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The challenge of democratic patient representation: Understanding the representation work of patient organizations through methodological triangulation

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ABSTRACT

Increasingly, patient organizations (POs) play a role in health policy making. Their involvement is expected to contribute to the democratization of decision making. It is therefore important to study this contribution. Scholars hardly draw on representation theory for this. Yet exploring POs as a case of representation is crucial to better understand how POs add to democratizing health policy.

Our study departs from the assumption that POs contribute to the democratization of health policy in case they perform democratic representation. We studied the representation work of 33 POs covering rare diseases in Austria, Germany and the Netherlands by conducting a thematic analysis of document and interview data collected in 2016.

The results show that POs work on turning their representative efforts into democratic representation by applying different mechanisms of authorization and accountability. Yet because of difficulties that come along with these mechanisms, POs differ regarding their contribution to democratizing health policy. Our findings further suggest that not all means of authorization and accountability work out in representation practice as hoped for in representation theory. We therefore recommend policy makers to pay attention to what means of authorization and accountability POs use for their representation work.

1. Introduction

Patient organizations (POs) engage in health policy making in various countries. They lobby politicians, organize protests and petitions, publish opinion statements on proposed legislation, engage with mass media and–more and more often–get invited to participate in different settings of policy decision making. They participate in public hearing processes as well as in advisory and decision-making boards (sometimes with and sometimes without voting rights). There are many examples of policy topics that POs have joined the debate on–such as eHealth, telehealth, patient safety, health literacy, education for future healthcare professionals, access to healthcare provision in general and specific drugs, medical devices, and methods of alternative medicine in particular [1–13].

Literature has discussed the engagement of POs in health policy making critically, problematizing, for instance, the financial dependence of many POs on sponsors such as the pharmaceutical industry, medical device manufacturers, and the government [14–16]. A study on the Austrian case revealed that POs worry about their policy engagement because of difficulties such as work overload and lacking resources [2]. Engaging in health policy making is not the sole activity that POs carry out. In Austria–as in many other countries–self-help organizations constitute the majority of POs. In addition to raising public awareness for the disease(s) that the organization covers, their main aim is to promote peer support of patients (and their family caregivers) [17]. To this effect, they support patients (and family caregivers) to mutually support each other in coping with their diseases.

At the same time, literature has formulated many hopes connected to POs getting more engaged in health policy making. Along with arguing the inclusion of the experiential knowledge of patients will result in an increased quality of decisions, scholars reason that the engagement of POs promotes democratizing health pol-

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icy decision making [12]. However, the question as to what way their engagement contributes to democratizing health policymaking remains mostly unexplored in the literature.

To gain a better understanding of how POs contribute to shaping health policy decision making in a more democratic way, it is important to draw on the concept of representation. Representative claims theory describes representation as an “ongoing process of making and receiving, accepting and rejecting claims” [18]. When engaging in health policy making, POs claim to represent the interests of patients [2,19]. When being invited to participate in health policy making, they are accepted as patient representatives by those extending the invitation. Just because they perform patient representation, doing so does not necessarily mean that POs automatically contribute to democratizing health policy. Instead, work needs to be done on the representative relationship to turn representation into democratic representation [20–23].

For assessing the democratic value of a representative claim, it has become customary for scholars to look at the relationship representatives have with those they claim to represent. This relationship can be operationalized concerning authorization and accountability–meaning how representatives are directed or selected and how representatives can be held accountable for what they have done on behalf of their proclaimed constituency [21,22,24,25]. Elections are a well-known means of authorization (electing one’s own representatives) and accountability (re-electing or voting out one’s own representatives). Another formal means is membership. In organizations that offer membership, constituents (in our case patients) can become a member of the claims-making organization (in our case a PO). It is then that “membership will serve both authorization and accountability: through joining (authorization) and through exit or anticipation of exit (accountability)” [22]. There are also informal mechanisms that representatives can establish to strengthen the democratic value of their representative claim–such as allowing deliberation in meetings or other contacts, accounting for one’s conduct in the public debate and making action plans and goals publicly available [20–22].

Both formal and informal mechanisms for authorization and accountability do not promote democratic representation in case the group “empowered to authorize and demand accountability is different from the constituency whose interests the representative claim affect” [22]. Thus, it is essential to pay particular attention to how representatives align means for authorization and accountability to their proclaimed constituency.

This study presents how POs work on turning their representative efforts into democratic representation. The objective of our study is not to explore whether POs consider themselves as or aim to be considered democratic institutions. We also do not seek to explore what POs believe to be their contribution to democratizing health policy. Instead, our study departs from the assumption that POs contribute to the democratization of health policy when they perform democratic patient representation as conceptualized above. The paper proceeds in three steps. After describing our research design, we will present our results and show that POs have various means of authorization and accountability in place. Following that we discuss the difficulties POs are confronted with in their representation work and argue why more research needs to be done into the complex empirical reality of representation.

