Chapter 2

Patient Advocacy and the Policy Making Process

ABSTRACT

Recent developments in the policy-making literature and practice have highlighted the growing role of patient advocacy, that is, the participation of patients in policy making through the presence of their representatives at institutional working tables. This chapter has a twofold aim: (1) to frame the activity of patient organizations' advocacy into the public management and administration theory and (2) to describe how patients' organizations can participate to the public policy making from an operational point of view. The chapter starts by providing background information about patient advocacy. Then it introduces the core literature streams of public management and administration. Finally, a feedback analysis shows possible policy cycles linking patient-aided steps of interactive policy making.

BACKGROUND

Patients' organizations are non-profit entities made up of a group of voluntary people, aggregated to pursue common purposes: to represent patients, to provide them practical information for a better management of their own pathologies, to support patients and their entourage (families and caregivers), to organize public campaigns promoting awareness about the diseases, to collaborate with health facilities and institutions, and to carry out advocacy activities. The latter function, representing the main focus of the present chapter, requires

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providing a definition of patient advocacy. Indeed, patient organizations are no just spokespersons for patients' needs but key stakeholders, empowered and informed, active participants in the health policy choices. Sometimes the term 'advocacy' is used to indicate the concept of any activity carried on by patients' organizations. It is not the case of this chapter, which instead uses this word by recalling its Latin etymology ('to add a voice') and thus accepts the meaning *to promote and defend the patients' cause by bringing their needs to the policy makers* (Aloe & De Stefano, 2017).

Patient advocacy builds on patient empowerment and engagement, two relevant concepts influencing each other. Empowerment is a social process occurring when people, organizations and communities acquire expertise on their own lives, gain mastery of their affairs, change their social and political environment, and improve equity and quality of life (Wallerstein, 2006; Rappaport, 1987).

In the healthcare sector, it translates into people's conscious participation in the management of healthcare. Empowerment can be seen at an individual or at a community level. Individual empowerment means people's feeling of a sense of control over their lives (Woodal *et al.,* 2010)., which research positively links to mental and physical health (Wallerstein, 1992; 2003). However, individual empowerment is limited because it does not consider the wider environmental influences on people's health (Woodal *et al.,* 2010). Thus, it is the case to complement the individual's notion to the collective one, i.e. the community empowerment, able to overcome individual interests of skill formation, and to create communities that can support social changes by mean of partnerships, participation and collective action (Wallerstein, 2006).

Thus, it becomes necessary to valorize patients' expertise about their own illnesses and the necessary know-how to coexist with them, at the same time increasing individual and collective patients' knowledge and skills. The latter can only happen through patients' engagement, i.e. involving them in decisions regarding planning, management and evaluation of healthcare services, and thereby contributing to the sustainability of the health system (Balduzzi, 2009). Indeed, patient advocacy implies the use of strategic information to change public policies and allocative decisions that have a direct impact on people's lives, as well as to direct collective and individual behaviors to the improvement of individuals and communities' health (Aloe & De Stefano, 2017).

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