

Chapter 5

Designing Sustainable Social Media Health Communication Campaigns for Promoting Rare Diseases

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ABSTRACT

The third goal of the United Nations Sustainable Development Agenda aims to ensure individual's wellbeing and a long and healthy life. As such, health is perceived as an essential part of sustainable development. While progress has been made over the past decades, far too little attention has been paid to misdiagnosed and rare diseases. In the context of promoting "health for all", communication is of uttermost importance. By means of a content analysis for selected rare disease campaigns, the present contribution seeks to highlight the way the UN's health goal is communicated as part of health campaigns for rare diseases. Amongst others, this chapter sets out to understand how the goal is communicated, which aspects are stressed, and whether there are differences in message strategies across different platforms relative to rare diseases. Ultimately, the potential of social media for communicating rare diseases is carved out. Research limitations and directions for future research are also addressed.

INTRODUCTION

In the light of the third objective of the United Nations Sustainable Development Goals (SDGs), individual's life-long health, well-being and quality of life has been regarded as one of the most relevant indicators of the sustainable development of society (UN, 2019). In detail, Goal 3 sets out to end the epidemic of infectious and noncommunicable diseases as well as reduce malnutrition rates amongst

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others by 2030 (UN, 2019). While improvements have been made over the past decades in the health sector, especially in the area of infant and maternal mortality, HIV/AIDS and malaria, other diseases – amongst them “rare” or “orphan” diseases – continue to be life-threatening (Denis, Margaret, Fostier, Cleemput, & Simoens, 2010). Rare diseases are defined as diseases that only affect a small number of the total population (Orpha.net, 2012; WHO, 2018, World Economic Forum, 2017). Due to the fact that they do not affect a large number of people, they often remain under the public’s awareness threshold and are not part of people’s agenda, as they are mainly unknown to the large public.

Achieving the goal of “health for all” in a mediatized world poses new challenges and opportunities for all stakeholders involved, including governments, communities and patients (Schiavo, 2007). Indeed, communication plays an important and sometimes decisive role in raising awareness, promoting individual acceptance and creating legitimization to achieve “health for all.” In this context, health communication campaigns are of uttermost importance, because they are concerned with “influencing, engaging and supporting individuals, communities, health professionals [...] to champion, introduce, adopt, or sustain a behavior, practice or policy that will ultimately improve health outcomes” (Schiavo, 2007, p.xxi). Moreover, health campaigns are concerned with providing guidance as to how to address and improve social problems (Rossmann & Ziegler, 2013).

By means of a content analysis of selected campaigns addressing selected rare diseases (exemplified through Ataxia, and Epidermolysis Bullosa EB) as well as campaigns for Rare Disease Day, this chapter aims to understand how the UN’s Sustainable Development Goal 3 is communicated in a “sustainable” way, as part of national and international health campaigns. For the purpose of this paper, we define sustainable health campaigns as promotional material that provides individuals with the right information, at the right time, in a comprehensible, appealing, and engaging manner, in order to bring about lasting (behavioral) change.

Sustainable health campaigns are concerned with educating the public about and creating permanent awareness for diseases, further calling upon individuals to become involved in their health or assist others in seeking help. At the same time, stigmatization of diseases and/or people affected should be reduced (Schiavo, 2007).

This chapter addresses the following research questions:

- **RQ1:** Which channels are used to promote rare diseases?
- **RQ2:** Which message appeals or design elements are used to attract attention? Is the reasoning rather rational or emotional?
- **RQ3:** To which extent are elements of selected health theories integrated into these messages and inasmuch are they used to achieve audience engagement?
- **RQ4:** Do messages differ across platforms, as well as across rare diseases?
- **RQ5:** Inasmuch are the criteria of a “sustainable” health campaign fulfilled?

This chapter is structured as follows: The next section introduces the concept of rare diseases and the importance of health campaigns to create awareness for rare diseases. Then, ad appeals in health communication, cross-media (health) campaigns and the use of social media in health communication are discussed. Finally, different campaigns used to create awareness for rare diseases are analyzed (i.e. Rare Disease Day, Ataxia and Epidermolysis Bullosa). In conclusion, the previously proposed questions are answered for all three campaigns. Afterwards, results are compared and both limitations and directions for future research are addressed.

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