2. Research design

Given the explorative nature of our research we prepared a qualitative study design. We studied POs covering rare diseases in Austria, Germany and the Netherlands, using document and interview data collected in 2016.

Table 1
Selection of (interviewed) organizations per country.

Country of Study	Number of POs
Austria	11 (8)
Germany	11 (10)
The Netherlands	11 (6)
All countries	33 (24)

Notes: Not all selected organizations agreed to be interviewed. The number of interviewed POs is given in the brackets ().

POs focusing on rare diseases make an excellent case to study the representation work by POs. The EU defines rare diseases as conditions that affect not more than 5 out of 10,000 people. Research has revealed that POs that cover rare diseases engage substantially in policy making [26–30]. Drawing on this insight, we chose to explore POs covering rare diseases due to richness in relevant information. Expecting points of contrast, we selected POs from Austria, Germany and the Netherlands. Despite different traditions of involving POs in health policy decision making, POs in all three countries have been witnessed to increasingly engage in political activism [2,5,7–9,12,31,32]. By excluding parental POs from our sample, we aimed at bounding complexity. To strengthen the power of our findings, we only added cases to our sample in which a rare disease was covered by a PO in all three countries. In total, we found 11 cases per country that matched our criteria–thus 33 POs. Except for one Dutch PO (a foundation), all selected POs were associations that offer memberships. All POs offered services like information provision and promoted patient peer support and were led by an elected and voluntary board and had no paid staff that perform representation. We cannot provide any further information on our selected POs other than the criteria mentioned above since we promised all selected POs anonymity. We did so in order to motivate our interview respondents to speak freely about the inner workings of their organizations (Table 1).

We used more than one method to gather our data. Applying methodological triangulation, we (i) collected online documents and (ii) conducted interviews.

First, we searched the websites of our selected POs for their statutes and constitutive documents as well as for all texts referring to their representation work that were published online in 2015. Online documents included newsletters, magazines, brochures, leaflets, open letters, standpoints as well as shorter items announced in the news section of the website.

Second, we conducted semi-structured interviews with officials of the selected POs. Respondents were invited to explain which constituency their PO claims to represent and to elaborate on formal means of authorization and accountability–such as elections and membership. We questioned them about the interaction with their proclaimed constituency, about means to justify their conduct to the represented and about opportunities for the constituency to pose questions and pass judgement on the organization’s conduct. Respondents were asked to give examples to illustrate their statements. The interviews lasted between 40 min and one and a half hours. The interviews with Austrian and German respondents were held in German, while the interviews with Dutch respondents were held in English. We recorded and transcribed all interviews.

For the thematic analysis [33] of our data we composed an analytical scheme of themes: (i) the representative claims of POs and their proclaimed constituency; (ii) formal means of authorization and accountability described by representation theory; (iii) informal means of authorization and accountability. For analyzing our data, we paid particular attention to how POs align mechanisms for authorization and accountability to their proclaimed constituency.

3. Representation work of patient organizations in practice

In the following section, we describe the formal and informal mechanisms of authorization and accountability that POs have in place. First, however, we show whom POs claim to represent, which is vital for understanding how their established mechanisms for authorization and accountability contribute to making their representative work democratic.

3.1. Patient organizations and their proclaimed constituency

Patient organizations differ regarding whom they claim to represent. We found POs that claim to represent patients only. Others add caring relatives of patients to their constituency.

> We represent the interests of people suffering from [name of the disease] and their families and caring friends. (Statute, German PO)

Moreover, some POs claim to represent only members of their association and other POs make broader representative claims which include non-member patients (and non-member family caregivers).

> We view ourselves to be the representatives of all those affected in Austria. We are not so strict about whether somebody is a member or not. (Respondent, Austrian PO)

3.2. Patient organizations and formal means of authorization and accountability

POs have different mechanisms in place that are expected to serve both authorization and accountability. As explained in the introduction of this paper, political theorists argue that through offering membership organizations establish an authorization mechanism. Indeed, all selected POs were associations that offer membership except for one Dutch organization which was a foundation. However, we learned that many patients join a PO because they want access to specific services that the organization is offering–such as information and peer support–and that the decision to become a member often has little to do with showing support for the representation work of the PO. Thus, our findings suggest that membership as a means for authorization turns out unclear in case where organizations perform more tasks than mere representation.

There is a second difficulty with membership as an authorization mechanism that arises in practice. We found that not all POs aligned their regulations for membership with those they claim to represent. Not all POs that claimed to represent patients only, consequently offered membership exclusively to patients. Furthermore, we found POs in Austria and Germany that offered membership to any legal person.

