

Chapter 1

The Patient–Centered Model and the Diffusion of Patients’ Organizations

ABSTRACT

Healthcare management recognizes the importance of a patient-centered model whereas decision-making takes place pursuing social value, and empowered patients collaborate with healthcare operators in order to receive the best possible care. In this regard, patients’ organizations are social groups taking care of patients’ interests along several dimensions. This chapter introduces the phenomenon of patients’ organizations and briefly describes the possible roles they can play within healthcare, both at macro and micro levels. The chapter organization is as follows: the background section introduces the importance of patient empowerment and describe the patient-centered healthcare model in general terms and as far as hospital organizational implications are concerned. It is followed by the definition of patients’ organizations and a brief description of their diffusion. The chapter continues with a section about the social roles of patients’ organizations, also considering the challenges posed by the digital transformation. It ends with conclusions and future research directions.

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BACKGROUND

In the last decades, the definition of healthcare quality has evolved to take into consideration not just clinical outcomes but also patients' personal needs (Berghout *et al.*, 2015; Luxford *et al.*, 2011; Sepucha *et al.*, 2004). Such trend can be summarized by the affirmation of the 'patient-centered' care (Pelzang, 2010; Mead & Bower, 2000, 2002; Lawrence & Kinn 2012; World Health Organization, 2007), a model of healthcare provision characterized by respect and responsiveness of *individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions* (Institute of Medicine [IOM], 2001).

The introduction of the term in the medical field is ascribable to Balint (1957), whose research has progressively inspired medical and healthcare management literature, reporting the need for a shift from the traditional, paternalistic and professional/provider-focused approach to an egalitarian and patient-focused one. The results of this process are relevant healthcare improvements, especially on clinical outcomes, patient satisfaction, equity and efficiency (Arora *et al.*, 2009; Ford-Gilboe *et al.*, 2018; Prag *et al.*, 2017; Rathert *et al.*, 2013; Stewart, *et al.*, 2000; Street *et al.*, 2009). For these reasons, policy makers all over the world have included patient-centeredness within their agendas (Selby & Lipstein, 2014; Santana *et al.*, 2017).

At the same time, new tools and indicators have been developed to measure healthcare quality from the patient's perspective (Epstein & Street, 2011; Sawyer *et al.*, 2014; Sepucha *et al.*, 2004). In addition, the patient-centered care, called *partnership approach* by Cooper *et al.*, (2016), can be related to the person-centered model (Santana *et al.*, 2017) including also people not directly affected by illnesses but involved in the process of care, e.g. families and caregivers.

The core of the patient centered approach is its multi-dimensionality; according to the Picker Institute (Gerteis *et al.*, 1993), eight dimensions identify patient-centered care:

1. respect for patient preferences, values and expressed needs;
2. information, education and communication;
3. coordination and integration of care and services;
4. emotional support;
5. physical comfort;
6. involvement of family and friends;

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