

Chapter 4

Digital Media in Rare Diseases or “Knowledge Is Power”: The Role of EURORDIS in Creating Awareness and Diagnosing Rare Diseases

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ABSTRACT

This chapter focuses on the use of digital media by EURORDIS-Rare Diseases Europe and is specifically committed to understand its contribution to the awareness and diagnosis of rare diseases. To perceive the use of digital media and role in creating awareness of rare diseases, the contents of its website and Facebook page were analyzed. In specific, a promotional video of EURORDIS and a collection of 12 videographically documented stories from 2018 and 2019. The results show the use of various types of content and inherently practices, such as information, clarification, personalization, support, appeal, and empowerment, and of several rhetorical resources. In the dimension of pathos, the author finds elements that motivate awareness and inspire the receiver. Some elements of the logos used are credibility of sender (ethos), testimony (ethos), description of disease and identification of symptoms, exemplification and personalization, factual data, statistic data, and the use of metaphors and repetition.

INTRODUCTION

Due to the inadequacy of the treatments, “rare disease patients have begun acting like scientists and studying themselves” (Polich, 2012, p. 167). In this context, the internet, because it addresses a large public of rare diseases, attracts patients who are internet users highly stimulated to seek information and online communities, being receptive to new interventions that respond to their needs. The internet, by providing information on rare diseases, may promote increasing competence in decoding clinical research studies and afford new insights that may be useful when the patient consults the health professional and in exploring new therapeutic modalities. This is tantamount to making tremendous progress

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in patient self-advocacy (Liuccio, Belotti, Comune, Zambito & Schulz, 2015, p. 5). When individuals access accurate and reliable information, they can make informed decisions. So, it can be said that “knowledge is power”.

In this scenario, the author proposes to study the messages and practices of digital communication of EURORDIS-Rare Diseases Europe, concretely in its website and Facebook page, in order to understand the use of digital media and its role in creating awareness to rare diseases. EURORDIS is a unique, non-profit alliance of 837 rare disease patient organizations from 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.¹

Awareness is the ability to directly know and perceive, to feel, or to be cognizant of events. In a broader sense, it is the state of being conscious of something (Korompilias, 2018, p. 71). Additionally, it has been prominent in public relations and communication campaigns. For example, Grunig and Hunt (1984) classified publics as latent, aware and active, describing the aware public as the one that recognizes that there is a problem. The emphasis on awareness in public relations and public communication circles coincided with an increase in education initiatives in the health and medical fields, because “the skills public health advocates need to amplify the voice of public health and ensure that the stories being told reflect basic public health goals and values” (Wallack, Dorfman, Jernigan & Themba-Nixon, 1993, pp. 2-3). Awareness is associated with consciousness. Anything that we are aware of at a given moment forms part of our consciousness (Velmans & Schneider, 2007, p. 1).

Furthermore, it is intended to analyze the video’s potential, concretely a promotional video of EURORDIS and a collection of videographically documented stories from 2018 and 2019, present in the website, from people who share their experiences of living with a rare disease, in order to perceive how these messages can be useful in the sensitization and diagnosis of rare diseases. The defended argument is that the messages and practices of digital communication of EURORDIS contribute to awareness and diagnosis of rare diseases. Therefore, it is assumed as a starting question: *How do messages and practices of digital communication of EURORDIS contribute to create awareness and facilitate the process of diagnosis of rare diseases?* Methodologically, qualitative content analysis is used to deal with message content and rhetorical analysis to deal with form and style.

BACKGROUND

Social media, used within health care contexts for communication purposes, is increasing and becoming more acceptable (Burke-Garcia & Scally, 2014; Moorhead, 2017). Specifically, these digital tools are likely to enable: (a) Improved interactions with others; (b) More available, shared, and tailored information; (c) Increased accessibility and widening access; and (d) Increased peer/social/emotional support. These are some of numerous benefits of social media for healthcare communication (Moorhead, 2017).

Roberts, Seymour, Fish II, Robinson and Zuckerman (2017) assume that the digitally networked global public may have influenced the discourse, sentiment, and response to the Ebola epidemic originating in West Africa. The authors analyzed 109,400 English-language stories about the keyword “Ebola” published from 1 July 2014 to 17 November 2014 from the media sets U.S. mainstream media, U.S. regional media, U.S. political and popular blogs, Europe Media Monitor, and Global Voices to understand how social network theory and models of the networked global public may have contributed to health communication efforts on Ebola epidemic. The Centers for Disease Control and Prevention (CDC)

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