

Communication strategies employed by rare disease patient organizations in Spain

Antonio Castillo-Esparcia ¹
Paloma López-Villafranca ¹

Abstract *The current study focuses on communication strategies employed by rare disease patient organizations. The aims of these organizations are: educate and inform the public about rare diseases, raise awareness of the problems related to rare diseases, and achieve social legitimacy in order to give visibility to their demands. We analyzed the portrayal of rare disease and patient organizations by Spain's major media organizations in terms of circulation and viewership - the press (El País, El Mundo, La Vanguardia, ABC and El Periódico), radio (CadenaSer, Onda Cero, Cope and RNE), and television (Telecinco, Antena 3, La 1, La Sexta, Cuatro) - between 2012 and 2014. We then carried out a descriptive analysis of communication activities performed via the World Wide Web and social networks by 143 national organizations. Finally, we conducted a telephone questionnaire of a representative sample of 90 organizations in order to explore the association between media presence and funding and public image. The triangulation of quantitative and qualitative methods allowed us to meet the study's objectives. Increased visibility of the organizations afforded by an increase in the coverage of the topic led to an increase in membership - but not in donations - and increased awareness of these diseases.*

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¹ Facultad de Ciencias de la Comunicación, Andalucía Tech, Universidad de Málaga. Campus de Teatinos, s/n. 29071 Málaga España. acastilloe@uma.es

Introduction

To understand the importance of communication for patients who suffer from rare diseases, it is necessary to understand why they are rare. The name of these diseases is the first obstacle that the patient must face, since the disease is denominated according to its prevalence: they are rare because they affect five in every 10,000 people in the European Union. Therefore, they are rare and far removed from the reality of other citizens due to the unlikelihood of them suffering from such diseases. However, there are over 7,000 rare diseases and, according to the Spanish Federation of Rare Diseases (*Federación Española de Enfermedades Raras*- FEDER), they affect over three million people in Spain.

Another important factor - and one of the main complaints among patients - is the difficulty sufferers face in obtaining diagnosis and treatment and in accessing specialized centers and referral units:

“A comprehensive health system should promote the homogenization of healthcare and of the portfolio of services; but how can the system be efficient and highly specialized without the existence of the so-called referral centers/services/units”¹.

People affected by rare diseases are aware of the need to create international organizations, and this is how, in 1997, the European Organization for Rare Diseases (EURORDIS) emerged, a nongovernmental patient-driven alliance of patient organizations whose aim is to improve the quality of life of people living with rare diseases. This alliance stands to defend patients by promoting research and the development of medication, as well as awareness raising and other actions that palliate the effect of these diseases on the life of patients and family members. Based on various studies and opinion surveys involving EURORDIS members, Mavris and Le Cam² highlight patients' strong interest in and commitment to promoting research, despite their limited numbers and lack of resources. The authors emphasize the need to involve patients, given that they have significantly contributed to research funding and the development of medication. In 2010 alone, patient organizations contributed 13 million Euros to research in Europe, while organizations such as the French Association against Myopathies (*l'Association Française contre les Myopathies* - AFM), make an annual contribution of 60 million Euros towards research. Akrich³ suggests that patient activism is a

determining factor for changing the situation of patients with rare diseases.

However, for patients, apart from fundraising, the search for information about the rare diseases they suffer is essential. Orphanet, the reference portal for information on rare diseases and orphan drugs, has contributed towards providing information to users in a rigorous fashion and using standard nomenclature⁴.

Social networks are an essential tool for patient organizations. Rare Connect is an online social network managed by communities of patients with rare diseases created in 2010 alongside EURORDIS, the European Network of Rare Diseases, and the National Organization for Rare Disorders (NORD). Tommasetti et al. suggest that patient empowerment is much more than simply sharing information. Rare Connect focuses on improving the lives of rare disease patients, sharing experiences, innovative health solutions and the results of research into these diseases⁵.

FEDER was created in 1999 with the aim of unifying criteria and transmitting common demands. However, the major support provided to small patient organizations is still not enough to enforce their rights and meet individual demands. To overcome geographical barriers, these organizations communicate through web pages, social networks, and online videos. Moreover, they share material that can be useful to other patients, such as academic and scientific articles, which are also shared between members of the scientific community. To achieve visibility and promote fundraising for scientific research they struggle to have their voices heard in the traditional media: newspapers, radio and television. Rabeharisoa et al., 2014, highlight the role of these organizations in the creation of mutual aid groups, the increase in service users' demands and more active participation in the design of services, referred to by various studies as “evidence-based activism”⁶.

The role of patient organizations in the third sector

According to Salamon and Anheier⁷, rare disease patient organizations share five characteristics that are common to third sector organizations: they are formally organized; they have general objectives and resources to meet these objectives; they are private (not part of the public sector); they are nonprofit making; self-governed, since they have their own governing bodies; and altruistic, which implies some degree of vo-

luntary participation, either because they are a channel for voluntary work or because they are managed on a voluntary basis.

According to studies conducted by EURORDIS, rare disease patients and their families face the following difficulties: lack of access to accurate diagnosis; lack of information and scientific knowledge; social consequences; lack of adequate medical care; high cost of medication; and inequalities with respect to care and treatment⁸. Sánchez Valverde and García Fuentes⁹ suggest that scientific advances have led to the more efficient diagnosis of rare diseases. However, given their low prevalence, one of the major challenges facing the health system is the creation of referral centers and enhancing research networks.

