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SYMPOSIUM: COLLECTIVE REPRESENTATION IN HEALTHCARE POLICY

Legislating Patient Representation: A Comparison Between Austrian and German Regulations on Self-Help Organizations as Patient Representatives

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Abstract Governments are increasingly inviting patient organizations (POs) to participate in healthcare policymaking. By inviting POs that claim to represent patients, representation comes into being. However, little is known about the circumstances under which governments accept POs as patient representatives. Based on the analysis of relevant legislation, this article investigates the criteria that self-help organizations (SHOs), a special type of PO, must fulfil in order to be accepted as patient representatives by governments in Austria and Germany. Thereby, it aims to contribute to the discussion on the role of governments in steering SHOs. There are different degrees of regulation (very little in Austria, more in Germany). Governments in both countries not only formulate explicit criteria for SHOs with respect to patient representation but also guide SHOs representing patients through implicit criteria for associations. We discuss the findings against concepts of responsiveness, authorization, and accountability. Our findings indicate that governmental steering is not negative per se as indicated by previous research but—depending on legislative criteria—can promote transparency and democratic quality in patient representation.

Keywords Patient organizations · Self-help organizations · Patient representation · Democratic representation · Representative claims theory · Responsiveness · Independence

Introduction

Increasingly, governments are inviting patient organizations (POs) to participate in healthcare policy decision-making (Löfgren et al. 2011). This happens especially in countries with healthcare systems classified as "social insurance systems," such as the Netherlands, Austria, and Germany (Saltman et al. 2004; Van de Bovenkamp et al. 2010; Van de Bovenkamp and Trappenburg 2011; Forster 2016). There are multiple reasons for governments to involve POs. Besides normative arguments emphasizing democratic decision-making and the increased legitimacy of such decisions, there are also functional reasons (Charles and DeMaio 1993; Van de Bovenkamp et al. 2010). The integration of experiential knowledge of patients in healthcare policy decision-

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making is expected to lead to better—more patient-oriented—decisions (Van de Bovenkamp et al. 2010) and contributes to a plurality of perspectives in policy decision-making (Schicktanz 2015).

Studies have shown that governments intervene quite substantially in the work of POs. In order to get funded or be invited to decision-making processes, POs have to correspond to governmental expectations (Van de Bovenkamp and Trappenburg 2011; Baggott and Jones 2015). Research from the Netherlands revealed that the Dutch government has created its own friendly opposition by steering patient organizations' structural arrangements, their activities, and their ideology (Van de Bovenkamp and Trappenburg 2011; Waardenburg and Van de Bovenkamp 2014). Other studies have discussed the danger of POs getting invited by governments to solely increase the legitimacy of governmental decisions and advance government's interests (Rojatz 2016; Souliotis et al. 2017). Findings like these give reason to conclude that governmental intervention might compromise the authenticity of POs, which calls into question their credibility to act as representatives based on the experiences and the will of their members.

This paper takes a closer look at the circumstances under which governments invite POs to take part in policy decision-making. We argue that POs perform patient representation when participating in healthcare policy decision-making in line with their avowed purpose to represent patients and/or carers during their advocacy efforts. In order to better understand this representation process, it is important not simply to look at the activities of such organizations as POs (see also the paper of Van de Bovenkamp and Vollaard 2018 in this issue) but also at how the recipients of their interventions value them. According to representative claims theory, representation is a process that begins with a claim, with X claiming to represent Y. Representation then only comes into being in case such a representative claim is being accepted by the actor to whom the claim is addressed (Saward 2010). From this point of view, patient representation comes into being when governments accept a PO as patient representative. However, little is known about the criteria that predetermine governmental acceptance of the representative role of POs (Baggott and Forster 2008; Keizer and Bless 2010).

