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SYMPOSIUM: COLLECTIVE REPRESENTATION IN HEALTHCARE POLICY

One For All, All For One? Collective Representation in Healthcare Policy

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Abstract Healthcare collectives, such as patient organizations, advocacy groups, disability organizations, professional associations, industry advocates, social movements, and health consumer organizations have been increasingly involved in healthcare policymaking. Such collectives are based on the idea that individual interests can be aggregated into collective interests by participation, deliberation, and representation. The topic of collectivity in healthcare, more specifically collective representation, has only rarely been addressed in (Western) bioethics. This symposium, entitled: "Collective Representation in Healthcare Policy" of the *Journal of Bioethical Inquiry* draws attention to this understudied topic from a variety of disciplines, within a variety of socio-cultural contexts. We draw attention to important ethical, cultural, and social questions, and into the practices, justifications for, and implications of collective representation of patients in healthcare policy.

Introduction

The world-famous motto of Alexander Dumas historical novel *The Three Musketeers*: "One for All and All for One, united we stand divided we fall," highlights the strength of collectives and unity. Collectives do not only stand strong in literal fights, as the novel indicates, but also play a role in healthcare. Yet the topic of collectivity in healthcare, more specifically collective representation, is a topic that receives only marginal attention within the field of (Western) bioethics as this field focuses strongly on individuals and individual rights (Pugh 2018; Beier et al. 2016). This symposium of the *Journal of Bioethical Inquiry* draws attention to this understudied topic from a variety of disciplines, such as political sciences, medical ethics, public health, health policy, and sociology of medicine, within a variety of socio-cultural contexts (Germany, Austria, the United Kingdom, Israel) in order to further the bioethical debate on this topic. After a brief outline of the topic of collective representation in bioethics and healthcare policy, we will introduce this symposium by summarizing the contributions to this issue.

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Collective Representation in Healthcare

In the field of healthcare, collectives have been grouped under several umbrella terms such as patient organizations, advocacy groups, disability organizations, professional associations, industry advocates, social movements, and health consumer organizations. Such collectives can unite individuals in terms of "united we stand, divided we fall." They are based on the idea that individual interests can be aggregated into collective interests by participation, deliberation, and representation. The collective of individuals unite for a shared cause and advocate, lobby for, or put shared interests and goals on the political agenda. This political work is sometimes also combined with offering supplemental care and service provision such as self-help groups (Epstein 2011; Gerhards et al. 2017). In that respect, healthcare collectives may be rather similar to the musketeers, who shared their political goal but were also friends and were looking after each other.

The involvement of such advocacy groups in healthcare policy-making has been argued to be essential for the democratization of health politics (Epstein 2008; Dryzek 2000). Furthermore, it has been regarded necessary to supplement and counter expert-dominated healthcare systems in many countries with first-hand knowledge of patients (Schicktanz 2015; Hutchison et al. 2017). The involvement and inclusion of "affected people" is increasingly recognized in most Western countries. This approach has entered the health sector over the past decade with governments, research organizations, or health authorities using deliberative and participatory methods to engage the public in discussions about their healthcare systems. Nevertheless, many practical and ethical questions remain open. These include questions regarding organizational mechanisms and organizational structures; as well as more normative questions with regard to the claim to represent all patients and the epistemic assumption that patients have a particular type of knowledge. With this symposium we draw attention to the normative dimensions, complexities, aims, and underlying assumptions of including such collectives in health policy.

Summary of the Contributions to This Issue

"One for all, all for one" seems to fit well to the topic of collective representation, but the contributions to our symposium also show that we should not naively assume that all healthcare collectives function like this motto. Two papers in this Symposium point out that the way the *one* should represent *all*, is not always obvious (Baggott and Jones 2018; Rojatz et al. 2018). Baggot and Jones draw in their paper on representative theory as described by Hanna Pitkin (1967) to outline how patient organizations (POs) have influenced healthcare policy in the United Kingdom. They describe that POs strive to represent patients', users', and caregivers' interests by claiming to speak on behalf of their constituency. The paper explores the strategies of POs to bring the voice of those groups to the fore in health policymaking. The authors argue that policymakers themselves are less concerned with formal mechanisms adopted by groups and are more concerned with credibility and trustworthiness of POs.

Moreover, Rojatz et al. (2018) explore which criteria for accepting self-help groups (SHOs), as a specific type of PO, must be fulfilled in order to be accepted as a patient representative. By juxtaposing legislative criteria for SHOs in Austria and Germany against representation theory, they reveal that regulation helps to ensure that patient representation meets democratic standards such as responsiveness and independence. The authors thereby point out the advantages of governmental steering of patient representation.

The symposium continues with two contributions that explore collective representation from a critical perspective (van de Bovenkamp and Vollaard 2018; Schicktanz et al. 2018). The contribution of van de Bovenkamp and Vollaard draws attention to situations where *several* representatives claim to represent "*all*." They describe how aside from POs, also other (self-proclaimed) representatives claim to speak up for patients/people with disabilities. Their contribution draws attention to the various strategies for accountability and authorization that these representatives draw upon. The authors show empirically that different representatives speak for different groups and represent different aspects of such groups and argue that the variety of representatives can be regarded positively.

The paper of the guest editors to this issue, Schicktanz et al. (2018), examines who is considered "*all*" in Alzheimer patient advocacy and who is included or excluded in such organizations. The paper draws on a German–Israeli comparison of interviews with patient representatives and service recipients of Alzheimer POs. As the case of Alzheimer POs indicates, the inclusion mechanisms are interlinked with the current debate of medical illness conceptions. The paper indicates a cultural entanglement of stigma and advocacy in the context of dementia, based on differences in the conceptions of dementia and when the diagnosis has been made.