On the other hand, there are laws that protect rare disease patients, such as the Orphan Drug Act, created in 1983 in the United States, that provides incentives for research and the development of medication. In Europe, the European Agency for the Evaluation of Medicinal Products (EMA) was created in 1995, which provides support – although evidently clearly insufficient – for the development of orphan drugs¹⁰. Patients and family members seek funding through solidarity-based initiatives to initiate or continue supporting scientific research to discover a treatment and cure for rare diseases. They are generally organized into associations with very little financial capacity, whose members are directly or indirectly affected by the disease and do not have the time or means to achieve their objectives. Another problem faced by third sector organizations is the rapid turnover of personnel, which hinders the continuity of programs¹¹.

Fundraising to ensure treatment in specialist centers and support the development of orphan drugs has become one of the major priorities of these organizations. Patients lack access to treatment generally because there is no specific treatment and research is nonexistent due to lack of public funding and because the pharmaceutical industry has no interest in certain drugs because they are simply not profitable.

An orphan drug is a medication with high a therapeutic interest and scientific viability that is not available locally due to different reasons or circumstances: because it is not sold (as an industrialized product) nationally since its effective and safe use for the health problem in question (indication) is not proven¹².

FEDER and the Spanish government work in close collaboration to boost the organization's visibility through the media, and a milestone for

FEDER was when the Spanish Ministry of Health declared 2013 the National Year for Rare Diseases.

Rare diseases in the media

We analyzed the media's portrayal of rare diseases based on the framing theory, which, as McCombs et al. (cited by Iguartua and Muñoz)¹³ suggest, could be considered as the second level of the agenda-setting theory, in which the media influences not only what we think about (the first level of agenda-setting), but also how we think about it (second level).

Tankard¹⁴ suggests that the framing theory plays a mediating role in the process of selection, emphasis, exclusion and development, while Iguartua et al.¹⁵ propose that the perception of social problems is conditioned by the contribution of the media and “it has been observed that the greater the media emphasis on a given social theme or topic, the greater the public concern about the topic”.

Rare disease patients in the press

Using the framing theory, Castillo Sánchez¹⁶ analyzed the coverage of World Rare Disease Day in the printed media (hereafter referred to as *the press*) by addressing rare disease news frames using an inductive approach to data collection. Castillo Sánchez¹⁷, who also analyzed the Spanish press' visual portrayal of rare diseases, suggests that these diseases require a consolidated theoretical space within the media, especially with respect to the discursive treatment of diseases and disability. The author emphasizes that an image reinforces a text, particularly when it shows affected patients and family members accompanied by institutional representatives and topics that are closer to home geographically speaking.

The Centre for Biomedical Network Research on Rare Diseases (CIBERER), the ECCO group (*Universidad de Almería*) and GIDYC group (*Universidad de CEU Cardenal Herrera*)¹⁸ have carried out a number of studies that analyze press discourse on these diseases. One of the most interesting findings is that the training and development of communicators is essential to improving information and that information would be more effective if there was a correlation between what official sources say is done and what is actually carried out.

A quantitative analysis of news stories in the press on Rare Disease Day (29 February 2012) in Andalucía, Spain, Urrutia¹⁹ suggests that the

discourse was poorly structured, contained erroneous information, reflecting the weakness of the patient organizations and the need for a change in focus without resorting to morbidity and pessimism.

Bañón Hernández²⁰ concludes that patients are considered a minority group with generally little capacity to exercise any significant influence on political and social matters because they have been systematically excluded from major discussion forums.

Rare disease patients in radio and television

Studies exploring health communication via television have been rarer than studies involving the press. A study of larger audience daily television news programs conducted by Francescutti et al.²¹ showed that the coverage of health-related news was particularly scarce, despite the value that the Spanish public places on such topics. Patients and family members have become key subjects of features, followed by doctors, pharmacists and authorities on the topic. Advances in treatment are overshadowed by medical negligence and error. The programs use mainly official sources and the health reality presented on television as little or nothing to do with what actually happens. The authors conclude that certain diseases are overrepresented, while others are underrepresented, including dubious medical conditions.

Science is typically covered on television through specific health programs. In 2013, due to the National Year for Rare Diseases, a number of special slots were created covering rare diseases. Patient organizations played a special role in the Spanish public television channel, TVE, in seven showcase programs and a telethon.

Rare diseases are also covered by the public radio channel, RNE, and have a notable following in private radio stations. Coverage of health on Spanish radio is generally through specialized programs that have been on air for decades and disseminate scientific and health information of general public interest, sometimes meeting demands for information on specific diseases. According to Aledo²², radio is an ideal means for promoting normalization and the social integration of people with disabilities and/or rare diseases.

Communications within patient organizations and the World Wide Web

The concept Health 2.0 emerged following the widespread adoption of the internet over recent years in the health field. Basagoiti and Fernández-Luque²³ refer to this term in their article *Salud 2.0: una oportunidad para la información directa al paciente* where they highlight that it is a simple and swift means of accessing information. One of the key advantages of the internet “revolution” is accessibility to information and resources, drastically reducing the inequalities produced by geographical, cultural and organizational barriers.

Armayones y Hernández²⁴ suggest that Health 2.0 has evolved into web 3.0, an even more effective means of searching for and disseminating information about diseases. The roles of “advisor” and “support figure” have appeared on the web, which consist of people who have been diagnosed that are not easily found in the physical world or a way of experimenting sensations in the future in this setting.