Austria and Germany make good cases to study the criteria for governmental acceptance of POs: In both countries, patients organize themselves mainly in the form of mutual self-help (aka self-help or mutual aid groups). In these groups, those affected and/or their relatives/carers meet regularly to share their daily experiences dealing with their condition. Moreover, they support each other in coping with and managing their situation through ongoing dialogue (Trojan and Kofahl 2011). Over time, these groups can join together to form self-help organizations (SHOs) which are characterized by activities such as raising public awareness about their conditions and advocacy in healthcare policy (Kelleher 2006). Given this mutual exchange of experiences among those affected within SHOs, they are considered to be "key mediating structures" between patients and the healthcare system (Branckaerts and Richardson 1988; Chaudhary et al. 2013). Thus, SHOs are not only the most important form of patient organization in Austria and Germany but are also promising patient representatives.

With our study, we aim to contribute to the discussion on governmental steering of patient representation and on how we should value such intervention. It does so by answering the following research question: With what criteria do SHOs have to comply in order to be accepted as patient representatives on the national level of healthcare policy decision-making in Austria and Germany? To answer this question, we used national legislation as an indicator of the conditions under which patient representatives are accepted by Austrian and German governments. Moreover, we discuss the findings against concepts of responsiveness, authorization, and accountability.

The article proceeds as follows. First, we explain the methods used for our study. Next, we go into the results of our analysis showing the criteria defined by Austrian and German governments for patient representation. In the last section of our paper, we ask how we should value these criteria and conclude that government interference in SHOs can contribute to making patient representation more democratic.

Methods

To answer our research question, we analysed legislative texts. We were interested in the governments' criteria for SHOs representing patient interests according to national law in Austria and Germany. We chose Austria and Germany for our exploratory study because both healthcare systems can be characterized as "social insurance healthcare systems" and increasingly recognize SHOs as patient representatives. However, they differ in their regulation for patient representation by SHOs.

Whereas Germany has quite elaborate regulations for patient organizations representing patient interests, Austria does not (Forster 2015).

To identify relevant legislative texts, we conducted a keyword search in the national legal information systems of Austria and Germany in May 2017. Our search terms are illustrated in Table 1.

This search strategy led us to national legislation containing paragraphs with our keywords. We excluded legislative texts not referring to patient representation. In Austria, we also identified texts on patient representation referring to patient representative bodies ("Patientenvertretung") without defining which organizations are meant. We excluded these from our analysis because there was no certainty about whom—SHOs or other actors—the passage addressed.

We developed an extraction scheme to extract the same content from all texts (when applicable). We extracted information on which types of organizations are considered eligible to represent patient interests (e.g. a kind of civil society organization), criteria for organizations representing patients (e.g. ascribed functions, organizational characteristics to be fulfilled, ideology), and the consequences for SHOs if they do (not) fulfil the criteria defined in the legislative texts. Additional information on the country, the name of the legislative text, and the date of extraction was collected.

Data were analysed using framework analysis (Ritchie et al. 2003). After familiarization with the extracted information, data were paraphrased in our own words. After applying this to all extracts, we used an excel sheet to compare the criteria for organizations representing patients in Austria and Germany. It also facilitated our discussion on similarities and differences in patient representation regulations between the two countries.

In Austria and in Germany, governments accept SHOs that are organized as associations. In both countries, there are general regulations for associations (A3, G5). Although criteria for SHOs as patient representatives don't refer explicitly (e.g. by cross-referencing) to regulations for associations, we considered legislation on associations as implicit regulation of patient representation. This is because SHOs organized as associations must fulfil these criteria in addition to the specific regulations on patient representation. Therefore, we included legislative texts on associations (A3, G5) defining the requirements for them. We also included legislative texts defining SHOs (G6) (Mayring 2010). An overview of all texts included is presented in table 2.

Findings

In the following, we present the results of our analysis. We start by providing an overview of regulations that explicitly address SHOs as patient representatives. Next, we show that, in addition to those explicit criteria, there are also implicit criteria in both countries.

