

Enacting Divides: Successful Alliances in Health Activism in Bulgaria

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ABSTRACT

The paper aims to explore the current state of a particular instance of patient activism in Bulgaria through tracing the sociotechnical network architecture of the assisted reproductive technologies. It argues that in the local context this is the patient activism, which could be assessed as successful or, in ANT's terms, it has forged heterogeneous alliances, able to sustain themselves, proliferate and enroll new protagonists. Based on interviews with patients and activists, on media representations, and online discussions, this research tries to trace the local heterogeneous arrays of protagonists and show how ARTs network successfully stabilizes and gains power.

KEYWORDS

Assisted Reproduction, Eastern Europe, Hybrid Collectives, Patient Activism, Translation

INTRODUCTION

This paper aims to explore the current state of one particular form of patient activism in Bulgaria through tracing the sociotechnical network architecture – its material, human and ideational instances – of the assisted reproductive technologies (for the sake of brevity I will call it “ARTs activism”). I argue that in the local context this is the patient activism, which could be assessed as successful or, in ANT's terms: it has forged heterogeneous alliances, able to sustain themselves, proliferate and enroll new protagonists. In other words, this paper is an attempt to gain some insight on the processes of attaining power through health activism in Bulgaria.

Right at the outset I would like to note that the issue of defining “success” of a patient organization is neither simple, nor a straightforward matter as Steven Epstein rightly emphasizes (Epstein, 2011). According to him we should use more assessment criteria, enabling us to take into account intended and non-intended effects and the numerous ways such actors could bring about transformation. Their activity should not be “reduced solely to aspects of resource mobilization and identity politics” (Wehling et al., 2011, p. 265). Here I shall situate this property in the framework, outlined by Michel Callon, who succinctly explains that the vigor and efficiency of the activist performance “depends entirely on the ability of the concerned groups to make themselves recognized by future allies, or in other words through “the interissement and the enrolment of all those who are not directly concerned with the disease in question. Either the concerned group is capable of this type of mobilisation ...; or else it is incapable of doing so and consequently sinks into oblivion and non-existence”. (Callon, 1999, pp. 92-93). So, we could say that a patient organization is successful, when it appears to construct stable alliance – socially visible hybrid network, capable of recruiting new supporters. In other words, when “patients are “socialized”... [or] becom[ing] stakeholders in scientific, clinical, medical, and social networks” (Callon & Rabeharisoa, 2008, p. 240).

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This paper falls in three parts. First, it will briefly sketch the important changes in the nature of health activism over the past several decades and reconstruct the notion of the “partnership model”, discussed in different studies (Rabeharisoa, 2003; Rabeharisoa & Callon, 2004; Callon & Rabeharisoa, 2008). Then it will present a conceptual framework, arguing that the concept of translation could highlight how the ARTs activism succeeds and what is its key move, allowing the network to form, to become recognizable and to expand. Based on interviews with patients and activists, on media representations, and online discussions, I will try to trace the local heterogeneous arrays of protagonists and show how ARTs network successfully stabilizes and gains power.

HEALTH ACTIVISM IN HETEROGENEOUS COLLECTIVES

The research on patient groups and health movements is a broad and burgeoning field, drawing on diverse theoretical frameworks and mobilizing an array of methodological toolkits. There is little doubt that recent advances in biosciences and biotechnologies have significant impact on various received patterns of social bonding as well as the power to engender novel forms of social groupings. In their efforts to respond to and to offer some insights on the specific nature of these processes, on their consequences and on the ways our contemporary societies should try to govern and mould them, social science reflection has directed its attention to the ongoing transformations of citizenship, capturing them through the concepts of biological (Petryna, 2002; Rose & Novas, 2005) or genetic citizenship (Kerr, 2003; Heath, Rapp & Taussig, 2004). These notions together with the concept of “biosociality” (Rabinow, 1996) are employed as tools for analyzing the emerging new dynamics, constellations and redefinitions of identities, collectivities, activism and governance at the intersections of society and biomedical knowledge today.

Health-related social movements are examined as instances of such novel groupings and it is emphasized that their activism is a successful act of undermining of the old regime of demarcation between expert and lay knowledge, and its institutional patterns. This participatory turn in knowledge production, instigated by the democratic deficits, typical for the old regime of knowledge production, consists in entirely new forms of engagement of patient organizations that made them more visible and prominent actors in directing research and influencing healthcare policies. “[T]hey fund research, engage in public controversies over ethical and juridical issues ... and form partnerships with researchers to define and carry out research in cooperation” (Langstrup, 2015, p. 172). The paternalistic model in which patients are seen as passive receptacles of expertise is challenged and new forms of empowerment arise, having the potential to reconfigure the collective, which we inhabit (Callon & Rabeharisoa, 2008, p. 243). In this framework patient activism is interpreted through notions as “ethics of care” (Heath et al., 2004) and is seen as operating within economies of hope (Novas, 2006, 2007). One of the exemplary cases, demonstrating the power of the simultaneous production of knowledge, of new identity and of new collective is the history and activity of the French association of patients with muscular dystrophy (AFM) (Callon, Lascoumes, & Barthe, 2001; Rabeharisoa & Callon, 2004; Callon & Rabeharisoa, 2008). It differs from the health activisms around genetic conditions in the past, whose efforts were mostly related to providing social and economic support to the affected, since a major part of its activity is funding and directing scientific research in the field. The history of AFM shows that it is possible for the lay persons to enter into the territories of “secluded research” (Callon, Lascoumes & Barthe, 2001, p. 75). Exactly this move yields the fundamental transformation of the ontological status of the patients with muscular dystrophy. As Callon and Rabeharisoa argue the nature of the matter of concern - becoming full-fledged human beings – is a radical one and the process of transforming something, which initially was merely an excluded group of “individuals concerned by their own death and suffering or those of their children” in a collective, which is recognized and included, was not a one-step shift from exclusion to inclusion: “It was necessary for both the patients and their social environment to change... it was possible owing to a dual movement

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