Chapter 7

Networks in Rare Diseases: Identities, Partnership, and Advocacy in Brazil

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ABSTRACT

Rare diseases are characterized by their low prevalence in a population, and since 1980 a social movement has gathered around this cause in many countries. In Brazil, the category of rare diseases emerged in 2000, culminating with the enactment of a National Policy geared at rare diseases. Rare disease patient organizations are the main actors of this social movement and since this is very recent in Brazil, this research was conducted to explore the topic. Using netnography as method, a content analysis of the Social Media Network Facebook was performed, aiming at understanding the way social movements have assembled around rare diseases and its role in portraying this type of diseases in Brazil. This chapter offers important insights into the way patient organizations are using social media to convey ideas and discourses, and to foster lay expertise on rare diseases.
INTRODUCTION

Rare diseases are defined by their low prevalence in population, and in the past years they have only been described in the biomedical literature as a way to classify a disease (Wilson, 2013). Then, the term ‘rare diseases’ has evolved in order to become a category, a way to classify people who share the experience of living with a rare disease. Actors of a social movement in health began to use this term in consequence of a series of events that took place – e.g. development in surgery treatments, gather disease information in a database (e.g. Orphanet), emergence of networks and associations, and media coverage (Dooms, 2016; Huyard, 2009a).

The legislation on pharmaceutical products has changed in the United States of America (USA) over the years, and it also became required to demonstrate the effectiveness and safety of those substances in order for them to be commercialized. This made pharmaceutical products safer, but also raised the cost of drug development. Therefore, the industry focused only on the development of drugs for common diseases, which could be profitable.

Before the early 80s, diseases which were not contemplated by research of new treatments and were considered ‘orphan diseases.’ By contrast, in the following decades, people with ‘orphan/rare diseases’ and their families had begun to claim access to treatment and a way to solve those inequities was a new law – the Orphan Drug Act, which included several incentives for the development of drugs for orphan/rare diseases (Greene & Podolsky, 2012).

The Orphan Drug Act, enacted in 1984 had two criteria to define what was meant by an orphan drug (Huyard, 2009a): (1) the drug would be used to treat diseases with a prevalence of lower than 200,000 patients in the United States of America; or (2) although the disease prevalence would exceed 200,000 patients, the drug would not be profitable in the American market. The incentives granted by this law focused on the industry’s profitability and not on its innovation capacities. Therefore, people with rare diseases tended to be overlooked as health consumers and, as such, they began to make political demands for access to specific treatments.

In Europe, the social movement of rare diseases has emerged in the 1990s. The French government, alongside rare diseases patient organizations, founded a non-governmental organization (NGO) dedicated to rare diseases, EURORDIS – Rare Diseases Europe (EURORDIS, 2018). The policy geared at rare diseases in the European Union (EU) also included incentives for the pharmaceutical industry.

It is worth noting that the European policy makes a clear distinction between orphan diseases and rare diseases. Orphan diseases are the ones that mainly affect people living in the underdeveloped world, which makes them an unprofitable market due to economic restrictions and rare diseases are the ones that mainly affect few