Torrente et al.²⁵ highlight the importance of virtual spaces in that they offer people with specific health problems the opportunity to share experiences, seek, receive and provide information, advice, and even emotional support, online.

Gabarrón y Fernández-Luque²⁶ analyze the phenomenon of online videos directed at health promotion and highlight that one of the advantages of online platforms is their low cost and immediacy, but also warn against lack of rigor and other aspects related to lack of quality. In a study about the use of these platforms by the third sector, Almaraz et al.²⁷ confirm that there is an collective intelligence in the plurality of the civil society that enables knowledge generation on the web.

Objectives

This study has the following aims:

- 1) To identify the communications strategies employed by rare disease patient organizations.
- 2) To obtain an understanding of the image of patient organizations portrayed by the Spanish media.
- 3) Explore the association between greater media coverage and donations and improvements in the public image of these organizations.

Methodology

Triangulation of quantitative and qualitative methods was used to explore the relationship between communications strategies and the portrayal of patient organizations by the media. To do this we performed the following:

1) Analysis of the journalistic content of the press, radio and television to explore portrayal of patient organizations by the traditional media and its impact. The period covered by this study was 2012 to 2014, in order to prove the impact in the years preceding and following the National Year for Rare Diseases(2103).

With respect to the press, Spain's top five daily newspapers in terms of circulation, according to the Office for Justification of Circulation (*Oficina de Justificación de Difusión – OJD*), were analyzed: *El País*, *El Mundo*, *ABC*, *La Vanguardia* and *El Periódico*. The study sample comprised 276 units in these newspapers. The radio study sample consisted of 157 pieces; while the television sample comprised 94 pieces broadcast by the country's top channels in terms of viewership, according to the General Media Survey (*Estudio General de Medios – EGM*): *Telecinco*, *Antena 3*, *La 1*, *La Sexta*, *Cuatro*, *Cadena Ser*, *Onda Cero*, *Cope* and *RNE*.

The following variables were considered:

a) Basic identification data; type of media; year and month in which the information was generated; location in the newspaper (section), space occupied and duration (radio and television).

b) Indicators related to content and topic (issue). The topic was categorized into the following groups: human interest, organized acts, economic, scientific, political, and other topics of interest. With respect to the content, we analyzed the genre and frequency of the use of given words related to the disease.

c) Information sources (politicians, scientists, doctors, concerned organizations, members of patient organizations, pharmacists, individual patients, personalities, others).

d) Images: press – typology; photographs, tables, graphs and same themes; television – type of montage, participants in the films.

2) Descriptive analysis of the webs, social networks and blogs of the patient organizations - we analyzed the tools used by the organizations to communicate through the internet, their webpages, social networks and blogs to determine the presence of tools that enable interactivity between webpage users – in line with the theories proposed by Cho e Cheon²⁸ – and level of partici-

pation in social networks and blogs that enhance the function of users as sources of information.

We also studied various categories of web communication tools considering variables related to communication 2.0 and using an analysis template including the following variables:

a) Identification data: number of associations with the web, social networks and blogs. Type of web (1.0, 2.0), and existence of virtual press rooms.

b) Identifiers related to the content: use of communication tools (videos, photographs, magazines, dossiers, news, information circulars), content syndication, message type (informative, solidary, persuasive).

c) Variables related to interaction: need to register, number of followers social networks, periodicity of content in social networks and blogs.

3) Use of telephone questionnaires to obtain data concerning the importance of communication to the organization, profile of the communications personnel, web and social network management, organization's perceptions about media impact and effect on membership.

The population sample comprised 230 organizations registered in the Burgros State Reference Centre for Rare Diseases Patients and their Families (*Centro de Referencia Estatal de Atención a Personas con Rare diseases y sus Familias de Burgos - CREER*), dependent of IMSERSO, contacted during the study period (2012 to 2014). We limited the sample to 143 national organizations, from which we achieved a 63% response rate. A total of 90 telephone questionnaires were conducted using multiple-choice questions and polychotomous responses, where the person being questioned is asked to select one or more options. Closed questions following the inverted funnel sequence were used, which begin with closed basic questions and progress to more detailed questions at the end, thus facilitating answering²⁹.

Results

Framing in the press, radio and television

The newspaper that provided the greatest coverage of rare diseases was ABC, with 44% of information generated in terms of news pieces during the study period, followed by *El País* (22%), *El Mundo* (14%), *La Vanguardia* (11%), and *El Periódico*.

With respect to radio and television, it was observed that the public broadcasters provided

the greatest amount of coverage. Both RNE and TVE provided greater coverage than the rest of the stations and channels analyzed by the study. RNE showed greater patient involvement and dissemination of information about rare diseases than private stations such as *la Cadena Ser* and *Onda Cero*. RNE accounted for 42% of the information and programs related to rare diseases, while *la Cadena Ser*, *la Cadena Cope* and *Onda Cero* accounted for 25%, 18%, and 15%, respectively.

TVE – both the first and second channels – also provided greater coverage than the private channels. The broadcaster accounted for 56% of the units related to the topic over the study period, while *Cuatro*, *Telecinco*, *Antena 3*, and *la Sexta* accounted for 16%, 13%, 10%, and 5%, respectively (Graph 1).

