305.

VALKENBURG, P. M., H.A. SEMETKO AND C.H. DE VREESE (1999): «The Effects of News Frames on Readers' Thoughts and Recall», *Communication Research*, 26 (5), pp.550-569.

VAN DIJK, T.A. (1996): *La noticia como discurso. Comprensión, estructura y producción de la información*, Paidós Comunicación, Barcelona.

VAN DIJK, T.A. (2008): «Some Observations on the Role of Knowledge in Discourse Processing», *Trends and Directions. Proceedings of the 12th English in Southeast Asia Conference*, Bangkok: School of Liberal Arts, King Mongkut's University of Technology Thonburi, pp.89-102.

VAN GORP, B. (2007): «The constructionist approach to framing: bringing culture back in», *Journal of Communication*, 57 (1), pp.60-78.

VARELA, J. (ed.) (2003): *Análisis multivariable para las ciencias sociales*. Pearson-Prentice Hall, Madrid.

VICENTE, M.M., AND P.L. RABADÁN (2009): «Resultados actuales de la investigación sobre framing: sólido avance internacional y arranque de la especialidad en España», *Zer*, 14, (26), p. 17.

WEAVER, D.H. (2007): «Thoughts on Agenda Setting, Framing and Priming», *Journal of Communication*, 57, pp.142-147.

WARREN, C. (1951): *Modern News Reporting*, translated into Spanish as *Géneros periodísticos informativos*. Mitre, Barcelona, 1975.

WOLF, M. (1991): *La investigación de la comunicación de masas*, Paidós, Barcelona.

ZÖLLNER, H. (1995): «The CARE telematics project», in M. Laires et al. (eds.), *Health in the New Communications Age*, IOS Press, Amsterdam, pp. 273-289.

Appendix

Identification of the media cited in the discursive analysis

AAR= D. del Alto Arag.	ENC= Norte Cast.	NEG=Negocio
Abc= Abc	EPA= Periódico Aragón	NME= Noticias Médicas
ACC= Acceso.com	EPE= El Periódico	NVA= Nuevo Vale
ACS= Acta Sanitaria	EPO= Época	OCU= OCUsalud
ADN= ADN.es	EPS= El País Semanal	OSA= Osaca
ALM= La Voz Almería	EUP= Europa Press	PED= Period. Dig.
ANI= ANIS	EUR= Eureka	PEQ= Pequelia
ARA= Aragón Dig.	EUS= Europa Sur	PEX= Periódico de Extr.
ARL= Arag.Liberal	EV= El Diario Vasco	PMF= PMFarma
ATL= Atlántico	EXP= Expansión	PRO= El Progreso
ATS= Atlas News	FVA= Fund.Vanesa.com	PRO= Pronto
AVI= Diario Avisos	GAC= La Gaceta	PRS= PR Salud
BUE= Buena Salud	GDI= Gente digital	PUB= Público
CDI= Ciencia Directa	GEN= Gente	PUN= El Punt
COD= Correo Dig.	HER= Heraldo de Arag.	RAC= Radio Compañía
COF= Correo Far.	HIN= Huelva Informac.	RIO= La Rioja
CON= Cons. Eroski	HOY= HOY	RTV= RTVE
COP= COPE	ICA= IcalNews	SDN= Sordonautas
COR= CÓRDOBA	IDE= IDEAL	SEG= Segre
CRM= Crónica Madrid	INF= Información	SOD= Solidaridad Digit.
CSM= Cast.-M.es	INT= Introversió	SPO= Sport
DAV= Diario de Ávila	JAE= JAÉN	SUP= Supertele
DBG=Dobleboggey	LAN= Lanza	SUR= SUR
DBU= Diario de Burgos	LAO= La Opinión	TER= Terra Noticias
DCA= Diario de Cádiz	LAP= La Provincia	TLP= Teleprensa
DDH= Diar. Dig. Henares	LAQ= La Quincena	TOT= Totana.com
DEI= DEIA	LAR= La Razón	TRI= Trib. Albac.
DIA= El Día	LAS=La Semana	TV5= Telecinco
DIB= Diario de Ibiza	LAV= La Vanguardia	VER= La Verdad
DID= Diar. Directo	LEV= Levante	XGA=Xornaldegalicia.com
DIM= Diario Médico	LID= Libertad Dig.	XLS= XL Semanal
DIS= Diario Salud	LNE= La Nueva España	XXI= Siglo XXI

DIT= El Día de Toledo	LOC= La Opin. La Cor.	YAH= Yahoo! Noticias
DIV= Diario Valladolid	LOG= Opinión Galicia	YOD= Yo Dona
DJE= Diario de Jerez	LOT= La Opin. Te.	20M= 20 Minutos
DME= DMedicina	LPR= Las Provinc.	3SS= 3SSanidad
DNA= Diar. Nava.	LRE= La Región	
DPO= Diar. Pontevedra	LUK= Luko	
DSC= Discapnet	LVA= La Voz Asturias	
DSE= Diario de Sevilla	LVG= Voz de Galicia	
ECA= El Correo And.	M21= Medic. XXI	
ECD= Eco Diario	MAP= Madrid Press	
ECG= El Correo Gallego	MAR= Marca	
ECO= El Confidencial	MAX= Maxillaris	
EDC= Día de Córdoba	MDE= Mundo Deportivo	
EDM= Diario Montañ.	ME= Revista Médica	
EFV= Faro de Vigo	MED= Mediterráneo	
EGL= El Global	MOR= Madrid.org	
EIG= El Ideal Gallego	MTV= Medicina TV	
ELI= El Imparcial	MUR= Murcia.com	
ELM= El Mundo	MUY= Muy Interes.	
ELP= El País	NDN= Noticias de Nav.	