Explicit Criteria for SHOs as Patient Representatives in Austria and Germany

In Austria, there are few criteria for the representative role of SHOs. What types of organizations should be considered SHOs is not defined in the legislation. Legislation does nominate self-help umbrella associations

Table 1 Search strategy

Search term	Translation	Number of documents Austria	Number of documents Germany
Patientengruppen	patient groups	3	13
Patientenorganisationen	patient organizations	3	3
Selbsthilfegruppen	self-help groups	8	9
Selbsthilfeorganisationen	self-help organizations	1	1
Patientenvertreter	patient representative	3	0
Patientenvertretung	patient representative bodies	2	0
Patientenvertretungen	patient advocacy groups	16	0
Patientenbeteiligung	patient participation	0	1
Maßgebliche Organisationen	[technical term to describe relevant organizations—in the context of patient representation]	0	2

Table 2 Overview of included legislative texts

Document	Country	Code
Legislation on organizations identified by keyword search		
Vereinbarung zur Sicherstellung der Patientenrechte: Patientencharta *2006* (Patientencharta Wien)* *[Agreement to safeguard patients' rights: Patient Charter 2006]*	AT	A1
Bundesgesetz, mit dem ein Bundesgesetz zur partnerschaftlichen Zielsteuerung-Gesundheit (Gesundheits-Zielsteuerungsgesetz—G-ZG) erlassen wird *2017* *[Federal Act, with which a federal law on partnership-based target-oriented health management is to be enacted]*	AT	A2
Verordnung zur Beteiligung von Patientinnen und Patienten in der Gesetzlichen Krankenversicherung Patientenbeteiligungsverordnung *2003* *[Patient Participation Regulation 2003]*	G	G1
Verordnung zur Beteiligung der auf Bundesebene maßgeblichen Organisationen für die Wahrnehmung der Interessen und der Selbsthilfe der pflegebedürftigen und behinderten Menschen sowie der pflegenden Angehörigen im Bereich der Begutachtung und Qualitätssicherung der Sozialen Pflegeversicherung *2013* *[regulation on the involvement of organizations at federal level that are relevant for the protection of the interests and self-help of people in need of care and disabled persons as well as of caregiving relatives in the field of assessment and quality assurance of the Social Nursing Care Insurance 2013]*	G	G2
Sozialgesetzbuch: Fünftes Buch *1988* *[Social Code: Fifth Book 1988]*	G	G3
Sozialgesetzbuch: Neuntes Buch *2001* *[Social Code: Ninth Book 2001]*	G	G4
Additional legal texts		
Bundesgesetz über Vereine *2002* [Federal Act on Associations 2002]	AT	A3
Bürgerliches Gesetzbuch *1896* *[Civil Code 1896]*	G	G5
Sozialgesetzbuch: Elftes Buch *1994* *[Social Code: Eleventh Book 1994]*	G	G6

AT = Austria; G = Germany

*The text is drawn up for each Austrian federal text with similar content. Instead of naming all nine identical documents, we chose to cite the Vienna version as an example.

as patient representatives and offers them an institutionalized position to represent patients: “Umbrella associations of patient self-help groups shall be given the opportunity to be consulted on draft regulations and patient-relevant laws” (Art 30 A1, translation DR). Austrian self-help umbrella associations may further delegate a joint representative to the major national advisory body on healthcare (A2). Our findings suggest that Austrian regulations emphasize the role of self-help umbrella associations in representing the interests of patients. However, regulations do not provide specific criteria that self-help umbrella associations must fulfil with respect to patient representation.

Next to offering umbrella associations of patient self-help groups an institutionalized position in patient representation, regulations also mention self-help groups, which attend to patient interests (A1). These self-help groups are mentioned in relation to public bodies established to support and represent patients. These public bodies, also known as patient advocates, are considered independent and are not bound by directives or instructions. They are expected to support individual patients in conflicts with healthcare facilities as well as represent collective patient interests. They can do the latter by, for instance, providing official statements in decision-making processes that are relevant for patients (A1). These public bodies “have to seek cooperation with self-help groups that safeguard patient interests” (Art 29 Par. 2 A1, translation JF). Details or criteria for this cooperation are not provided (A1).

Although legislation provides an institutionalized position to SHOs as patient representatives, we found hardly any criteria that SHOs must meet in order to be accepted as patient representatives. Therefore, we argue that legislation in this respect remains rather vague in Austria.

Compared to the Austrian regulation, German legislation is more extensive. Core characteristics of self-help groups and SHOs are defined by law.