Finally, two more papers explore POs' self- claimed definitions of illness or diagnostic categories as part of collective advocacy in the interaction with scientific governance and health policymaking (Luce 2018; Blease and Geraghty 2018). The paper of Luce draws attention to the meanings and motivations behind national and international patient organizations' participation in the U.K. regulatory processes leading to the legalization of mitochondrial replacement techniques (MRTs). By exploring such logic and their meanings, she critically reflects upon the active mobilization of "mitochondrial diseases" as a unifying diagnostic category. Furthermore, drawing on ethnographic examples of mitochondrial disease POs and their representatives, she also analyses the POs cross-border collective support of the legislation of MRTs in terms of commitment to patient and community solidarity in the context of national, international, and transnational patient advocacy. She points towards differences between the patient groups and POs described as the Mito community and argues that mitochondrial disease patient organization leaders would benefit from a safe and open space for deliberation about the many complexities of implementing MRTs within an era of increasing transnational mobility.

The paper of Blease and Geraghty (2018) critically focuses on the use of militant metaphors in healthcare policy. The paper examines how the activities of POs for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) can be interpreted in a larger context of contested illness and restricted access to healthcare. These POs are commonly described with militant metaphors, which the authors oppose as a suitable description for their activities. The authors argue that the widespread negative stereotyping of patients and the marginalization and exclusion of patient voices by medical authorities provides a better explanation for the expression of frustration among patients with ME/CFS.

For all the diversity of these six contributions, this symposium illustrates a general claim, going beyond the superficial binary opposition of "All" and "One," and looking instead at the full spectrum in between. Indeed, the binary opposition fails to capture the particular questions, problems, and possibilities that arise when individuals unite with shared goals in mind. These questions gain increasingly more importance as collective representation is increasingly sought and practiced. We hope this symposium will pave the way for more interdisciplinary research, including ethical, cultural, and social questions, into the practices, justifications for, and implications of collective representation of patients in healthcare policy.

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References

Baggott, R. and K.L. Jones. 2018. Representing whom? U.K. health consumer and patients' organizations in the policy process. *Journal of Bioethical Inquiry* 15(3). https://doi.org/10.1007/s11673-018-9859-4

Beier, K, I. Jordan, C. Wiesemann, and S. Schicktanz. 2016. *Understanding Collective Agency in Bioethics*. Medicine Health Care and Philosophy 19(3): 411–22.

Blease, C., and K.J. Geraghty. 2018. Are ME/CFS patient organizations "militant"? Patient protest in a medical controversy. *Journal of Bioethical Inquiry* 15(3). https://doi.org/10.1007/s11673-018-9866-5

van de Bovenkamp, H.M., and H. Vollaard. 2018. Representative claims in healthcare: Identifying the variety in patient representation. *Journal of Bioethical Inquiry* 15(3). https://doi.org/10.1007/s11673-018-9861-x

Dryzek, J.S., 2000. *Deliberative democracy and beyond.* New York: Oxford University Press.

Dumas, A. 1982. *The three musketeers*. New York: Penguin Classics.

Epstein, S. 2008. Patient groups and health movements. In *The handbook of science and technology studies*, edited by E. Hackett, O. Amsterdamska, M. Lynch, W.J. Cambridge, 499–439. Cambridge: MIT Press.

——. 2011. Measuring success: Scientific, institutional and cultural effects of patient advocacy. In *Patients as policy actors*, edited by B. Hoffman, 257–277. Rutgers University Press.

Hutchison, K., W. Rogers, and V.A. Entwistle. 2017. Addressing deficits and injustices: The potential epistemic contributions of patients to research. *Health Care Analysis* 25(4): 386–403.

Gerhards, H., K. Jongsma, and S. Schicktanz. 2017. The relevance of different trust models for representation in patient organizations: Conceptual considerations. *BMC Health Services Research* 17(1): 474.

Luce, J. 2018. Mitochondrial replacement techniques: Examining collective representation in emerging technologies governance. *Journal of Bioethical Inquiry* 15(3). https://doi.org/10.1007/s11673-018-9873-6

Pitkin, H.F. 1967. *The concept of representation*. Berkeley: University of California Press.

Pugh, J. 2018. Navigating individual and collective interests in medical ethics. *Journal of Medical Ethics* 44(1): 1–2.

Rojatz, D., J. Fischer, and H.M. van de Bovenkamp. 2018. Legislating patient representation: A comparison between Austrian and German regulations on self-help organizations as patient representatives. *Journal of Bioethical Inquiry* 15(3). https://doi.org/10.1007/s11673-018-9864-7

Schicktanz, S. 2015. The ethical legitimacy of patient organizations' involvement in politics and knowledge production: Epistemic justice as a conceptual basis. In *The public shaping of medical research: Patient associations, health movements and biomedicine*, edited by. P. Wehling, W. Viehover, and S. Koenen, 246–264. London, U.K.: Routledge.

Schicktanz, S., N. Rimon-Zarfaty, A. Raz, and K. Jongsma. 2018. Patient representation and advocacy for Alzheimer disease in Germany and Israel: The relevance of stigma and disease conception. *Journal of Bioethical Inquiry* 15(3). https://doi.org/10.1007/s11673-018-9871-8