# Chapter 13

# Health-Related Communication and Rare Diseases:

## A Passport for the Patient Journey

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## ABSTRACT

*Rare diseases are often characterized as diseases with low prevalence in population that stem from genetic disorders or environment conditions. As a result of its low prevalence and lack of knowledge of its causes, symptoms, and/or treatment, patients' access to healthcare, and their quality of life may be affected. A key challenge is also the physician-patient interaction that differs from traditional medical care settings by demanding physicians' experience in dealing, for example, with psychological problems associated with the diagnosis process. Information and Communication Technologies can facilitate the interaction between the sources of information and patients, overcoming geographical distances. This chapter discusses the role of Information and Communication to extract health data in rare diseases and reinforce physician-patient interactions. It argues that Information and Communication are crucial to meet patients' needs, drivers, and decision-making that tend to occur during the patient's journey (pre-diagnosis, diagnosis, and post-diagnosis).*

## INTRODUCTION

Rare diseases impact negatively upon on patients' access to high-quality healthcare and both patients and care-givers' quality of life (Hesselgrave, 2003; Huyard, 2009; Pasculli, Resta, Guastamacchia, Suppressa, Sabbà, 2004; Schieppati, Henter, Daina, & Aperia, 2008). Part of this impact may be owing to the uncertainty often associated to this kind of diseases and, subsequently, have an impact on trust in physicians and healthcare systems.

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Lack of certainty is, indeed, one of the greatest challenges that is likely to predominate in disease diagnosis and treatment. Babrow, Kasch and Ford (1998) point out that uncertainty can result from complex situations (e.g. multicausal or contingent pathways to outcomes), properties of information (e.g. clarity, completeness, volume, or consistency), probabilistic thinking (e.g. belief in a single probability or a range of probabilities), the structure of information (e.g. how or whether information is integrated with other information), and lay epistemology (e.g. individual beliefs about the nature of knowledge).

In health-related communication, investigating the way uncertainty is managed by patients (Brashers, Goldsmith, & Hsieh, 2002; Martin, Stone, Scott, & Brashers, 2010) and their social network members (Donovan-Kicken & Bute, 2008) has been a continuing concern within socio-medical context. Patients and caregivers usually rely on community social support to help with information seeking (Brashers, Neidig, & Goldsmith, 2004; Cline & Haynes, 2001), coping skills and disease management (Patsos, 2001), reinforcing perceived relational stability and changes in the patient's perspective on the disease impact (Doyle, 2015).

Provider-patient relationships can be also fundamental to aid in uncertainty management; however, they can also exacerbate certain moments of uncertainty when dealing with the dualism of a "credible authority" and information scarcity. In fact, Mishel (1988) draws our attention to the fact that a "credible authority" (i.e, trust and confidence in health care providers) are important predictors of uncertainty. If, on the one hand, they can be a valuable source of information or advice and facilitate decision-making, on the other hand, they may express uncertainty towards incidence (i.e. number of newly diagnosed cases) of rare diseases (Brashers, Hsieh, Neidig, & Reynolds, 2006; Gordon, Joos, & Byrne, 2000).

In health provider-patient interactions, mirroring uncertainty (Clayton, Dudley, & Musters, 2008) can also occur, having an impact on patient's satisfaction and anxiety (Blanch, Hall, Roter, & Frankel, 2009). It can be manifested through the following ways: (a) Question asking (Eggly et al., 2006); and (b) Information sharing (Nakash, Dargouth, Oddo, Gao, & Alegría, 2009). Given that this process may be amplified with the use of Information and Communication Technologies (Lewis, Gray, Freres, & Hornik, 2009) and affect patients' attitudes (Parrott, 2009) and health (Pecchioni, Thompson, & Anderson, 2006), understanding the role of communication among different stakeholders (i.e. patients, caregivers, physicians, policy-makers) in rare diseases is of utmost importance.

The aim of this chapter is to discuss the role of information and communication to extract health data in rare diseases, and the implications in the patient's journey (pre-diagnosis, diagnosis and post-diagnosis).

## HEALTH-RELATED COMMUNICATION AND RARE DISEASES IN THE DIGITAL AGE

Although a precise definition of health-related communication is lacking, it is undeniable the importance of the transdisciplinary involving both health and social sciences (Lambert, & McKevitt, 2002; Schiavo, 2007). The Centers for Disease Control and Prevention (2019) defines it as:

*The study and use of Communication strategies to inform and influence individual decisions that enhance health.*

The interpersonal and intrapersonal interactions (Ruesch, 1951) may involve different channels (e.g. letters, newspapers, mass media, mobile media, VR, games) and health stakeholders (e.g. physician, patient,

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