> Any legal person that is willing to support our goals can become a full member of the association. (Statute, German PO)

We learned that those POs which offer membership to any legal person also have non-constituents as members – such as healthcare professionals. In sum, this means that a large number of members is not necessarily a sign of broad constituent authorization.

Offering membership to non-constituents also bears consequences for the elections of the board. The board, which takes decisions on what to advocate for, gets elected by the members of the organizations. In general, elections serve as formal means of authorization and accountability and are seen as strengthening the democratic value of a representative claim by showing constituent consent and contributing to public control. Our findings, however, suggest that there are cases in which elections do not adequately serve their purpose. In an association, every full member has the right to vote for the board election, meaning that many POs also allow also non-constituents to cast a vote. Offering voting rights to non-constituents is problematic for democratic reasons. As explained before, it is crucial that the group of people that gets to elect the representative match the group of people that the representative claim is about and that only members of the constituency get to cast a vote.

We found two additional problems with elections as a mechanism for authorization and accountability. Many respondents reported difficulties in finding candidates who want a position on the board. Being a board member is an unpaid honorary position that comes with legal and other responsibilities and a substantial workload. Respondents guessed that because of these reasons people hesitate to run for board membership. As a consequence, many POs could not offer their members more than one candidate for each board position. The last problem related to this authorization and accountability avenue is about low voter turnout. Respondents reported that many members do not cast their votes because they take little interest in the board.

> They [the members] want their organization to fight for them, to stand up for them, to do things for their good. But they don't care who is in the board. (Respondent, Dutch PO)

3.3. Patient organizations and informal means of authorization and accountability

The fact that there are difficulties attached to the formal mechanisms of authorization and accountability does not mean that there is no means of authorization and accountability in place. In addition to formal mechanisms, there are also many informal ones. We learned that POs trust different informal authorization and accountability avenues to strengthen the democratic basis of their representative claims.

For POs it is imperative to deliberate with their constituents for authorization purposes. Respondents argue that by learning what their constituents need and want, POs are directed in how to serve as representatives. POs learn from constituent stories about courses of diseases, successes as well as setbacks in treatments, medical and other problems related to being affected by the disease, deficiencies, and gaps in healthcare provision and so forth.

> We have knowledge about what patients like and want and need. We are well informed in this regard. (Respondent, German PO)

POs not only learn from stories their members share with them but also from stories they get through direct contact with non-member constituents.

> A lot of patients come to us that are no members. They don't want to pay the membership fee. And they are afraid of getting outed as being sick and that everyone points their finger at them. In the end I probably talk to more non-members than members. (Respondent, Austrian PO)

As shown in Table 2, POs offer their constituents numerous contact opportunities. We learned that next to authorization these communication opportunities also serve accountability. Respondents explained that through interaction POs account for their representation work by reporting back to their constituency what has been done on behalf of them.

> We are always explaining to the patients what is happening and why we are protesting against what kind of things. (Respondent, Dutch PO)

Table 2
Interactive contact opportunities for patient organizations and their constituents.

Contact opportunities regardless of local distance
- Telephone
- E-Mail
- Facebook
- Online Fora with login

Face to face contact opportunities
- Members Appointments - such as the annual general assembly of the PO or meetings for networking and exchange
- Information and public events - such as a booth at a fair or protest marches
- PO organized workshops and trainings
- Discussion fora - such as standing working groups or round tables
- Visits to individual constituents

POs also prepare written information on their representation work–such as annual reports and reviews, newsletters, magazines, brochures, leaflets and short items announced in the news section of their website. These can also be seen as a mechanism of accountability. Moreover, we found POs that published concrete points of view and wrote down their policy positions for everyone to read. Examples of such publications are letters to politicians or other policy makers, in which POs demanded changes in health policy, raised concerns about certain developments or suggested solutions to pressing problems.

Despite different efforts to account for their representative actions, some POs partially fail to inform at least parts of their constituency. Not all POs that claim to also represent non-members put the same effort in informing these non-members. In many cases meetings are for members-only. Newsletters, magazines and mails are also often spread solely among members just as access to online-fora is granted only to constituents holding a membership.

Aiming to strengthen their efforts regarding authorization and accountability, POs not only wait but ask for constituent input. Respondents stressed the necessity to motivate constituents to share their stories (for authorization purposes) and to pose questions and pass judgement regarding the representative actions taken by the PO (for accountability purposes). Respondents further note that some constituents are harder to reach than others. For instance, to get the chance to talk to patients during the advanced stage of the disease, representatives of POs occasionally visit patients at home or at the hospital.