> Self-help groups are voluntary, neutral, independent, and non-profit associations of persons affected personally or their relatives pursuing the goal of improving the life circumstances of those dependent on care and of their relatives and comparable persons close to them, through personal mutual support as well as through the aid of offers by volunteers and other persons prepared to commit themselves to civic engagement. Self-help organizations are associations of self-help groups. (§ 45d G6, translation DR)

In Germany, legislation allows for patient representation in, amongst other bodies, the Federal Joint Committee, the main decision-making body in healthcare (G3). Legislation provides criteria, which must be fulfilled in order to be accepted as a patient representative. SHOs that want to be accepted as patient representatives within this and other bodies must fulfil the following criteria:

1. Promote the interests of patients or of self-help-in accordance with their statutes—ideally not temporarily;
2. Comply with democratic principles regarding their internal structure;
3. Represent the interests of patients or the self-help of chronically ill and disabled people at the national level according to their constituency;
4. Exist for at least three years at the time of recognition and have been active nationwide during this period within the meaning of item 1;
5. Provide the guarantee for proper fulfilment of tasks. The nature and extent of the previous activity, the membership, and the performance should be taken into account;
6. Demonstrate, through disclosure of their financing, that they function neutrally and independently; and
7. Pursue charitable purposes. (§ 1 G1, translation DR)

These criteria are defined not merely for SHOs, but for all organizations claiming to represent the interests of patients and mutual self-help in order to be accepted as representatives (G1, G2). We found that German legislation holds all organizations representing patients to the same standards. When the above-mentioned criteria are fulfilled, organizations representing patients are granted administrative, factual, and financial support (G3). If there are questions concerning the fulfilment of these criteria, the Federal Ministry of Health is requested to review those organizations representing patients. Subsequently, it decides on a rejection or a revocation of acceptance of the organizations as patient representative (G1, G2).

Implicit Criteria for SHOs as Patient Representatives in Austria and Germany

We found that, in both countries, governments consider a SHO a legitimate representative when the organization has a statute and is organized as an association (A1, G1, G2). There is legislation in place that defines what is to be regulated in these statutes: associations are required to have certain internal structures and a membership structure in place (A3, G5). Statutes must determine who can become a member of the association and what goals and objectives the association pursues. Statutes must also regulate mechanisms for appointing the board and any other executive body of the association—via elections, for instance. The exact content of the statutes is defined by the associations' members. Members have to agree on the competence and period of office for the board and any other bodies. Moreover, they have to agree on the way in which and how often the board (or any other executive body) must inform them about what has been done on their behalf (A3, G5). Because members of associations decide upon the statutes, sovereignty is granted by assigning the decision-making power to them. Consequently, statutes can only be altered by members.

Discussion

We analysed national legislation on criteria to be fulfilled by SHOs in order to be accepted as patient representatives in Austria and Germany. In line with previous research (Forster 2015), we found different degrees of regulation (very little in Austria, more in Germany). Moreover, we learnt that governments in both countries formulate *explicit* criteria on patient representation as well as *implicit* ones for SHOs that are organized as associations. In the following we discuss how we should value the criteria for accepting the claim of SHOs to be patient representatives.

As shown in the introduction, research so far has come to a rather critical assessment of governments exerting influence on POs, arguing that governmental intervention might compromise the authenticity of

SHOs and therefore their credibility to act as representatives based on the will of their members (Van de Bovenkamp and Trappenburg 2011; Waardenburg and Van de Bovenkamp 2014). However, a lack of regulation can also cause problems. As our methods section shows, we had to exclude some Austrian legislative texts on patient representation because it was unclear to which patient representatives they referred—SHOs or not. Austrian self-help representatives themselves have addressed the lack of clarity about which organizations can be accepted by governments as patient representatives: "The opaque definition of self-help groups and of who is legitimized to represent patient interests allows for an uncontrolled growth of both" (APA 2009, translation DR). While German legislation establishes clarity on the binding nature of patient representation, the Austrian legislation leaves this rather open. The comparison of Austrian and German legislation shows that, thanks to defined criteria on patient representation, legislation can establish clarity about which organizations can be accepted as patient representatives by governments. Furthermore, legislation might prevent governments from randomly accepting or rejecting actors claiming to represent patients.

