

Chapter 67

The Role of ICTs in the Management of Rare Chronic Diseases: The Case of Hemophilia

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ABSTRACT

This chapter outlines a study that examines the role of Information and Communication Technologies (ICTs) in management of a rare and chronic disease, hemophilia. Evidence in literature shows how the adoption of ICTs can improve the management of chronic conditions. Furthermore, these tools may also give response to rare diseases' needs, while greatly improving the quality of life of those patients. A Web-based application that was developed to facilitate communication between Healthcare Professionals (HCPs) and patients in a specific Hemophilia Treatment Center (HTC), to improve the utility and quality of clinical data and treatment information, as well as to help the management of resources involved in a specific rare chronic disease, represents a practical case presented in this chapter. This technological solution allows the management of inherited bleeding disorders, integrating, diffusing, and archiving large sets of data relating to the clinical practice of hemophilia care, more specifically the clinical practice at the Hematology Service of Coimbra Hospital Center.

INTRODUCTION

The growing number of persons suffering from chronic diseases associated with the obstacles in dealing with their condition is one of the reasons that led some researchers to create mechanisms

and guidelines, which are expected to facilitate more effective medical practice, and consequently to improve health outcomes and life quality. The framework to guide quality improvement, called Chronic Care Model (CCM) reflects some of these guidelines, emphasizing the relevance of the

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interactions between clinicians and patients that consistently provide the assessments, support for self-management, and follow-up associated with good outcomes (Wagner et al., 2001). Elements of the CCM include community resources and policies, healthcare organizations, self management support, delivery system design, as well as decision support and clinical information systems (Bodenheimer, Wagner, & Grumbach, 2002; Wagner, et al., 2001).

The term chronic disease normally applies to conditions that can be treated but not permanently cured. Chronic disease means continual or recurring illness and often requires extensive care by a Healthcare Professional (HCP) with the cooperation of the patient in managing their own disease. While HCPs offer different types of treatment to minimize the effects of symptoms caused by chronic disease, the result of a chronic disease for the patient is a lifetime of discomfort, regular doctor's visits, medications and therapy for life, and sometimes treatments involving surgery.

In addition to chronic conditions, there is a significant number of this type of disease that is simultaneously rare. A rare disease, also known as an orphan disease, is any disease that affects a small percentage of the population. Their low prevalence requires special efforts to deal with them so as to improve diagnosis, care and prevention complications (Aymé & Schmidtke, 2007). According to evidences of *European Organization for Rare Diseases* (EURORDIS), rare disease patients "need earlier access, in particular to more specialized social services and consequently they require a comprehensive approach integrating medical and social care" (EURORDIS, 2011).

This is what happens with hemophilia, one example of rare chronic disease which affects about 400,000 people worldwide (WFH, 2005). The treatment of this chronic and rare disease is complex, very expensive and involves highly specialized skills, usually concentrated in Hemophilia Treatment Centers (HTCs). In Portugal, these HTCs are located in major cities, while the

patients are geographically dispersed all over the country; thus, patients sometimes have to travel long distances to visit their physicians that are in HTCs. This physical drawback provides also a stimulus for using ICTs in order to minimize the effects of physical distances and to promote the quick communication between healthcare providers and patients and/or their families.

Altogether, people with rare diseases, apart from inherited chronic health conditions, also suffer from added physical, social, and emotional problems (Baker, Crudder, Riske, Bias, & Forsberg, 2005). Usually, this type of patients receives fragmented care that is delivered across multiple providers, and sometimes this care is not provided in a coordinated manner. The concept of care coordination means activities sharing among several clinicians involved in a patient's care, to facilitate the appropriate delivery of health care services. Indeed, an effective management of rare chronic diseases requires a partnership between the patient/their families and healthcare providers (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Celler, Lovell, & Basilakis, 2003). Furthermore, people that suffer with rare chronic diseases are normally responsible for their own day-to-day care, and usually in the best position to measure the severity of their symptoms and the efficacy of their treatment (Celler, et al., 2003; Green, Fortin, Maclure, Macgregor, & Robinson, 2006). Facing these conditions, ICTs can have an important role in this coordination care, in the interaction between patients and HCPs, as well as in the management of other type of the resources involved in the monitoring, treatments and follow-up this particular kind of patients.

Literature reports the importance of adopting ICTs in healthcare practices to improve the communication between HCPs and patients, as well as the quality of services and patient care (Baker, Laurenson, Winter, & Pritchard, 2004; van der Lei, 2002; Walker et al., 2004). Notably, Web-based ICTs have the potential to support the ongoing care needs of patients with chronic diseases and

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