The annual results show that in 2014 coverage was greatest on radio and television, while in 2013 the press accounted for the greatest number of news pieces about rare diseases. The following shows the proportion of coverage of rare diseases provided by each type of media for each year of the study period:

- The press: 2012 - 26%; 2013 - 39%; 2014- 35%.
- Radio: 2012- 17%; 2013- 33%; 2014- 50%.
- Television: 2012- 20%, 2013- 27%; 2014- 53%.

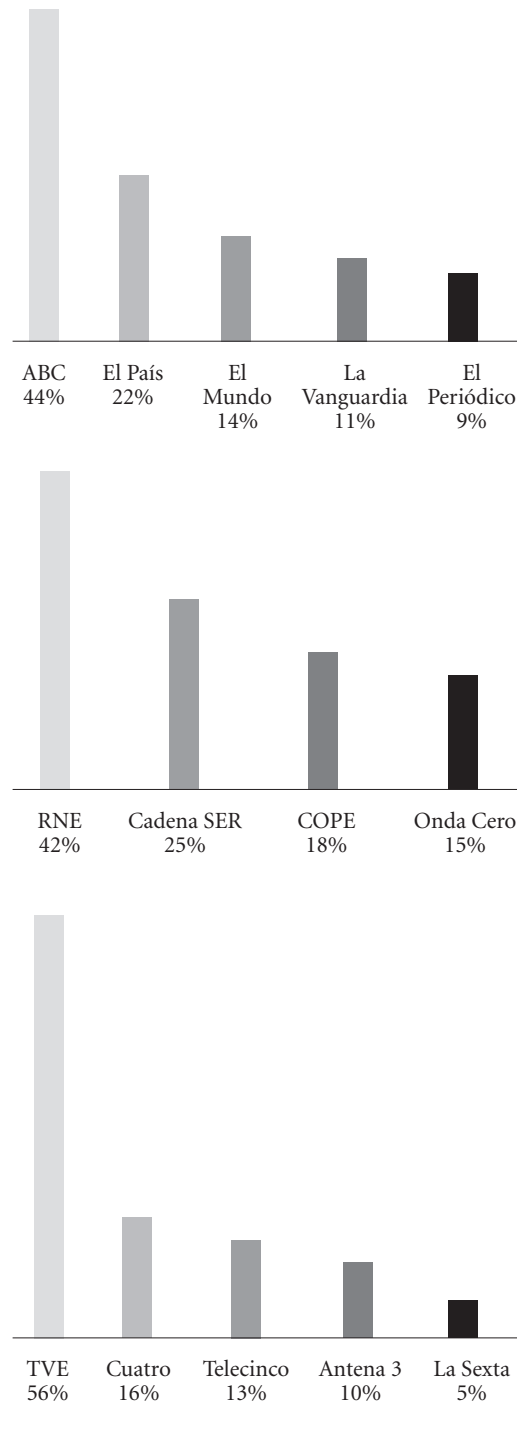
Considering individual months, February is traditionally the month in which coverage is greatest in all types of media, due to the World Rare Disease Day (28 February in 2012, and 28 February in 2013 and 2014).

With respect to the press, the majority of pieces in 2012 and 2013 were located in the *society* section (36% and 24% pieces, respectively). In 2014, however, there was a change in trend, and the section with the largest number of news pieces was the *science special* section, with 20% of news pieces versus only 8% in the *society* section.

The majority of the pieces took up less than a quarter of a page in 2012 (22%), 2013 (19%), and 2014 (45%). The amount of space taken up by information decreased over the study period.

The average duration of pieces on the radio and television was one to five minutes.

The genre most used by the press and television is news (72% and 35%, respectively), while on the radio it is the interview (50%). The other genres used by the press are: opinion (13%), report (12%), and interview (3%), while the radio used the news (22%), report (14%), round table (8%), feature (3%), debate (2%), and report



Graph 1. Coverage on press, radio and television, from 2012 to 2014.

Source: Authors' own creation

(1%). Television used report (32%), interview (26%), advertorial (3%), debate (2%), documentary (1%), and report (1%).

The main information source used by the press, radio and television were the members of the organizations. For the press, doctors and scientists are also a key source and are used to complement information when a scientific perspective is required. Other key sources for radios are doctors and researchers, while on television the main participants are patients and their families in human interest items, as shown in Graph 2.

