

## Chapter 60

# Why Do Patients Protest? Collective Action Processes in People With Chronic Illnesses: A Psychosocial Perspective

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### ABSTRACT

*Despite the relevance of the topic, an exhaustive psychosocial reflection on the processes that may facilitate patients' protest is still missing. The chapter provides a theoretical and empirical overview of psychosocial pathways for patients' collective action. Five core factors are reviewed: perceived injustice, group efficacy, group identification, moral convictions and social embeddedness. Each of them provides a different explanation of collective action processes and is examined for its potential impact among patients. The chapter closes suggesting some core elements for a theoretical explanation of patients' collective action and its relationship with patient engagement. Practical and theoretical implications of patients' collective action are discussed to identify new directions for future research and interventions.*

*Quel che ci accomuna è, soprattutto, la scelta di prendere in mano il nostro destino, di essere noi i protagonisti di questo movimento civile ed umano, senza deleghe in bianco a chicchessia.*

*[What we share is, most of all, the choice to be protagonists of our fate, to be ourselves the protagonists of this civil and human movement without proxies to anyone.]*

*– Alberto Damilano, From the homepage of the Italian network of people with amyotrophic lateral sclerosis (website: <http://www.comitato16novembre.org/>).*

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## INTRODUCTION

Looking at local and national news in many European countries, it is not surprising to see and read about patients taking part in demonstrations, holding flags and posters to defend their own rights. Just to make some examples, we can refer to the pro-Stamina stem cell treatment demonstration that took place on December 2013 in the center of Rome (Italy). The police attempted to block the march and two protesters were stopped by the police. Few months later (June 2014), a group of workers and patients of the Bellvitge University Hospital (Spain) demonstrated against the healthcare budget cuts and blocked a nearby highway for several minutes. Again, on October 2014, a mass protest of patients was held in Kiev and in some regions of Ukraine. The protest was titled “Black Tuesday”. Patients picketed the Cabinet of Ministers, and demanded from the government to procure medicines for critically ill Ukrainians. They brought hundreds of shoe pairs that symbolized the death of the patients in case the government did not procure the necessary medicines.

As suggested by most patient engagement literature, nowadays, patients appear to be increasingly aware of their rights, and more demanding in the fruition of healthcare services. They are concerned with their own needs and preferences, and have become more critical in expressing judgments about the received health services (e.g., Guyatt, Mulla, Scott, Jackevicius, & You, 2014). On the other side, healthcare organizations do not always recognize and accept patients’ active role. This may be a source of strain that, under certain circumstances, can result in a real collective mobilization.

Despite the relevance of the question we ask in the title, for patients and society, an exhaustive psychosocial reflection on the processes that may facilitate patients’ protest is still missing. The available analyses focused on single groups or episodes (e.g., Rabeharisoa, 2006), while a broader theorization is actually desirable. This echoes Zoller (2005), when she wrote that we are more likely to hear discussion of AIDS activism or breast cancer activism than we are to hear ‘health activism’ or other converging terms.

This chapter contributes to the book “Promoting Patient Engagement and Participation for Effective Healthcare Reform” by enlarging the analysis of patient engagement and participation with a group-based perspective, which is distinctive of the social psychology approach. Among the disciplines that were interested on the topic, our chapter focuses on the psychosocial processes at the basis of patients’ collective action, conceived as one of the ways through which patients can produce (or resist to) a change in their health care system. Before we proceed to the social psychological answer as to why patients protest, we devote a few words to describe patients’ collective action itself.

## BACKGROUND: PATIENTS AS ACTIVISTS

In the psychosocial domain, collective action is often defined as a specific form of participation where individuals undertake actions as group members, with the aim to improve the group’s conditions (e.g. Wright, Taylor, & Moghaddam, 1990; see also Van Zomeren & Iyer, 2009). According to Wright et al. (1990), collective action is proposed in contrast to individual action, that is specifically directed at improving one’s personal conditions rather than group.

A wide range of behaviors can be classified as collective action, ranging from participation in protest demonstrations and strikes to seemingly individualistic acts such as signing a petition (Van Zomeren & Iyer, 2009) or contributing to a cause through an individual donation. More generally, despite some

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