


Chapter 5

Public Media Coverage of Rare Diseases and Disorders: The Case of Spanish Public Broadcasting Corporation

Yolanda Berdasco-Gancedo

 <https://orcid.org/0000-0003-0291-0617>
Universidad a Distancia de Madrid, Spain

ABSTRACT

Rare diseases and disorders are, as the names suggest, a strange or unusual health condition, and so the coverage given by the media is not as extensive as it could be. However, researchers point out that this situation is changing little by little, and there is now more information about those who suffer from these conditions, and their experience. It is quite interesting to see how the public media, especially in the case of Spain, are making a great effort to give a voice and space to people affected by such diseases. In the case of public media, there are many other aspects to be considered. Firstly, the Spanish Broadcasting Corporation, Radio Televisión Española (RTVE) is not tied to private finance. Secondly, these channels are expected to be more independent and, subsequently, there may be no additional pressure to reach high audience share or obtain external funding from private media companies. This is especially interesting in the case of radio broadcasting, as it tends to be a medium with a high level of credibility, and closeness to the audience.

DOI: 10.4018/978-1-7998-2088-8.ch005

INTRODUCTION

Public media services are committed to improving people's quality of life and serving the public interest by contributing to an informed society and having a great impact on individual's daily living (*e.g.* voting, behaviour change, protesting) (Perse, Kubey, & Csikszentmihalyi, 1991; Wright, 1960). Indeed, a number of organizations, such as United Nations Educational, Scientific and Cultural Organization (UNESCO) have attempted to clarify the role of Public Service Broadcasting (PSB) and explain what would be expected from those media. One of the most obvious tasks of PSB is covering issues that are out of the scope of commercial media but meet the citizens' general interest. RTVE follows United Nations Public Service Broadcasting (PSB) recommendations¹ and as such, it aims to give a voice and a space to a general audience.

This chapter focuses on media coverage of rare diseases in Spanish public media. RTVE has a wide coverage of this area, using all the available channels: TV, radio, web services and social media profiles.

The investigation takes the form of a case-study in which RTVE broadcasts dealing with information about rare diseases are analysed, focusing on the content, data sources and the way information is included and presented.

The main aim of this chapter is to understand the way health-related information about rare diseases is covered in Spanish Public Broadcasting Corporation, namely, its conditions and treatments. Furthermore, it discusses the role of RTVE in satisfying Public Broadcasting Service (PBS) duties in spreading health-related information. Comparisons between public and commercial media are also made.

The author makes a distinction between programmes which deal with global and general information about these conditions, and those in which the individual situation of a person affected by a rare disease is presented. Likewise, the difference is noted between those programmes in which the disease and illness-related topics are the focus and those in which the interrelationships between different actors, such as doctors, organization spokespersons are in the spotlight.

The rationale for spreading health-related information about rare diseases is twofold: (a) underline that a rare disease exists; and (b) inform about the diagnostics and effects, in order to obtain some funding or research investment. Nonetheless, health-related journalism is still in need of accuracy, reliability and depth stories (Holtzman, et al., 2005; Smith, 2006).

By analysing information and communication in mass media, it is important to take into account polarization, frequency, or campaign initiatives, *e.g.* World Day of Rare Disease. Another significant aspect is also the relevancy to know whether they are using only traditional channels, *i.e.* television and radio to spread this