

## Chapter 8

# Communication and Education Processes Involved in COPD Patient Engagement Within the Italian Health System

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### ABSTRACT

*The World Health Organization has estimated that chronic obstructive pulmonary disease (COPD) is the fourth most common cause of death worldwide. Due to the economic and social extent of the problem, patient engagement must be comprised as a new resource for the achievement of higher health outcomes and lower costs. As many key processes involved in the COPD patient engagement consist of communication and education processes, modelling those processes in a whole framework, including actors and content needs, is a requirement. The main scope of this chapter is contributing to design such a framework within the Italian Health System. Final recommendations suggest to create a synergy among patient engagement and a set of legal tools, namely informed consent, integrated care and advance care planning. The synergy is based on the fact that both patient engagement and those legal tools have a common deep root in the universal principle of patient autonomy.*

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## **INTRODUCTION**

Noncommunicable diseases (NCDs) - that is medical conditions or illnesses that are non-infectious or non-transmissible - constitute the primary causes of death worldwide (World Health Organization, 2008a). In 2008, 57 million deaths occurred in the world; 36 million (63%) were due to NCDs, mainly cardiovascular diseases, diabetes, cancer and chronic respiratory diseases (Alwan et al., 2010). NCD deaths are estimated to rise by 15% between 2010 and 2020 (to 44 million deaths) (WHO, 2008b). The foremost causes of NCD deaths in 2008 were: cardiovascular diseases (48% of NCD deaths); cancers (21% of NCD deaths); and respiratory diseases, comprising asthma and chronic obstructive pulmonary disease (COPD) (11% of NCD deaths). In the EU, the estimated costs for COPD varied from 133.7 million in the Netherlands to 1.1 billion USD in Sweden (Van Boven, Vegter, Van Der Molen, & Postma, 2013). This trend consequently results in an enormous, steadily increasing economic and social burden (Lopez & Murray, 2006). In the last years, Italy carefully pondered the epidemiological and social impact of respiratory diseases. As a consequence, chronic respiratory diseases were comprised in the priority areas of intervention in the National Prevention Plan (Ministero della Salute, 2010–2012).

Being COPD a chronic and not completely reversible disease, its treatment needs to develop new health care models targeted on chronic conditions. This is necessary, in order to overcome the traditional approaches based on a concept of illnesses with abrupt onset and restricted duration - which can be typically cured by health professionals - towards new models of patient activation, participation and self-management. Patients with COPD often develop multiple disease-related symptoms as breathlessness, pain, fatigue, loss of appetite, dyspnoea, cough, phlegm, chest tightness, exercise intolerance, sleep disorders as well as loneliness and restriction of social activities (Shipman, White, Gysels, & White, 2009). COPD patients must also cope with the side-effects of treatment, such as anxiety and depression, which can significantly upsurge physical disability, morbidity, co-morbidity, and healthcare services utilization, affecting compliance with medical treatment (Maurer et al., 2008). All these aspects make COPD a disease with an extensive impact on the quality of life for both patients and their families (Grant, Cavanagh, & Yorke, 2012).

Due to the economic and social extent of the problem, patient engagement must be comprised as a new resource for the achievement of higher health outcomes and lower costs. Many key processes involved in the COPD patient engagement consist of communication and education processes. Nevertheless, many studies suggest that communication among COPD patients, health professionals and caregivers is a noteworthy problem which requires several improvements (Giacomini, DeJean, Simeonov, & Smith, 2012). Although modelling those processes in a whole framework, including actors and topics (or content needs), is clearly a requirement, this conceptualization had never been conceived. The main scope of this chapter is contributing to design such a framework within the Italian Health Service. A descending objective is that of providing legal and ethical recommendations to create a synergy among patient engagement and a set of legal tools, namely informed consent, integrated care and advance care planning.

## **BACKGROUND**

Nowadays, health care providers and health plans design swiftly changing expectations about patient participation. Currently, patients will not benefit from their health care unless they make use of considerable knowledge, skills and motivation to actively participate in the available care (Gruman et al., 2010).

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