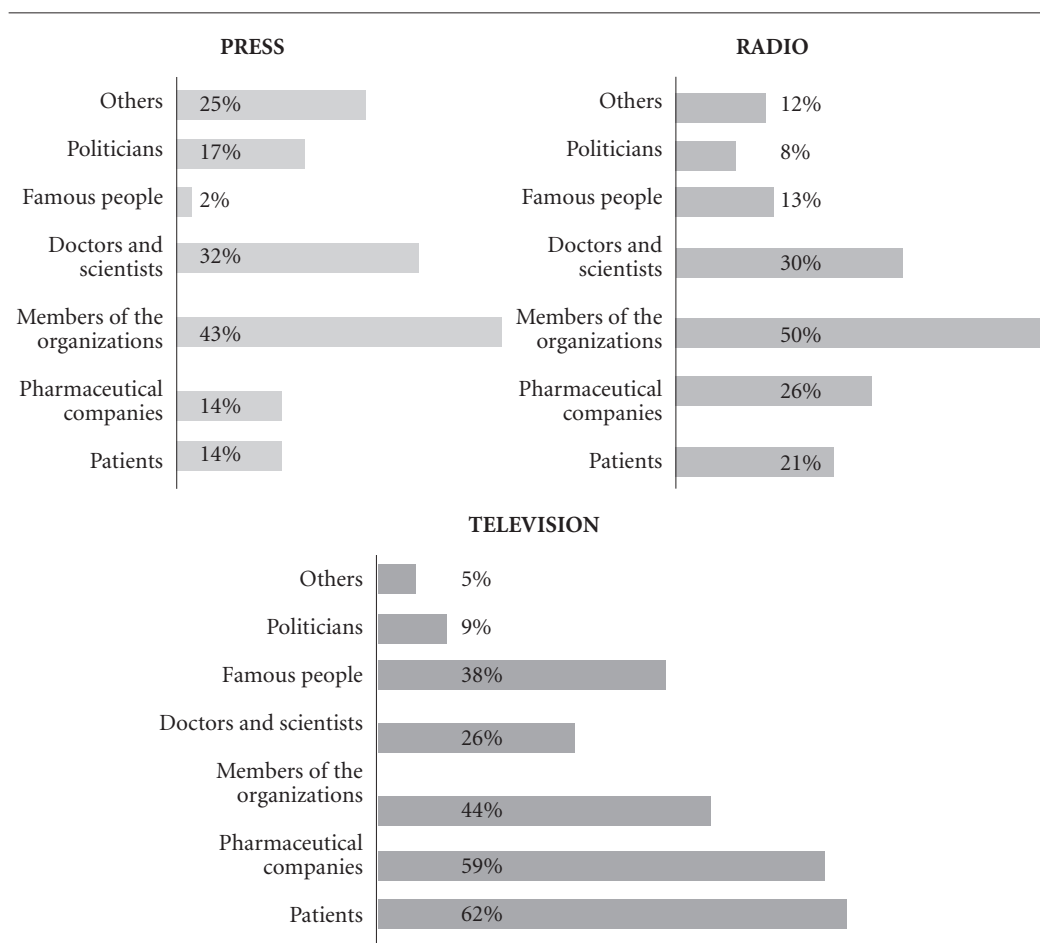
Famous people were important for radios throughout the study period. On television, interest in rare diseases increased due to the involvement of personalities, above all the Queen of Spain Doña Letizia, and due to special programs, with the participation of famous people from various areas who supported the cause. Politicians appear to have greater weight in the press than on

radio and television (17% compared to 8% and 9%, respectively as shown on Graph 3).

In the press, the most common topic was *human interest*, followed by *scientific*. On the radio the most common topic in 2012 was *organized acts*, while on television it was *human interest*. In 2012, *organized acts* were also a prominent topic on television up to 2013, when both topics (*human interest* and *organized acts*) were of equal importance.

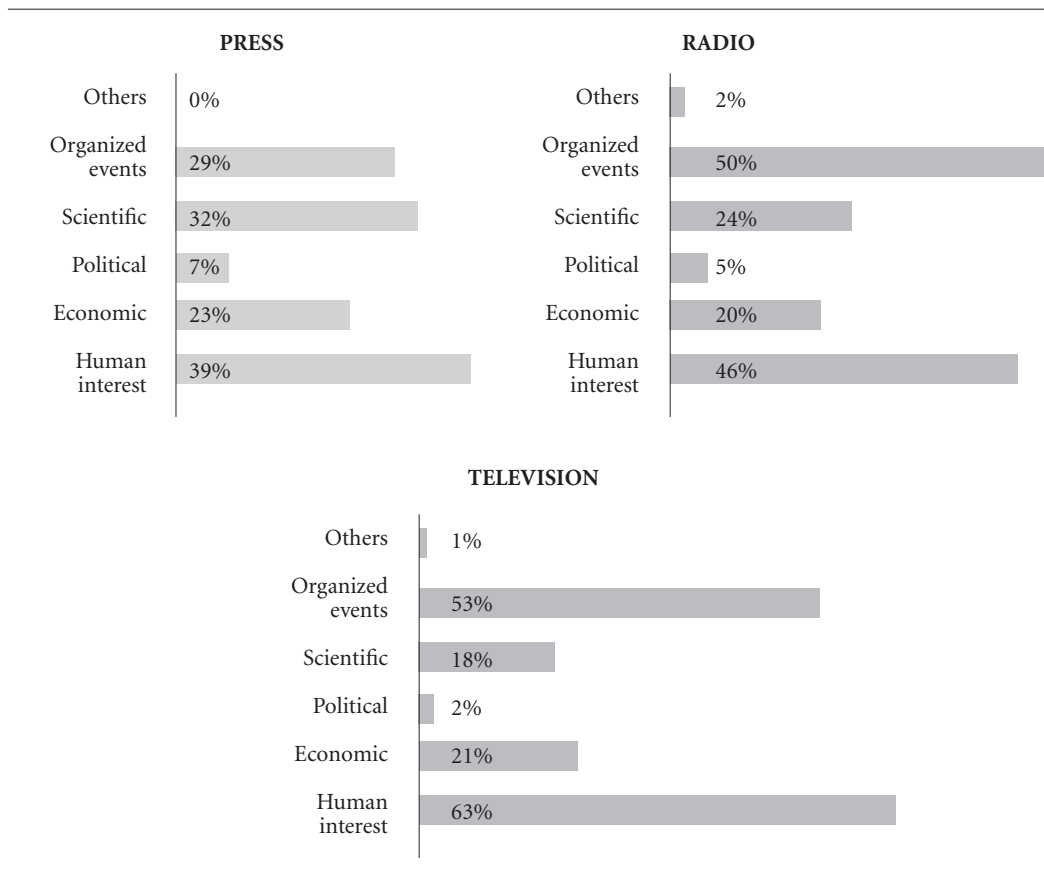
Given that the press was more likely to use scientific sources, scientific information was more prominent in newspapers: 32%, compared to 24% on the radio and 18% on television.