To conclude, we found POs in all three countries of study to work on turning their representative efforts into democratic representation. While we found both formal and informal mechanisms of authorization and accountability in place, our findings suggest that in practice not all means of authorization and accountability work out as hoped for in theory.

4. The challenge of performing patient representation democratically

In this section, we reflect on lessons learned by studying POs as a case of representation to gain insight into their contribution to democratizing health policy decision making. Drawing on concepts of authorization and accountability has proven to be insightful for studying the representation work of POs. We found that POs apply different formal and informal means of authorization and accountability to turn their representative efforts into democratic representation. POs attach more importance to informal means. They claim that it is vital to deliberate with their constituents for authorization and accountability purposes. Respondents argue that by learning what their constituents need and want they get directed as representatives. Regarding accountability, POs provide information on their representation work and offer their constituency various opportunities to pose questions and pass judgment on the organization's conduct.

Our findings point to further two difficulties that arise in (patient) representation practice. By discussing these difficulties in the following section, we aim to contribute to the scholarly literature on difficulties that POs face as patient representatives [1,2,19] as well as to literature on the empirical reality of representation [20,34,35]. We argue that POs differ regarding their democratic potential and that POs are confronted with challenges that–while not described by representation theory–arise in representation practice. POs differ regarding their democratic potential because they are dissimilar in alignment between the availability of authorization and accountability opportunities and their constituency. There are, for instance, POs that offer authorization and accountability opportunities to non-constituents (such as voting rights to healthcare professionals). Regarding those POs that claim to represent also non-member patients (and non-member family caregivers), we found cases in which means of authorization and accountability are not open to all constituents alike. Often opportunities–such as electing the board of the PO, deliberation in member meetings, or participation in online fora–only come with membership. Non-member constituents are also put at a disadvantage by POs that do not provide the same information for members and non-members. In sum, it appears challenging to harmonize the means for authorization and accountability with the proclaimed constituency. For democratic reasons, it remains important to do so [22].

POs are confronted with challenges that arise in representation practice. Many means of authorization and accountability do not work out in practice as described in theory [18,20,22,23,34–37]. We raise two concerns. First, our study shows that patients as constituents do not seem to care much for the authorization and accountability opportunities POs offer. While especially formal means of authorization and accountability meet very little constituent response, POs also face difficulties getting constituents engaged with informal means. Other papers also describe that POs struggle to get their members interested in their policy work [38]. Thus we suggest putting more future research efforts into exploring what makes patients and other represented care about being represented [39].

Second, our findings lead to questioning the practicality of means for authorization and accountability in multitasking organizations. Membership as an authorization opportunity is an excellent example to illustrate this concern. Patients join a PO for different reasons. Often, they are interested in offers of mutual self-help and search for support in overcoming daily problems related to their disease [38]. In multitasking organizations that not only specialize in representation, the act of becoming a member cannot automatically be interpreted as an act of granting constituent authorization for the representative work of an organization. Moreover, patients also don't join a PO because of various reasons–such as fearing to be outed or not wanting contact to others at a more advanced stage of their disease [40]. Again, such reasons have nothing to do with the representative aspirations of a PO. Thus, by not becoming a member, patients do not necessarily withhold authorization and reject the representative claim of the PO. While we lack empirical understanding of what constituent absence means for a representative claim, at least representative claims theory argues that nonobjection can be considered as an act of constituent acceptance of a representative claim [18]. Drawing on findings of our and other studies [41], we therefore argue that more research needs to be done into the complexity of the empirical reality of representation in which representatives often perform not only representation but also other tasks.

Our study has limitations. Results show that the POs we studied differ in reaching their democratic potential but given the explorative nature of our research we are not able to explain for what reasons they do so. We found no evidence pointing to country-specific differences, yet our findings do not qualify for conclusions regarding disparities between POs from different countries. With our study we hope to shape ideas about the democratization of health policy by introducing a representation perspective on how POs may contribute to that goal. However, to this end observational data on how POs perform representation are needed to verify routines of democratic patient representation.

5. Conclusion

Our study departed from the assumption that POs contribute to the democratization of health policy when they perform democratic patient representation. We found their representation work to indeed matter to the democratic value of a PO. In addition to its scholarly value, we believe our findings have practical value: We recommend health policy makers to pay attention to how POs perform representation and to attach particular importance to informal means of authorization and accountability as described in this paper. Formal means of authorization and accountability – which in representation theory as well as by law are considered very valuable [42] – appear to be tricky to put into practice. POs attach more importance to informal means of authorization and accountability. We, therefore, conclude that especially those mechanisms are essential to the contribution of POs for democratizing health policy decision making.

Conflict of interest statement

None.

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