Besides clarity about governmental acceptance of patient representatives, patient representation might also benefit from regulation for democratic reasons. In the following, we discuss in turn responsiveness and independence as two theoretically informed features that are established in legislation in our cases and contribute to making patient representation more democratic.

Research on SHOs has shown that the organizations' responsiveness can be affected by internal power centres and elite decision-making (Baggott et al. 2005; Souliotis et al. 2017). Considering findings such as these, we argue legislation on the responsiveness of SHOs to those they claim to represent might limit this problem. In line with political theorists working on representation, we argue that democratic representation requires *responsiveness*: the continuous interaction between the representative and the represented (Urbinati and Warren 2008; Montanaro 2012). Responsiveness is often conceptualized in terms of authorization and accountability (Pitkin 1967; Urbinati and Warren 2008; Montanaro 2012; Van de Bovenkamp and Vollaard 2017). The concept of authorization addresses the question of how a representative gets appointed or directed as such. Accountability is about the "relationship between an actor and a forum, in which the actor has an obligation to explain and to justify his or her conduct, the forum can pose questions and pass judgement, and the actor may face consequences"(Bovens 2007, 447). Legislation in both countries arranges for SHOs to offer membership to those they claim to represent and to let the members elect the governing boards of SHOs. Moreover, they have to agree on the way in which and how often the board (or any other executive body) must inform them about what has been done on their behalf (A3, G5). These means are mechanisms for authorization and accountability; through casting votes for a board member authorization is established and through the re-electing or voting out of a board member accountability is. Similarly, membership can be seen as a mechanism for both authorization and accountability. Constituents authorize the claims-making organization through becoming a member and hold the organization to account through exit or anticipation of exit (Montanaro 2012). We therefore argue that by linking criteria for SHOs to those for associations, legislation aimed at establishing responsiveness can foster SHOs to perform representation in a democratic manner.

Independence is a feature that, according to representative claims theory, adds credibility to the claims representatives make (Saward 2010). Literature on SHOs often addresses the financial dimension of independence, discussing the potential dependency of SHOs on sponsors, such as the pharmaceutical industry, medical device manufacturers, and governments (O'Donovan 2007; Van de Bovenkamp and Trappenburg 2011; Vitry and Löfgren 2011; Colombo et al. 2012; Schulz-Nieswandt and Langenhorst 2015). Funding by such sponsors—especially if POs depend on one or only a few big funders—make SHOs susceptible to external influence and might be accompanied by expectations and criteria of the funders. Disclosing the finances of SHOs—as required by German legislation—reveals possible conflicts of interests and potential steering of these organizations. Therefore, also in this regard regulation can help strengthen the credibility of SHOs as patient representatives.

Our research contributes to a more comprehensive discussion and appraisal of governmental influence of SHOs. However, the study has some limitations. Because of its explorative nature, it only focused on the national legislation of two countries. We suggest exploring additional country cases for future research. We focused on SHOs, but given that there are many actors claiming to represent patients (see Van de Bovenkamp and Vollaard in this issue), it would also be interesting to explore what criteria actors other than SHOs must fulfil to have their representative claims accepted by governments. Moreover, we are well aware that legislative texts are not the only source for regulating patient representation (Van de Bovenkamp and Trappenburg 2011) and that other documents, such as procedural rules of healthcare decision bodies, refine legislative regulations.

In this study we contribute to the existing literature by showing that governmental intervention in patient representation should not only be seen as negative per se as previous research indicates. Depending on the criteria used, government influence can play a positive role in ensuring democratic patient representation. First, legislation can ensure clarity about which organizations governments accept as patient representatives. This is important because of strengthening transparency in patient representation and avoiding governmental arbitrariness in accepting patient representatives. Legislation therefore might help to secure that POs/SHOs get accepted by governments as patient representatives even when being critical of the government. Second, our results show that legislative criteria on patient representation potentially strengthen democratic patient representation by promoting both responsiveness and independence. Future research will need to take a look at how SHOs put these criteria into practice. Furthermore, we encourage studies that explore whether governmental criteria match the acceptance criteria of patients.

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