With respect to visual framing, 94% of images were photographs, 5% were graphs, and 1% other. The predominant subject of the ima-



Graph 2. Press, radio and television sources.

Source: Authors' own creation



Graph 3. Most common topics.

Source: Authors' own creation

ges are patients showed as representatives and key resources for illustrating information. The following is a breakdown based on the number of appearances of each type of subject in the units of analysis studied:

- 33% of the news pieces showed patients.
- 20% showed personalities who support the cause.
- 14% show researchers.
- 9% of the images show medications and health resources.
- 8% show organization members.
- 5% show politicians.
- 4% show other images.
- 3% show graphs.
- 2% show members relevant institutions.

On television, the main subjects are patients and family members, which coincides with the sources (see Graph 2). The news and programs are based on the following: analytical montage using quick expressive close-ups that have a psychological impact (58%); synthetic editing, with longer shots and depth of field, showing a more complete view of reality (28%); and mix the two shot types (14%).

Descriptive analysis of patient communication on the World Wide Web

Eighty-two percent of the organizations have active webpages, while 58% use web 2.0 and 24% continue to use web 1.0.

Thirty percent of the webpages restrict content access to registered users. Thirty-seven percent use forums to share information and 11% of these forums are open to all users.

The descriptive analysis of the webpages of the patient organizations showed a lack of press rooms for user and media communication: only 21% of the pages had virtual press rooms. Only 20% of the webpages allowed for content syndication (RSS) to share content on the web and, despite the fact that a large number of users have a disability, only 3% of the pages were accessible.

The most commonly used communication tool was new sitem (71%), which were generally compiled from the media. Other tools used to a lesser extent include: videos (39%), photographs (38%), information circulars (38%), dossiers (36%), and magazines (24%).

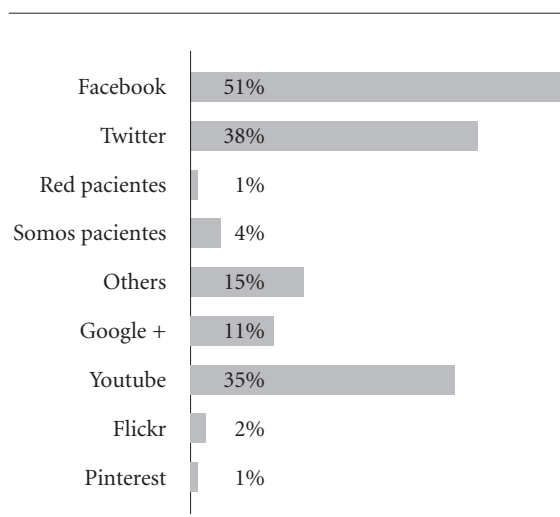
The most commonly used social network was Facebook, which was used by 51% of the patient organizations. Thirty-eight percent of the organizations used Twitter and 35% used YouTube, while 15% used the specialized rare disease networks RareConnect, Guiametabólica, and RareShare. Other networks were used to a lesser extent, as can be seen in Graph 4.

The patient organizations published mainly on Facebook: 38% publish content once every two or three days on Facebook, while 33% publish between 10 and 30 contents per month on Twitter. The organizations also use YouTube: 90% of the organizations that use this website publish at least five videos per month.

Forty-nine percent of patient organizations have over 500 followers. Only 5% have less than 50 followers.

Twenty-nine percent of patient organizations have blogs. The blogs generally show patients' experiences, using first names and surnames, through posts that are prepared by the actual patients and/or family members. With respect to rare diseases affecting children, the patients' mothers generally talk about the disease and specific needs and posts are generally directed to the public as a whole, recently diagnosed patients and other patients in a similar situation.

Of the 29% of patient organizations that have blogs, over half (55%) are linked to the organization's webpage. However, 45% are independent – this lack of integration of blogs and webpages represents a significant loss of potential blog users. Sixty-eight percent of organizations publish five contents per month, while 21% publish over five, and 11% over 10.



Graph 4. Social Networks.

