Chapter 10
Representation of Patients With Rare Diseases in Spanish Media

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ABSTRACT

There are more than 360 associations of patients with rare diseases in Spain that strive for visibility to obtain funding and encourage clinical pathologies. The Spanish Year of Rare Diseases has been a considerable effort to be part of media agenda since 2013 and a "collective voice" throughout the media has been encouraged with the international initiatives devoted to the cause. Over the past years, representation of patients with rare diseases in Spanish media has been very superficial, despite the renewed interest during the Spanish Year of Rare Diseases. Certain cases as "Paco Sanz" or "Los Padres de la Pequeña Nadia" have negatively affected this representation by using the disease to pursue economic benefit. This chapter reports on the representation of rare diseases through Spanish media and the way it evolved in the last 6 years. The findings highlight the effort that has been made by patient advocacy groups with rare diseases and their relatives and caregivers, who have been recognized and proactive to get the treatment and medication needed.

INTRODUCTION

Rare diseases are characterized by a low prevalence in general population, but they are often chronic, life-threatening and a high rate of people with such diseases are very likely to experience a deterioration in quality of life (Avellaneda, Izquierdo, Torrent-Farnell, & Rámon, 2007; Aymé & Schmidtke, 2007; Cohen & Biesecher, 2010; López-Bastida, Oliva-Moreno, Linertová, & Serrano-Aguilar, 2016; López-Bastida, Perestelo-Pérez, Mónton-Alvarez, Serrano-Aguilar, 2008; Pasculli, Resta, Guastamacchia, Suppressa, & Sabbà, 2004). According to the World Health Organizations (WHO, 2012), rare diseases are those who affect less than 100.000 patients, and they may stem from both a genetic condition and/or environmental cause or bacterial infection (Hunter, 2005).

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These diseases often affect the individual's longevity, being incurable and a threat to life. It was not until 1980s that policymakers and general community considered rare diseases worthy of scholarly attention. Avellaneda and colleagues (2007, p.178) claim that this interest has been a result of improving health conditions, increase in life expectancy and wellbeing in population (Aymé, Kole, & Groft, 2008). Commenting on these recent developments in society, Carretón and López (2016) draw our attention to the fact that these "orphan patients" (Kontoghiorghe, Andreou, Constantinou, & Kontoghiorghes, 2014) with rare diseases may have suffered from disease heritage and still face an 'unrecognized risk' (Trujillano, et al., 2017).

The Spanish Federation of Rare Diseases, FEDER (2018)[1] points out that there are more than 6000 rare diseases affecting 300 million people worldwide (cf. ASHUA, 2018) and more than 3 million patients in Spain (FEDER, 2018a). In terms of disease diagnosis and treatment, an average of five years is the estimated time that patients take to be diagnosed with the disease and, in 20% of the cases, it can exceed 10 years to have a proper diagnosis. Almost half of the patients do not receive any treatment and the same proportion show no improvements and get worse in their disease (FEDER, 2018b). Escobar (2018) argues that the major problem that patients and caregivers are facing is the lack of access to reliable information, physicians and experts in the field. As a result, they face a delay in disease diagnosis and, therefore, treatment (Knight, & Senior, 2006; Zurynski et al., 2017).

In Spain, there have been some attempts to raise awareness to rare diseases and its importance. For example, the Council of Ministers declared 2013 as the The Spanish Year of Rare Diseases with the purpose of uniting citizens and foster knowledge towards these diseases. The strategy adopted by the Ministry of Health (Ministerio de Sanidad y Política Social, 2009) fall under three courses of action: (a) sanitary (*i.e.* prevention and detection); (b) scientific (research promotion); and (c) social (through information and sensitization campaigns). In 2016, the International Year of Rare Diseases was celebrated and following the action approved by the Spanish State in March 2015, the health, social and economic consequences of rare diseases were analyzed. Subsequently, the Ministry of Health, Social Services and Equality of Spain addressed the following priorities: improving medical and psychosocial care of patients and their families; advancing research; and raising awareness to rare diseases among general population (Ministerio de Sanidad y Política Social, 2016).

In this chapter, a follow-up of a previous research undertaken by the author in 2013 in the field of communication and rare diseases is discussed and updated. In specific, it covers: (a) the courses of action carried out by patient organizations; (b) identify the patients' problems in coping with the disease; and (c) strategies adopted by public and private organizations to raise awareness towards rare diseases in the community. Whilst there has been a lack of information and resources in this field (Simoens, Cassiman, Dooms, & Picavet, 2012; Stakišaitis, Špokienė, Juškevičius, Valuckas, & Baiardi, 2007; Zurynski, Frith, Leonard, & Elliott, 2008) and the initiatives rely too much on volunteerism, health communication has become a central issue for patient organizations (Huyard, 2009; Pinto, Martin, & Chenhall, 2016; Rajasimha et al., 2014).

Furthermore, media has been important to disseminate health communication (Moorhead, Hazlett, Harrison, Carrol, Irwin, & Hoving, 2013; McMullan, 2006) and media professionals have a prominent role in communicating current advances in science and medicine (Nelkin, 1996; Petersen, 2001).