Chapter 7
Portraying Rare and Misdiagnosed Diseases in Movies:
A Content Analysis, 1980–2018

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ABSTRACT

This chapter examines the portrayal of rare and misdiagnosed diseases in 9 movies from 1980 to 2018. The analysis embodies the representation of rare diseases and the suggested audiovisual strategies to comprehend the message conveyed. Most of the movies introduced the disease by highlighting its symptoms. The binomial culture of cure and care often emerges, as well as the patient's desire for the mundane pleasures in life and over dependence in a health system. The high hopes in research advances and lack of information are majorly covered in the caregivers' attempts to seek tests and drug trials and their mediator's role in patient-physician interactions. The audiovisual strategies adopted vary between the accelerated montage to communicate the contrast between the frenetic side of everyday life and the patient's process of coping with the disease, deep focus from patients to parents, and close-ups to show the individual's reactions and perspectives.

INTRODUCTION

In an increasingly visual-oriented society, scholars (*e.g.* Grushka, 2009; McDonagh, Goggin,& Squier, 2005; Miguel, 2016; Müller, 2008; Sweeny, 2004) have been more and more interested in the way that visuals can facilitate individuals' "meaning-making" (Fei, 2007; Harrison, 2003) through the use of such elements as semiotics, perceptual theory, psychosocial factors and aesthetics that are often used to transmit pieces of data, information and emotion in multiple media (Hortin,1994). Indeed, visual composition, syntax and elements are so omnipresent in the representation of an individual's actions, objects and symbols that they may consciously or unconsciously have a strong impact on empathic re-lationships, actions, self-perception, decision-making and behavior change (Gumpert & Cathcart, 1985; Hortin,1994; Messaris, 1998).

In the medical context, visual language is also used to transmit information about, for example, the portrayal of common symptoms and the representation of a certain disease (i.e. representation in medi-cal literature, arts of Italian Renaissance, epidemic cartoons and TV series) (Gilman, 1998). But also in cartographies of epidemics (Koch, 2011), wayfinding, labelling and signage design in health care environments (Delvin, 2014; Hashim, Alkaabi, & Bharwani, 2014; Pati, Harvey Jr., Willis, & Pati, 2015) and in media campaigns (Randolph & Viswanath, 2004; Wakefield, Loken, & Homik, 2010). In these different media, health-related communication may also rely on allegories (e.g. Niemiec, 2010), parallels (Eysenbach, 2008; Koplan, 2003), non-verbal – *e.g.* gestures (Asan, Young, Chewning, & Montague, 2015; Bickmore et al., 2010), and metaphors (Krieger, Parrott, & Nussbaum, 2010). As Evers (1969, p.34, cf Hortin,1994, p.16) puts it:

Movies, photographs, commercials and even printed statements are representations of reality. They are metaphors, and therefore must be understood as metaphorical points of view. That is what mediacy is about (Evers, 1969, p.34 cf Hortin, 1994, p.16)

The use of movies in the medical context and its impact on stigma and attitudes towards certain ill-nesses or health education have been widely covered (e.g. Banos, 2007; Damjanović, Vuković, Jovanović, & Jašović-Gašić, 2009; Pirkis, Blood, Francis, & McCallum, 2006). However, its use to foster discus-sion, create awareness towards orphan drugs and demystify the challenges of rare disease research have been quite overlooked.

The aim of this chapter is to examine the portrayal of rare and misdiagnosed diseases in movies from 1980 to 2018. In specific, the messages that are transmitted relative to the disease, ethical dilemmas, interaction among different health stakeholders, and the audiovisual strategies used to convey such mes-sages (camera movements, color, lighting, montage, among others).

This chapter is structured as follow: The next section discusses the use of movies to convey health-related information, providing a brief overview of cinematography in the story-making process. The International Rare Disease Festival is presented as an example of an initiative that is paving the way into the use of movies as a *medium* to meet this purpose. It proceeds with the process of movie selection, the content categories used and data collection. The results section examines the way rare diseases are portrayed in movies and the audiovisual strategies used. The chapter concludes by summarizing the main audiovisual strategies used in movies and its purpose to convey a certain meaning to the information provided and portrayal of rare diseases.

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