Source: Authors' own creation

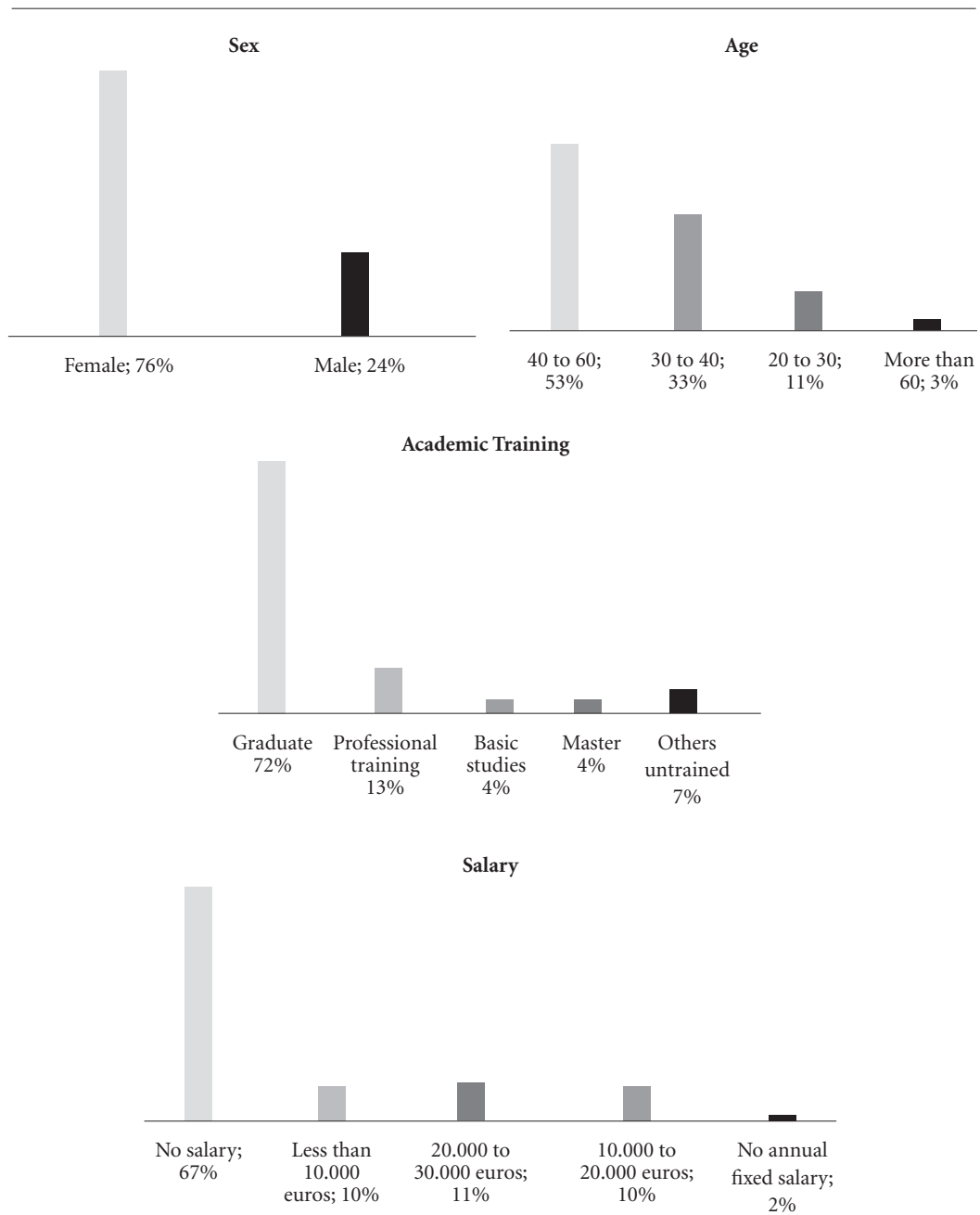
Impact of communication on achieving patient organization objectives

The main objective of the National Year for Rare Diseases was to increase the visibility of patients with rare diseases and patient organizations. The telephone questionnaires revealed the following information about the impact of communication on donations, research funding, and public image.

It is important to note that only 30% of the organizations had a person responsible for communications. The general profile of this person was as follows: woman (76% of organizations), aged between 40 and 60 years (53%), graduate (72%), fully voluntary (67%). Almost half of the people responsible for communications who were remunerated earned 10,000 Euros or between 10,000 and 20,000 Euros annually, while only 11% earned between 20,000 and 30,000 Euros (Graph 5).

Eighty-four percent of the organizations considered it necessary to have somebody dedicated to communications within the organization and the majority of the organizations did not have a specific person due to lack of funding (61%), lack of time (30%), and other priorities (22%).

With respect to the webpages, 84% organizations manage their pages themselves, of which only 16% have a specialized member of staff for



Graph 5. Profile of people working on communication departments of patients organizations.

Source: Authors' own creation

this function: 1% specialized in public relations, 7% in communications, 6% community managers, and 2% external.

The main target audiences of the organizations were patients and affected people (76%) and the population as a whole (also 76%),

followed by the media (24%), health professionals (24%), possible donors (21%), and other sectors (6%).

With respect to social networks, 80% are managed by the organizations themselves. The remainder use external professionals, 8% of whom

are communications directors, 8% community managers, and 4% other types of professionals.

More than half of the patient organizations (55%) prefer to make use of social networks. Main reasons include: to promote support among patients (74%); information sharing (63%); and to establish connections with society (56%). Those organizations that do not use social networks do not use them due to lack of resources and personnel (73%) or lack of time (64%).

Eighty-five of organizations manage their own blogs, while 15% use communications specialists (11% of whom are communications directors, 2% other types of professionals, and 3% community managers).

According to the questionnaires, 54% of patient organizations felt that the National Year for Rare Diseases had no impact on their organization in the media. However, 46% believe that visibility is greater in the media due to the National Year for Rare Diseases and to individual actions undertaken to increase visibility.

Although more than half of the organizations do not believe that the National Year for Rare Diseases had much media impact, 89% believe that it has improved knowledge of rare diseases.

Seventy-two percent of organizations believe that they have greater visibility in social networks, while 49% believe that they have greater visibility in the press, above all local press, followed by television (30%), radio (28%), and other types of media (12%), including digital newspapers.

Fifty-one percent of organizations believe they have had greater contact with the public as a whole due to National Year for Rare Diseases and to individual actions undertaken in recent years to increase visibility.

According to 77% of the organizations, the main reason that they wish to appear in the traditional media and social networks is to raise awareness about the rare disease in question. Other reasons include: to improve the visibility of the organization and the patients (54% of organizations), research fundraising (30%), promote specific rights (30%), publicize the organization's needs (16%), concrete specific goals (11%), and other (10%).

With respect to whether visibility in the media had increased membership and donations, around half of the organizations (46%) stated that it had led to an increase in membership over the last three years of between 5 and 25%, while the other half did not believe that it had led to an increase. However, according to 63% of organizations, this increase in membership was not

translated into an increase in donations, while 37% suggested an association between fund raising and appearances on television. Sixty-four percent of organizations did associate appearing in the media with an increase in funding.

With respect to relations between organizations and the government, 68% of the patient organizations stated that they had not improved, compared to 32% who thought that relations had improved over the last three years and 40% who believed that relations had improved with local government.

Discussion and conclusions

The findings of this study show that the majority of organizations do not have a specific person responsible for communications due to lack of resources and time. Organizations generally have few members and are rarely able to invest in contracting a communications specialist. Generally, therefore, communications work is carried out by volunteers who do not receive any type of remuneration and are typically women aged between 40 and 60 years.

Organizations develop their communication strategies principally through the internet. Over 80% of patient organizations have active webpages, over half of which use 2.0. Despite using the World Wide Web for communications activities, only 21% of organizations have a virtual press room and the majority of webpages are managed by the patients themselves, of whom only 16% are communications experts. Over half of the organizations use social networks for communication purposes and view these networks as their most important and most effective communication tool in terms of impact. Blogs are used to a lesser extent, principally as a tool for sharing personal experiences and more directed to the organization's target audience – other patients and people affected by rare diseases.

With respect to the image of patient organizations and rare diseases portrayed by the media, there is no consensus among patient organizations with respect to the impact of the National Year for Rare Diseases in 2013. However, the general view is that visibility and awareness of rare diseases among the general public has improved over the last three years.

With respect to the press, coverage increased in 2013 -the National Year for Rare Diseases - while coverage of rare diseases and participation of patient organizations on radio and television

was more notable in 2014. ABC and the public television companies TVE and RNE in particular provided greater coverage of patients and rare diseases.

However, rare diseases have generally been given little space in the press, radio and television. Newspaper articles generally take up less than a quarter of a page, while radio and television items have a duration of between only one to five minutes.

In general terms, the media has covered rare diseases through human interest stories, particularly television, where personal stories predominate. In this respect, the impact of television is greater than that of printed media and radio, because it is capable of bringing the audience closer to the subject and allows the audience to empathize with the patients' situation. On the other hand, radio gives more space to organized acts, such as the World Rare Disease Day, and explores the subject through interviews, therefore facilitating a more flexible approach and giving more space to specific rare diseases, while the press and television focus more on news items that transmit information in a more superficial manner. Furthermore, radio gives more space to the topic because it is part of the radio's agenda, while rare diseases is only an occasional focus in the coverage provided by press and television.

Patients and family members are key sources and subjects of news items, both in the press and television. However, while the members of organizations are on the front line of radio and the press, television promotes patients as spokes persons through personal stories and, as such, patients and family members are the main object of interest of this type of media

The space given to rare diseases is greater on the radio than in other types of media. However, patients believe that they achieve greater impact

using social networks, which is corroborated by our findings, which show that their communication efforts are concentrated on this tool. Organizations believe that they can achieve greatest impact in local press and television, which is interesting given that our findings show that television had the greatest potential audience, yet produced the smallest number of pieces on rare diseases.

With respect to the association between greater media visibility and donations and improvements in the public image of patient organizations, organizations confirm an increase in membership, but not in donations. The main aim of these organizations is to increase visibility and raise awareness of rare diseases, while the media prioritizes organized acts and the emotional appeal of human stories. As a result, rare diseases are dealt with in a general manner, while specific diseases remain largely unknown, as those affected by the disease confirm.

The organizations confirmed that relations with society and the government are more fluid. Contact between organizations and society occurs mainly through events, post, e-mail and telephone. Relations between organizations and local government has also improved, although the results of the questionnaires show that organizations believe that this level of government has the least ability to meet their demands.

Finally, it is important to note that, despite lack of personnel and resources, these organizations have made major efforts to become active in demanding and protecting rights, far removed from their former sorrowful and passive image. They have a place on the media agenda and, little by little by little, are gaining a place in the public's agenda, who has come to recognize the concept of rare diseases in the last few years and, little by little, some of the specific diseases. One

could categorically say that these organizations have achieved greater visibility, even though they may still be far from meeting their funding goals afforded by greater media presence. It is recommended that future research explores whether it is necessary to increase the number of communication experts and/or virtual rooms and the progress made by these organizations by analyzing communication campaigns and other strategies in this area.

Collaborators

P López-Villafranca and A Castillo-Esparcia were responsible for determining the research design, data collection and drafting the final version of this article.

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